
JMIR Rehabilitation and Assistive Technologies

Development and Evaluation of Rehabilitation, Physiotherapy and Assistive Technologies, Robotics, Prosthetics and Implants, Mobility and Communication Tools, Home Automation and Telerehabilitation
Volume 5 (2018), Issue 1 ISSN 2369-2529 Editor in Chief: Sarah Munce, MS, PhD

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Original Paper

Physiotherapy Questionnaires App to Deliver Main Musculoskeletal Assessment Questionnaires: Development and Validation Study

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Abstract

Background: Patient-reported outcomes (PROs) translate subjective outcomes into objective data that can be quantified and analyzed. Nevertheless, the use of PROs in their traditional paper format is not practical for clinical practice due to limitations associated with the analysis and management of the data. To address the need for a viable way to group and utilize the main functioning assessment tools in the field of musculoskeletal disorders, the Physiotherapy Questionnaires app was developed.

Objective: This study aims to explain the development of the app, to validate it using two questionnaires, and to analyze whether participants prefer to use the app or the paper version of the questionnaires.

Methods: In the first stage, the app for an Android operational system was developed. In the second stage, the aim was to select questionnaires that were most often used in musculoskeletal clinical practice and research. The Foot and Ankle Outcome Score (FAOS) and American Orthopaedic Foot and Ankle Society (AOFAS) questionnaire were selected to validate the app. In total, 50 participants completed the paper and app versions of the AOFAS and 50 completed the FAOS. The study's outcomes were the correlation of the data between the paper and app versions as well as the preference of the participants between the two versions.

Results: The app was approved by experts after the adaptations of the layout for mobile phones and a total of 18 questionnaires were included in the app. Moreover, the app allows the generation of PDF and Excel files with the patients' data. In regards to validity, the mean of the total scores of the FAOS were 91.54% (SD 8.86%) for the paper version and 91.74% (SD 9.20%) for the app. There was no statistically significant differences in the means of the total scores or the subscales ($P=.11-.94$). The mean total scores for the AOFAS were 93.94 (SD 8.47) for the paper version and 93.96 (SD 8.48) for the app. No statistically significant differences were found for the total scores for the AOFAS or the subscales ($P>.99$). The app showed excellent agreement with the paper version of the FAOS, with an ICC value of 0.98 for the total score (95% CI 0.98-0.99), which was also found for the AOFAS with the ICC for the total score of 0.99 (95% CI 0.98-0.99). For compliance, 72% (36/50) of the participants in the FAOS group and 94% (47/50) in the AOFAS group preferred the app version.

Conclusions: The Physiotherapy Questionnaires app showed validity and high levels of compliance for the FAOS and AOFAS, which indicates it is not inferior to the paper version of these two questionnaires and confirms its viability and feasibility for use in clinical practice.

(*JMIR Rehabil Assist Technol* 2018;5(1):e1) doi:[10.2196/rehab.9247](https://doi.org/10.2196/rehab.9247)

KEYWORDS

mobile phone; Foot and Ankle Outcome Score; American Orthopaedic Foot and Ankle Society; musculoskeletal assessment questionnaires; health survey

Introduction

Patient-reported outcomes (PROs) [1] translate subjective outcomes, such as pain, function, daily activities, and social participation, into objective data that can be quantified and analyzed. Establishing quantitative parameters facilitates the diagnosis, prognosis, clinical decision making, and analysis of the progression of dysfunction and diseases [2]. Questionnaires are essential in research and clinical practice because they are efficient, reliable, and affordable [3].

Nevertheless, the use of PROs in their traditional paper format is not practical for clinical practice due to limitations associated with the analysis and management of the data [4,5]. Thus, in the last several decades, electronic patient-reported outcomes (ePROs) have been developed as an alternative [6]. Initially, ePROs were developed in Web platforms [7] and software programs that were accessed via personal computers [8]; however, mobile phones have added portability and viability to the tools used in health care. Currently, there is an increase in the use of mobile devices. It is estimated that one-third of the world's population uses a mobile phone [9], which increases the use of new tools to measure people's health status.

Today, approximately 40,000 mobile health (mHealth) apps are available; this suggests that there is a significant need for this kind of electronic assessment tool [10]. The advantages of the clinical use of a mobile phone app are the possibility of producing high-quality and reliable data using a little amount of space and the possibility of performing uploads and backups to prevent loss of data [11]. From a technical perspective, mobile phone apps offer large processing power, high-speed data transfer, and touchscreen resources, which avoid the use of paper, pens, and pencils. They are also printer-free, making their utilization more viable than paper [11]. Despite the wide availability of mHealth apps, an app with validated health care ePROs musculoskeletal data has not yet been developed.

To address the need for a viable way to group and utilize the main functioning assessment tools in the field of musculoskeletal disorders, the Physiotherapy Questionnaires app was developed. Paper versions of questionnaires are most often used; therefore, it is necessary to conduct a validation study to compare the paper and mobile phone versions of the physiotherapy questionnaires [12]. Thus, this study aims to explain the development of the app, to validate it using two physiotherapy questionnaires, and to analyze whether participants prefer to use the app or the paper version of the questionnaires.

Methods

The study was conducted in two stages. In the first stage, the app for an Android operational system was developed. In the second stage, a pilot validation study of the app was conducted and user compliance was analyzed.

Development of the App for Mobile Phones

The app is a collection of questionnaires related to clinical and functional diagnosis. As such, it aims to facilitate a feasible and portable assessment of musculoskeletal disorders. The app was coded by bachelor's degree students in the Physical Therapy

Program in partnership with students from the Computer Sciences program at the Federal University of Ceará, Fortaleza, Brazil, under the supervision of their professors. The Android platform was chosen for the app, using its native coding in Java in the Android Studio Integrated Development Environment with the Software Development Kit. This operational system was chosen due to the popularity and homogeneity of the hardware used on Android mobile phones.

In the initial stage of the development of the app, the aim was to select questionnaires that were most often used in musculoskeletal clinical practice and research. This selection was based on a literature search and input from a list of experts.

The trial version of the app was tested by 15 musculoskeletal physiotherapy fellows during their clinical practice to determine its feasibility. Weekly meetings were conducted over a period of 4 months so the experts could provide feedback about the possible difficulties in using electronic questionnaires. Based on their input, changes to the layout and functioning of the app were made.

Validation of the App

The Foot and Ankle Outcome Score (FAOS) and the American Orthopaedic Foot and Ankle Society (AOFAS) questionnaire were randomly selected to validate the app. First, the ankle section was chosen, and then the questions in this section were randomized. After that, the FAOS and the AOFAS questionnaires were selected for inclusion in the app.

The FAOS was validated in Brazil. It aims to assess pain, symptoms, activities of daily living, and sports/recreation activities in subjects who have a sprained ankle despite the fact that this questionnaire is not specific for this condition [13]. The questionnaire is completely self-reported and it contains 42 questions.

The AOFAS also aims to assess the ankle region. This questionnaire is not considered to be a PRO because it is not completely self-reported; some questions require the intervention of the examiner. The AOFAS contains nine questions distributed into three categories: pain (40 points), function (50 points), and alignment (10 points), for a total of 100 points [14].

Participants

A total of 100 participants were included in the study. The participants were males (n=30) and females (n=70) between the ages of 19 and 36 years (mean 24.2, SD 5.7 years). All participants signed an informed consent form. Participants who were unable to understand how to use the app were excluded from the study. The study was submitted to and approved by the Ethics Committee in Research with Human Beings of the Federal University of Ceará, Fortaleza, Brazil (number 1.847.143).

Both the paper and the electronic versions of the questionnaires were given to 50 participants for appropriate validation, thus resulting in a total of 100 participants [15]. The participants were divided in two groups: 50 completed the paper and app versions of the AOFAS and 50 completed the paper and app versions of the FAOS. The study's outcomes were the correlation of the data between the paper and app versions as

well as the preference of the participants between the two versions.

Procedures

The data collection began after the participants signed the informed consent form. The paper and app versions were randomly distributed and the order of completion of each version was mixed. The time allotted to complete each version was determined. An interval of 15 minutes was established between the versions, as noted in the study by Ferrari et al [16]. After completing the questionnaires, the participants were asked: "Which method do you think was better to answer?" The participants had three possible ways to answer that question: (1) app, (2) paper, and (3) indifferent.

One researcher conducted a face-to-face assessment with all the participants using a previously structured explanation about how the app works and how to answer the paper version. In regards to the explanation on how to use the app, the participant was informed how to select the answer options and how to move to the following item in the questionnaire. After the participants completed the questionnaires on the mobile phone, the data were transferred to an email account that only the statistician had access to. After the data analysis was complete, all the information related to the questionnaires was removed from the device that was used to collect the data. Moreover, after the participants answered the paper version of the questionnaire, the examiner verified possible human errors and sent the data to the examiner responsible for the data extraction.

Data Analysis

To check the validity of the two versions of the physiotherapy questionnaire (paper and electronic), the Wilcoxon *t* test was used to determine the differences between the means of the scores for the two versions and the intraclass correlation coefficient (ICC) was used to measure the level of intrarater reliability between the total scores, question by question in the AOFAS and by subscale in the FAOS, between the app and the paper versions. We considered ICC values ≥ 0.75 as excellent agreement and ICC values < 0.75 as poor to moderate agreement [17]. Validity was defined by the correlation and the difference between the means of the scores of the two versions. The calculations were made using SPSS version 22.0 software for Windows, with a significance level of 5%.

Results

Development and Design of the App

A total of 18 clinical musculoskeletal-related questionnaires were included in the app. Thus, questionnaires relating to the ankle region (AOFAS, Foot And Ankle Ability Measure, FAOS, Lower Extremity Functional Scale, and Cumberland Ankle Instability Tool) [18-20], the knee (Victoria Institute Of Sport Assessment-Patella, Knee Instability Scale Modified For Evaluation Of Patelofemoral Pain And Instability, Fulkerson Scale, Lysholm Knee Scoring Scale, and Kujala Scoring Questionnaire or Anterior Knee Pain Scale) [21-24], the low back (Oswestry Low Back Pain Disability Questionnaire and Roland Morris Disability Questionnaire) [25], the shoulder (The

Disabilities of the Arm, Shoulder and Hand Questionnaire, Shoulder Pain and Disability Index, Simple Shoulder Test, University of California at Los Angeles Shoulder Rating Scale, Western Ontario Rotator Cuff and American Shoulder and Elbow Surgeons Standardized Shoulder Assessment Form) [26,27], and the cervical spine (Neck Disability Index) [28] were included.

The final version of the app is available as a free download in English and Portuguese at the Google Play Store. In the first few days after release, more than 1000 apps were downloaded in Brazil. The app is basically composed of four screens. First, the user is presented with the categories of the questionnaires divided by body region (see Figure 1 A). The user must then click on one of the questionnaires to be redirected to a screen containing a patient information record (see Figure 1 B). Next, the questionnaire appears (see Figure 1 C). After the user has completed the questionnaire, the total score and the score by subscale are shown, informing the user about the scores and references for those scores (see Figure 1 D). Finally, on the results screen there is an option to generate a PDF file of a report containing all the user's answers; the answers with a low score are highlighted (see Figure 2 A).

For the layout of the ePROs used for the pilot validation, the questions in the AOFAS were answered by touching one of four circles or, alternatively, touching the text (see Figure 1 B). The score was then assigned based on the validated paper version [14], generating a total score of 100 points. Conversely, in the FAOS, the alternatives were displayed in the form of spinners and they were ranked using a Likert scale (0 to 4), as shown in Figure 3. The total score and the score by subscale in the FAOS were converted to percentages, ranging from 0% to 100% [13].

To make it more feasible to use ePROs, the app was developed so that it would work offline to avoid usability issues due to poor internet connections. In addition to calculating the score, the electronic version of the physiotherapy questionnaires allowed users to generate an Excel file containing the values of all the items selected by the patients (see Figure 2 B), making the data collection and statistical analysis easier.

Validating the App

The mean of the total scores of the FAOS were 91.54% (SD 8.86%) for the paper version and mean 91.74% (SD 9.20%) for the app, with a difference of 0.20% between the two versions. There was no statistically significant differences between the means of the total scores or the subscales ($P=.11-.94$). The means, the difference between the means, the standard deviations, and the *P* values for the scores for the paper and app versions for each question in the FAOS are presented in Table 1.

The app showed excellent agreement with the paper version of the FAOS, with an ICC value of 0.98 (95% CI 0.98-0.99) for the total score. The same level of agreement was found in the comparison between the paper version and the app version for each of the FAOS subscales, with the lowest ICC value of 0.93 (95% CI 0.88-0.96) in the Sports and Recreation subscale. The values of agreement for the FAOS subscales are listed in Table 1.

Figure 1. Screenshots of the Physiotherapy Questionnaires app. (A) Questionnaires by body region, (B) patient information record, (C) questionnaire, and (D) results.

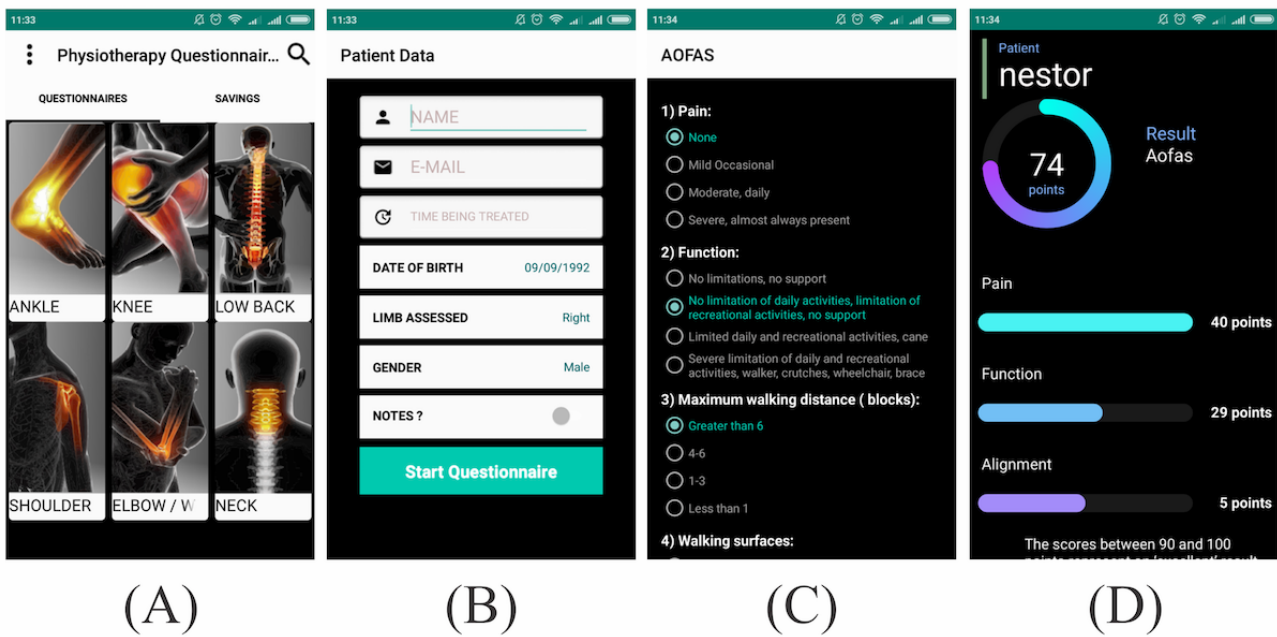


Figure 2. Example of (A) a PDF file and (B) an Excel file of a report containing all the user's answers.

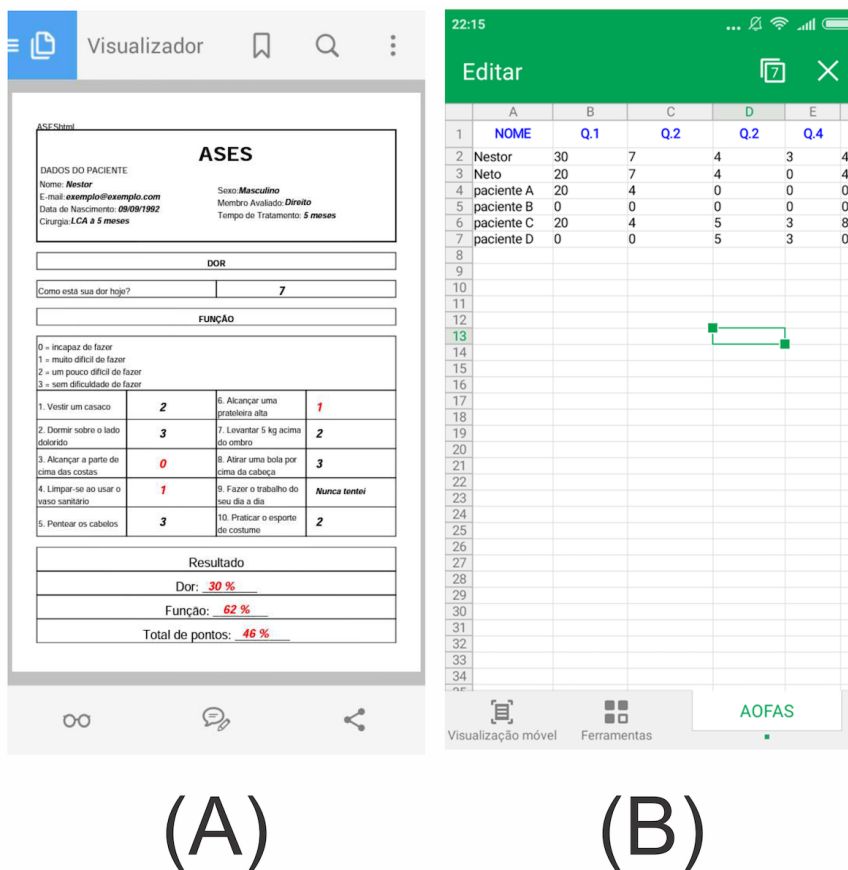
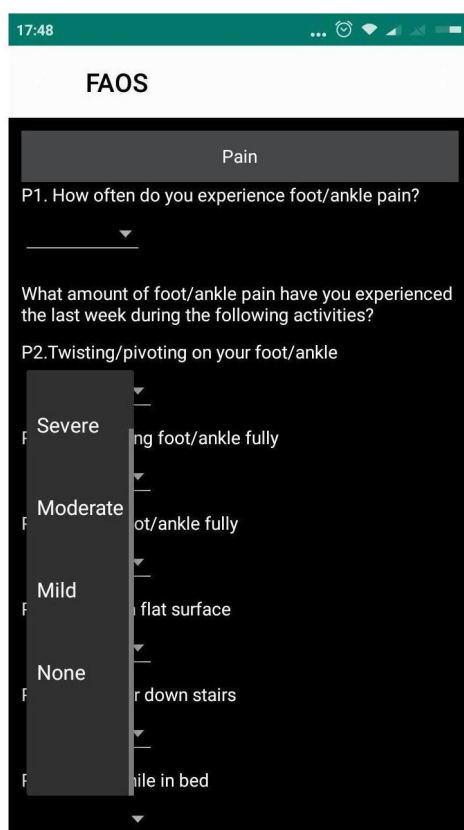


Figure 3. Screenshot of the app version of the Foot and Ankle Outcome Score (FAOS).**Table 1.** Comparison between the paper and app versions of the Foot and Ankle Outcome Score (FAOS).

Header	Paper (%), mean (SD)	App (%), mean (SD)	Mean difference (%)	<i>P</i>	ICC (95% CI)
Total	91.54 (8.86)	91.74 (9.12)	0.20	.23	0.98 (0.98-0.99)
Subscales					
Pain	91.34 (10.44)	90.96 (11.28)	0.38	.94	0.95 (0.91-0.97)
Symptoms	88.70 (9.87)	89.22 (10.92)	0.52	.14	0.92 (0.86-0.95)
Activities of daily living	95.98 (6.55)	96.22 (6.64)	0.24	.11	0.99 (0.98-0.99)
Sports/recreation	85.10 (20.98)	86.90 (18.74)	1.80	.28	0.93 (0.88-0.96)
Quality of life	86.54 (17.77)	86.78 (17.54)	0.24	.37	0.99 (0.99-0.99)

The mean total scores for the AOFAS were 93.94 (SD 8.47) for the paper version and mean 93.96 (SD 8.48) for the app, with a difference of 0.02 points between the two versions. The results were similar to the results for the FAOS; no statistically significant differences were found for the total scores for the AOFAS or the subscales ($P > .99$). The means, the difference between the means, the standard deviations, and the P values for the scores for the paper and app versions for each question in the AOFAS are presented in [Table 2](#).

Excellent agreement between the app version and the paper version was also found for the AOFAS. The ICC value for the total score in the AOFAS was 0.99 (95% CI 0.98-0.99). A similar level of agreement was also found for the AOFAS questions, with the lowest ICC value of 0.87 (95% CI 0.78-0.93) in question 3. It was not possible to calculate the correlation in

question 6 because there was no variation in the score of this question between the paper and app versions. The values of agreement for the AOFAS questions are presented in [Table 2](#). Details about the participants' preferences are presented in [Figures 4](#) and [5](#).

The mean time to complete the paper version of the FAOS was 170.18 (SD 47.30) seconds; the mean time to complete the app version was 189.50 (SD 69.61) seconds. Thus, the paper version was completed 19.32 seconds faster than the app version ($P = .004$). Conversely, the mean time to complete the paper version of the AOFAS was 83.82 (SD 42.27) seconds; the mean time to complete the app version of the AOFAS was 53.64 (SD 29.04) seconds. Thus, the app version was completed 30.18 seconds faster than the paper version ($P < .001$).

Table 2. Comparison between the paper and app versions of the American Orthopaedic Foot and Ankle Society (AOFAS) questionnaire.

Reliability	Paper (%), mean (SD)	App (%), mean (SD)	Mean difference (%)	P	ICC (95% CI)
Total	93.96 (8.47)	93.94 (8.48)	0.02	>.99	0.99 (0.98-0.99)
Questions					
Q1	37.60 (4.76)	37.60 (4.76)	0.00	>.99	1.00 (1.00-1.00)
Q2	9.82 (0.59)	9.98 (0.59)	0.06	>.99	0.88 (0.79-0.93)
Q3	4.88 (0.32)	4.84 (0.50)	0.04	>.99	0.87 (0.78-0.93)
Q4	4.44 (0.90)	4.44 (0.90)	0.00	>.99	1.00 (1.00-1.00)
Q5	7.78 (0.88)	7.78 (0.88)	0.00	>.99	1.00 (1.00-1.00)
Q6	8.00 (0.00)	8.00 (0.00)	0.00	>.99	— ^a
Q7	5.94 (0.42)	5.94 (0.42)	0.00	>.99	1.00 (1.00-1.00)
Q8	7.20 (2.42)	7.20 (2.42)	0.00	>.99	1.00 (1.00-1.00)
Q9	8.36 (2.51)	8.46 (2.55)	0.10	>.99	0.98 (0.96-0.98)

^aThe variables have zero variance.

Figure 4. Preference of participants between the paper and app versions of the Foot and Ankle Outcome Score.

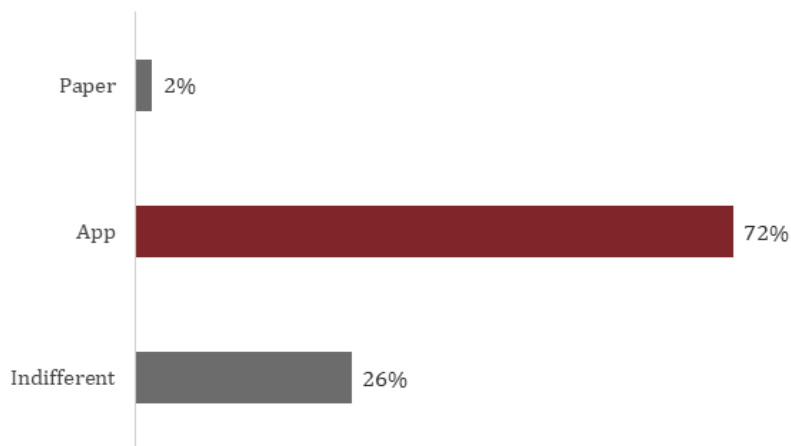
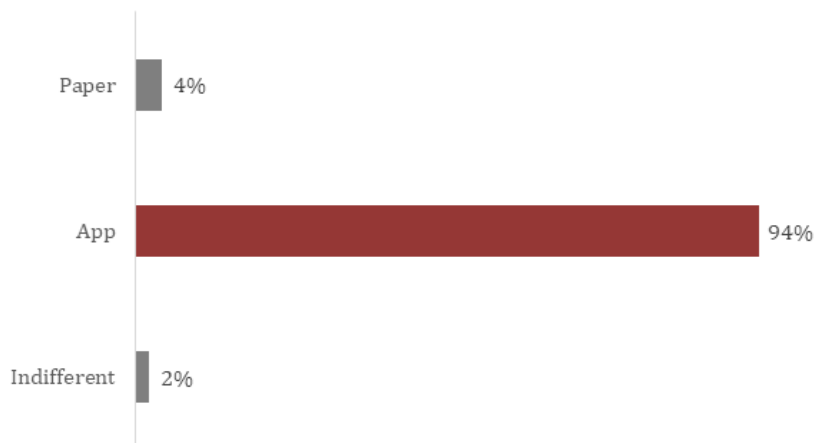


Figure 5. Preference of participants between the paper and app versions of the American Orthopaedic Foot and Ankle Society questionnaire.



Discussion

Principal Results

There is a lack of validated ePROs to help clinicians apply musculoskeletal measurement tools, especially in Portuguese [29]. This study aimed to develop an app and conduct a validation of two questionnaires used in the electronic version of the app. Although the wording of the questions in the proposed app was preserved, their layouts were adapted for use on mobile phones and the new format was approved by a list of experts as well as less-experienced patients. In this way, it is possible to ensure that the development of the app was successful.

The results of the study provide evidence about the agreement between the scales included in the paper and electronic versions in the PQapp. Although in a previous study Bierbrier et al [30] did not focus on musculoskeletal measurement tools, they did demonstrate the accuracy of the results of the app version of the physiotherapy questionnaire scales for mobile phones by testing a variety of mHealth apps obtained from iTunes and the Google Play Store. These data are important to ensure the reliability of the information obtained within the app, thus eliminating the possibility of human error. The results also provide important information about the validity of the reports generated by the electronic version of the AOFAS and the FAOS questionnaires [18] that are used to measure ankle instability.

The analysis of equivalence between an ePRO and its paper version can be conducted based on the degree of modification that was made to the electronic version [17]. In this study, it was necessary to moderately adapt the ePROs to create the app; this included reducing the font size and adding the use of ScrollView (scroll down to see all the alternatives) because some of the questions required more than one page. These modifications justify the need to conduct a validation study for the app. Due to logistical requirements and time unavailability for the validation of all questionnaires, our study is only a partial validation of the app. Thus, we decided to start by randomly choosing two questionnaires for the app: FAOS and AOFAS.

The concurrent validity of the FAOS and AOFAS questionnaires was supported by a strong positive correlation between the reports provided by the two different versions. The paper and mobile phone reports of other questionnaires have already been compared, and a high correlation between them has been found without any statistically significant differences. Bush et al [31] assessed active military personnel in the United States and reported similar answers for the means of seven dimensions between an app and a paper version of the questionnaire. Similarly, Garcia-Palacios et al [32] investigated the use of questionnaires for patients with fibromyalgia and reported no statistically significant differences between the means of the pain and fatigue scores obtained with the mobile phone and paper versions of the tool used in the study. For patients with rheumatic diseases, ePROs have been found to have excellent

agreement with their paper versions [33]. Kim et al [34] found a strong correlation between paper and mobile phone versions of the International Prostate Symptom Score in their study of validity and reliability.

Only a few studies have compared the mobile phone and paper versions of questionnaires related to musculoskeletal conditions [29]. The initial validation process for the app demonstrates that FAOS and AOFAS are ePRO pioneers for ankle and foot assessments on mobile phones. In their electronic versions, both questionnaires present equivalent data, as recommended by Belisário et al [29]

In regard to the use of touchscreen technology in questionnaires that assess health outcomes, the evidence suggests that patients prefer electronic methods rather than paper because the information can be provided more efficiently and accurately than the paper version; the electronic version also guarantees increased safety when answering questionnaires on a mobile phone [29,33]. It has also been reported that it is safer and faster to answer the questionnaires on a mobile phone [34,35]. The results of our study confirm that users prefer to answer questionnaires using the app version instead of the paper version of the questionnaires.

Belisário et al [29] affirmed that it is unclear whether it takes less time to complete a questionnaire on mobile phones than when using the paper version; however, they concluded that factors such as population characteristics, study design, and platform interface could have some effect on the result. In fact, our research showed a faster completion time for the paper version compared to the app version for the FAOS. This fact may be due to differences in the layout between the paper and app versions of this questionnaire. The alternatives were displayed in the form of spinners in the app (see Figure 3), which were revealed after the user clicked on the screen. In the paper version (see Figure 6), the alternatives were placed next to each other, which may have contributed to the faster completion time. Nevertheless, despite the statically significant difference of 19.32 seconds between the two versions, this value may not be clinically relevant.

Limitations

This study has some limitations. Regarding the analysis of participant preferences, the graphic content and layout aspects of the app were not evaluated during the data collection. Thus, future research might consider these factors to obtain a better assessment of participant satisfaction.

Moreover, we did not evaluate the experience/familiarity of the participants with mobile phones. Nevertheless, we believe that the high ICC values might be due to the fact that only young participants who knew how to operate a mobile phone were included in the study. This might have resulted in selection bias; however, this is the first study to show the validity of a mobile phone version of the FAOS and AOFAS questionnaires using scientific methods.

Figure 6. Paper versions (in Portuguese) of the American Orthopaedic Foot and Ankle Society (AOFAS) questionnaire and the Foot and Ankle Outcome Score (FAOS).

AOFAS

<p>1.Dor (40 pontos)</p> <p>() Nenhuma.....40</p> <p>() Leve, ocasional.....30</p> <p>() Moderada, diária.....20</p> <p>() Intensa quase sempre presente.....0</p>	<p>2.4 Mobilidade sagital(flexão + extensão)</p> <p>() Normal ou levemente restrito(30° ou mais)8</p> <p>() Restrição moderada(15° - 25°)4</p> <p>() Restrição Intensa(menos que 25% do normal)0</p>
<p>2.Funcional(50 pontos)</p> <p>Limitação nas atividades, necessidade de suporte</p> <p>() Sem limitação, sem suporte.....10</p> <p>() Sem limitação nas atividades diárias, limitação nas atividades ocasionais.....0</p>	<p>2.5 Mobilidade do Retro-pé(inversão + extensão)</p> <p>() Normal ou levemente 6 restrito(75% -100% do normal)</p> <p>() Restrição moderada(25%- 74% do normal)0</p>

FAOS

DOR	
P1 Qual a frequência que você sente dor no tornozelo ou no pé? Qual a intensidade de dor que você sentiu na última semana durante as seguintes atividades?	Nunca, Mensalmente, Semanalmente, Diariamente, Sempre
P2. Rodando sobre o seu tornozelo ou o pé	Nenhuma, Leve, Moderada, Acentuada, Extrema
P3. Forçando o seu pé completamente para baixo	Nenhuma, Leve, Moderada, Acentuada, Extrema
P4. Forçando o seu pé completamente para cima	Nenhuma, Leve, Moderada, Acentuada, Extrema
P5. Andando sobre uma superfície plana	Nenhuma, Leve, Moderada, Acentuada, Extrema
P6. Subindo ou Descendo escadas	Nenhuma, Leve, Moderada, Acentuada, Extrema
P7. Em repouso na cama	Nenhuma, Leve, Moderada, Acentuada, Extrema
P8. Ao sentar-se/deitar-se	Nenhuma, Leve, Moderada, Acentuada, Extrema
P9. Em pé	Nenhuma, Leve, Moderada, Acentuada, Extrema
OUTROS SINTOMAS	
S1 Qual o grau de rigidez do seu tornozelo/ pé logo quando você acorda?	Nenhum, Leve, Moderada, Acentuada, Extrema
S2. Qual o grau de rigidez após sentar, deitar ou ao descansar mais tarde durante o dia?	Nenhum, Leve, Moderada, Acentuada, Extrema
Sy1. Você tem inchaço no seu pé/tornozelo?	Nunca, Raramente, Às vezes, Frequentemente, Sempre
Sy2. Você sente ranger, estalar ou qualquer outro tipo de som quando...	Nunca, Raramente, Às vezes, Frequentemente, Sempre

Conclusions

The Physiotherapy Questionnaires app is a useful tool for health care professionals because it combines two main questionnaires used to assess musculoskeletal disorders. The app allows clinicians to easily and effectively calculate, save, and organize

the patient's answers to two physiotherapy questionnaires. The app showed validity and high levels of compliance for the FAOS and AOFAS, which indicates it is not inferior to the paper version of these two questionnaires and confirms the app's viability and feasibility for use in clinical practice.

Conflicts of Interest

None declared.

Multimedia Appendix 1

FAOS Questionnaire.

[[PDF File \(Adobe PDF File\), 146KB - rehab_v5i1e1_app1.pdf](#)]

Multimedia Appendix 2

AOFAS Questionnaire.

[[PDF File \(Adobe PDF File\), 343KB - rehab_v5i1e1_app2.pdf](#)]

Multimedia Appendix 3

Video promo pq app.

[[MP4 File \(MP4 Video\), 7MB - rehab_v5i1e1_app3.mp4](#)]

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Abbreviations

- AOFAS:** American Orthopaedic Foot and Ankle Society
- ePRO:** electronic patient-reported outcome
- FAOS:** The Foot and Ankle Outcome Score
- ICC:** interclass correlation coefficient
- mHealth:** mobile health
- PRO:** patient-reported outcome

Edited by G Eysenbach; submitted 23.10.17; peer-reviewed by M Kotter, B Davies; comments to author 27.12.17; revised version received 28.12.17; accepted 02.01.18; published 23.02.18.

Please cite as:

Teixeira Neto NC, Lima YL, Almeida GPL, Bezerra MA, Lima PODP, de Oliveira RR

Physiotherapy Questionnaires App to Deliver Main Musculoskeletal Assessment Questionnaires: Development and Validation Study
JMIR Rehabil Assist Technol 2018;5(1):e1

URL: <http://rehab.jmir.org/2018/1/e1/>

doi: [10.2196/rehab.9247](https://doi.org/10.2196/rehab.9247)

PMID: [29475827](https://pubmed.ncbi.nlm.nih.gov/29475827/)

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Original Paper

A Kinematic Sensor and Algorithm to Detect Motor Fluctuations in Parkinson Disease: Validation Study Under Real Conditions of Use

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Abstract

Background: A new algorithm has been developed, which combines information on gait bradykinesia and dyskinesia provided by a single kinematic sensor located on the waist of Parkinson disease (PD) patients to detect motor fluctuations (On- and Off-periods).

Objective: The goal of this study was to analyze the accuracy of this algorithm under real conditions of use.

Methods: This validation study of a motor-fluctuation detection algorithm was conducted on a sample of 23 patients with advanced PD. Patients were asked to wear the kinematic sensor for 1 to 3 days at home, while simultaneously keeping a diary of their On- and Off-periods. During this testing, researchers were not present, and patients continued to carry on their usual daily activities in their natural environment. The algorithm's outputs were compared with the patients' records, which were used as the gold standard.

Results: The algorithm produced 37% more results than the patients' records (671 vs 489). The positive predictive value of the algorithm to detect Off-periods, as compared with the patients' records, was 92% (95% CI 87.33%-97.3%) and the negative predictive value was 94% (95% CI 90.71%-97.1%); the overall classification accuracy was 92.20%.

Conclusions: The kinematic sensor and the algorithm for detection of motor-fluctuations validated in this study are an accurate and useful tool for monitoring PD patients with difficult-to-control motor fluctuations in the outpatient setting.

(*JMIR Rehabil Assist Technol* 2018;5(1):e8) doi:[10.2196/rehab.8335](https://doi.org/10.2196/rehab.8335)

KEYWORDS

Parkinson disease; movement disorders; movement; gait

Introduction

Parkinson disease (PD) is the second most frequent neurodegenerative disease after Alzheimer, with an age-standardized annual incidence rate of 160 per 100,000 subjects aged 65 years or older [1]. Patients suffering from this disease present a motor disorder characterized by muscle stiffness (rigidity) and slow movement (bradykinesia), sometimes accompanied by tremor and freezing of gait (patients feel their feet are stuck to the ground and cannot take a step). These symptoms are related to a deficiency in neurotransmitter dopamine in certain brain areas that are in charge of the motor control. Therefore, exogenous administration of L-Dopa or other dopaminergic agonists constitutes the first line of treatment in PD [2]. As the disease progresses, patients experience motor fluctuations between a so-called On-state, where symptoms are under control and the patient can move fluently, and a so-called Off-state, where motor symptoms reappear or worsen [3]. It is currently considered that Off-periods are related to the waning of dopaminergic medication effects and that they can be relieved by keeping stable plasmatic levels of medication. Thus, dose fractionation, prolonged-release preparations, or drug infusion pumps can be used with the aim of providing more physiological continuous dopaminergic stimulation. Furthermore, patients with advanced PD may present dyskinesia—involuntary and excessive movement of one or more body segments—which is related to excessive dopaminergic stimulation and, again, may be ameliorated by keeping plasmatic dopaminergic drugs at a stable level [4].

To make appropriate therapy adjustments to reduce motor fluctuations and dyskinesia, physicians need detailed information on the time course of these symptoms, which may appear several times a day. Due to the fluctuating and irregular nature of motor manifestations, such information is hard to collect in office. Thus, physicians may ask patients to keep written records of the times of the day when fluctuations occur. However, such records have severe limitations, in terms of the quality of the collected information, due to memory bias and low patient adherence [5]. Therefore, devices capable of automatically and continuously detecting and recording motor fluctuations would be very welcome in the clinical practice; they could help physicians optimize therapy schedules, thus, enhancing patients' quality of life. Furthermore, they would be extremely useful tools in clinical trials for new therapies, where the basic evaluation parameter is the time in Off state, which is very difficult to measure reliably and uniformly by other means.

Inertial sensors, especially accelerometers, have been used to detect and quantify various motor symptoms of PD. Zwartjes et al studied the severity of bradykinesia, hypokinesia, and tremor in 6 PD patients using 4 inertial sensors (located on the wrist, thigh, foot, and sternum) and found a correlation between their measurements and the Unified Parkinson's Disease Rating Scale (UPDRS) [6]. Salarián et al measured tremor and bradykinesia in 10 patients, using an accelerometer on each forearm and also found a good correlation with the UPDRS [7]. During the course of the European project PERORM [8], a system with 5 sensors was developed, which classified the severity of bradykinesia, tremor, and dyskinesia with 87%

accuracy. Keijsers et al detected dyskinesia in 6 patients, using 3 inertial sensors, with 96.6% accuracy [9]. Other authors have used inertial sensors to analyze the freezing of gait [10-12], although the accuracy of their detection algorithms was lower, often below 70%. A few authors have attempted to detect motor fluctuations (On and Off-periods) rather than individual symptoms [13-15]. However, to the best of our knowledge, at present there is no device available in the market or being tested in research studies capable of detecting motor phases (On and Off) frequently and accurately enough to help physicians adjust the dopaminergic medication regimen. Our research team developed an accelerometry-based sensor device and the corresponding algorithm, which can make frequent readings of the patient's motor state, with the aim of providing a useful tool for therapeutic schedule adjustments [16]. The goal of this study was to analyze the accuracy of the kinematic sensor and the algorithm under real conditions of use, in a group of PD patients with motor fluctuations.

Methods

Participants

This prospective validation study was conducted on a sample of 23 patients with moderate to severe PD and motor fluctuations. Patients unable to recognize different motor states (On and Off), presenting gait disorders other than those of PD, or unable to walk without the help of a third person were excluded.

The study was conducted entirely in the province of Barcelona, Catalonia (Spain), between 2013 and 2016. Participants were selected by convenience sampling among those attending the neurology clinics of any of the 4 participating hospitals (Consorci Sanitari del Garraf, Centro Médico Teknon, Hospital de Vall d'Hebron, Hospital Germans Trias i Pujol), or among the members of the Catalanian Association for Parkinson (Asociació Catalana Per al Parkinson) and its subsidiaries. The sample size was chosen on the basis of previous experience in similar validation studies [8,13,17].

Data Collection

On the first day of the study, all patients were administered the motor section of the UPDRS [18]. Sociodemographic data (sex, age, and marital status), years of evolution of the PD, and the drug regimen were also recorded. Participants were asked to wear the kinematic sensor attached to the waist (left lateral side) for a variable number of daytime hours, within a period of 1 to 3 consecutive days, according to their individual preference. The location on the waist was comfortable for patients and suitable to provide precise information about the body movements [19-21] (Figure 1).

During the study, patients were living in their usual environment, carrying on their usual daily activities, and were not suggested or prevented from doing any specific task. Patients were also asked to simultaneously keep a specially designed diary, where they had to record their motor state (On or Off) every 30 min. All patients were previously instructed regarding the use of the diary and the recognition of their motor fluctuations. Patients were blind to the records provided by the sensor they were

wearing. Researchers were not present during the time patients were wearing the sensor in order to prevent interferences in their natural activities. However, a researcher was in charge of calling them by telephone every 2 to 3 hours to reinforce the use of the diary and record the motor state reported by the patient at the moment of the telephone call. The sensor and its battery charger were handed over on the first day and collected on the last day of the study. The patients or their accompanying person were in charge of recharging the device during the hours it was not being used. Local Ethics Committees approved the research protocol at each participating institution. All participants signed an informed consent form before their inclusion in the study.

Algorithm Overview

The sensor readings were based on measurements from the accelerometer—sampled with a 40 Hz frequency—and provided output in nonoverlapping 10-min periods. The output of every 10-min period consisted in: presence or absence of gait bradykinesia plus presence or absence of dyskinesia.

Since patients in the Off-state do not present choreoic-type dyskinesia; detection of dyskinesia was considered an indicator of the On-state. Failure to detect dyskinesia left the classification of the motor state to the presence or absence of bradykinesia: Off-state for clearly bradykinetic gait, On-state for normal gait, and intermediate-state for abnormal gait that however did not reach the threshold to be considered bradykinesia. Failure to detect any movement (neither dyskinesia nor gait) led us to consider the motor state unknown. The algorithmic process to detect bradykinesia and dyskinesia has been described in detail elsewhere [16]. However, a short description is offered below for the sake of self-completeness.

Briefly, a first algorithm was designed to analyze patients' bradykinetic gait in the following 5 phases:

1. Walk detection was based on 3.2-sec signal segments, which were characterized by their power spectra and analyzed with a support vector machine (SVM). The SVM had been previously trained with labeled signals from 20 different PD patients, who did not participate in the On and Off state monitoring for data collection in this study. Walk detection accuracy was higher than 90% [23].
2. Stride detection was carried out on those signal segments, on which the SVM detected that the patient was walking. It was based on biomechanical properties reflected in the acceleration signals; namely, every time the patient took a step (the so-called initial contact event, when the foot touches the ground) a local relative extremum was observed in the 3 acceleration signals, which was leveraged to identify the strides. The first two and the last two strides in a walking bout were disregarded in order to avoid analyzing gait initiation and finalization.
3. Characterization of every stride in terms of movement fluidity—a feature closely related to bradykinesia, which the authors found to be correlated with the On and Off-states in a previous study [24]. This feature consisted in the power spectra within the 0 to 10 Hz band of the acceleration measurements comprising a stride. In this way, by providing the detected strides (once gait initiation and finalization strides had been disregarded), a scalar value representing movement fluidity was obtained. In our aforementioned earlier work, we found higher values for patients in the On-state and lower values for those in the Off-state.
4. Calculation of the average of all strides comprised in every nonoverlapping 10-min period.
5. Comparison of this average with the patient's individual threshold. If the average fluidity in a 10-min period was higher than the threshold, gait bradykinesia was considered for that patient in that period; whereas if it was lower, bradykinesia was ruled out. Finally, if the average value was close to the threshold (within the range: $\text{threshold} \pm 1.7 \text{ m/s}^2$) intermediate gait was considered.

Figure 1. Inertial sensor.



The algorithm’s final output was presence or absence of gait bradykinesia or indeterminacy, in case the subject had not walked within the analyzed 10-min period (Figure 2). The patient-specific threshold was established in an unsupervised manner based on the distribution of gait fluidity measurements recorded while monitoring each patient. In particular, the threshold was calculated by using the histogram of fluidity measurements. Thus, if 2 separated bell-shaped curves were observed, each one with at least 15% of data, the threshold was established at the mean value between them. However, if 2 bell-shaped curves were not obtained, or if they did not contain enough data, the bradykinesia threshold was established at the highest bradykinesia value below the mode with a frequency of at least 60% of the frequency of the mode.

A second algorithm was designed to analyze choreoic dyskinesia on the basis of the frequency content of the accelerometer measurements. This second algorithm was organized in the following phases:

1. Walk detection and postural transition detection, based on 3.2-sec acceleration signal segments, where the above mentioned SVM was used to determine whether the patient was walking, plus analysis of the power spectra between 0.1 and 0.6 Hz (by comparison with a previously determined threshold, which was the same for all the patients) to establish whether the patient was engaged in a postural transition (eg, stand-to-sit or sit-to-stand). In case walking or postural transition was detected in a signal segment, the following phase 2 was skipped, given that such actions were considered to possibly hide dyskinetic movements.
2. Dyskinesia detection. For every 3.2-sec segment in which the patient was not walking or in postural transition, the power spectra between 1 and 4 Hz were compared with a threshold (previously determined and the same for all patients) to assess whether the patient presented dyskinesia in that segment.
3. Aggregation per minute. If the ratio of segments, which were analyzed within a certain minute (ie, the ratio of segments without walking or postural transitions) was lower than 30%, the output of the algorithm for that particular

minute was undetermined. If the ratio of segments with positive dyskinesia detection was higher than 40%, presence of dyskinesia was considered for that minute. Otherwise absence of dyskinesia was considered.

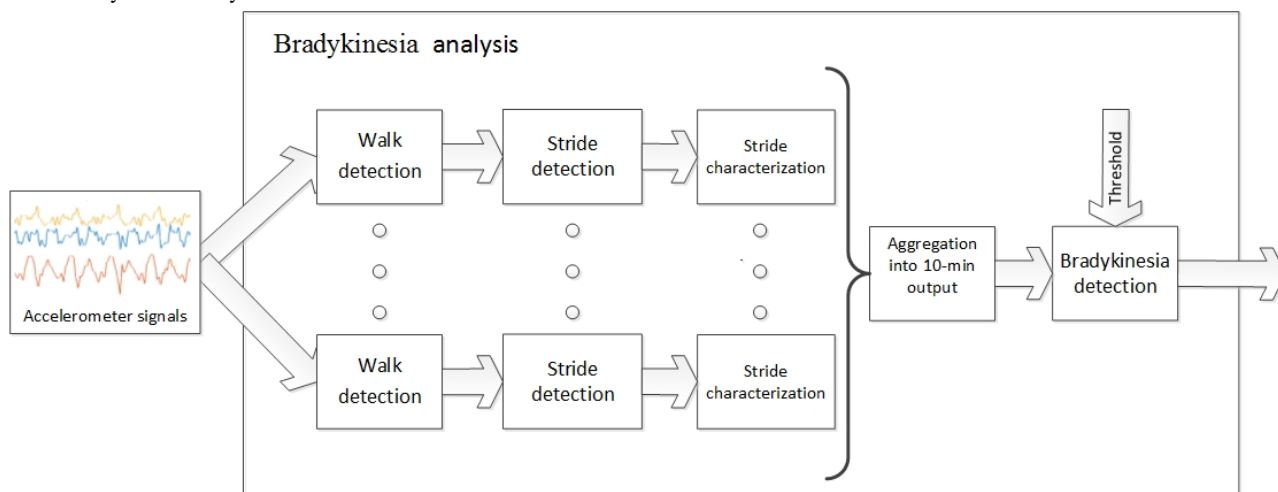
4. Finally, the output for periods of 10 nonoverlapping consecutive minutes was obtained. If 8 out of the 10 min in a certain period were undetermined, the output of that 10-min period was considered to be undetermined. Otherwise, presence or absence of dyskinesia was considered on the basis of the most frequent per-minute output in that period.

Patients’ motor state was estimated in 10-min periods, according to the output of the above described algorithms. The motor state was classified as On-state when the patient did not show gait impairment or showed dyskinesia, Off-state when the patient showed bradykinetic gait and did not show dyskinesia, intermediate-state when the patient showed intermediate gait and did not show dyskinesia, and any other situation was classified as unknown motor state. In patients, who did not show dyskinesia, the motor state was established according to bradykinetic gait. Finally, the 10-min periods were analyzed in groups of three consecutive ones. In case the outputs of the first and the third periods were equivalent and that of the second period was unknown, the output of the second period was considered to be the same as the first and the third ones.

Training and Testing of the Machine Learning Algorithms

The training of the bradykinetic gait-detection algorithm, which corresponded to training the SVM for gait detection, was carried out with data from 20 PD patients from a previous research study [22]. The bradykinesia feature was identified in that study and did not require any training procedure as it merely characterized the strides. Finally, the threshold to be compared with the averaged bradykinetic features was calculated for each patient, according to the procedure described above (using the histogram of fluidity measurements), which did not require any machine learning algorithm and was applied in an unsupervised manner (ie, diaries were not used).

Figure 2. Bradykinesia analysis.



The dyskinesia-detection algorithm only required one supervised learning model, which was the SVM used in gait detection. Dyskinesia and postural transitions were detected by comparing the signal's power spectra with specific thresholds, established in 2 previous research studies [22,24]. Finally, the thresholds for the analysis of the 1-min and 10-min periods had also been established in previous research studies and were used as constant values to analyze the signals from all patients.

In summary, the only part of the algorithm that was adapted to each patient was the bradykinetic gait threshold, which was unsupervised. The remaining parts of the algorithm were constant and had been established in previous research studies.

Statistical Analysis

To evaluate the accuracy for classification of the algorithm readings, they were compared with the records on the patients' diaries. Time slots with no information on a patient's diary were excluded from the analysis. Accuracy was calculated by using the following formula:

$$\text{Accuracy} = (\text{TP} + \text{TN}) / (\text{TP} + \text{TN} + \text{FP} + \text{FN})$$

where TP are true positives, TN true negatives, FP false positives, and FN false negatives.

Positive predictive value (PPV) and negative predictive value (NPV) were calculated by using the following formulas:

$$\text{PPV} = \text{TP} / (\text{TP} + \text{FP})$$

$$\text{NPV} = \text{TN} / (\text{TN} + \text{FN})$$

where TP are true positives, TN true negatives, FP false positives, and FN false negatives.

The sensitivity (number of Off-episodes detected out of the total Off-episodes occurred) and the specificity (number of On-episodes detected out of the total On-episodes occurred) were not calculated, as the actual number of Off and On-episodes cannot be found out in an unsupervised experiment (patients do not rigorously record all the motor-phases in their diaries, which is the reason why better outpatient monitoring standards are sought).

The raw accuracy measurements for the total sensor's readings were calculated by comparison with the patients' records, whenever they were available (for this calculation, patients with longer monitoring times contributed more to the result). Additionally, average accuracy measurements were calculated by calculating the accuracy for every individual patient and averaging the results (for this calculation, the data from every patient weighted the same) Statistical analysis was conducted with the SPSS V.21.0 software package (IBM Corp, Armonk, NY).

Results

Participant Data

Out of 32 initially contacted patients, 6 were excluded because they did not experience motor fluctuations or were unable to recognize their motor state, and one was excluded because of inability to walk. The data from 2 patients were not valid because of errors during the data collection process: sensor malfunction (data were deleted or recorded incorrectly) or misuse (not switching the sensor off properly or not noticing error messages). A total of 23 patients with complete datasets were eventually included. Table 1 shows the sociodemographic and health-related data from the 23 participants.

Table 1. Characteristics of the participants (N=23).

Characteristic	Statistics
Age in years, mean (SD)	63.8 (9)
Male, n (%)	16 (70)
Female, n (%)	7 (30)
Married, n (%)	16 (70)
Single or widower, n (%)	7 (30)
Years of disease, mean (SD)	9.8 (5)
Total L-Dopa dose (mg/day), mean (SD)	723 (486)
UPDRS ^a (motor section), median (IQR ^b)	21 (16)
Percentage of daily time in Off-state	
1% to 25%, n (%)	16 (70)
26% to 50%, n (%)	7 (30)

^aUPDRS: Unified Parkinson's Disease Rating Scale.

^bIQR: interquartile range.

Table 2. Sensor and algorithm's validation results.

Patient	Positive predictive value (%)	Negative predictive value (%)	Accuracy (%)	Total sensor detections	Sensor output with gold standard available	Total diary annotations	Monitoring time (hours)	Number of monitoring days
1	80	83	82	19	11	10	11.2	1
2	N/A ^a	100	100	4	1	5	4.2	1
3	100	100	100	29	16	16	8.6	1
4	100	100	100	12	7	6	3.1	1
5	100	100	100	7	4	14	11.0	1
6	100	100	100	8	3	6	18.6	1
7	N/A	100	100	34	27	19	10.9	1
8	N/A	100	100	10	2	6	9.0	1
9	92	100	95	38	19	22	19.0	2
10	N/A	92	92	102	74	44	40.1	3
11	100	83	88	53	16	33	27.0	2
12	80	100	92	19	13	9	18.1	2
13	94	73	84	48	31	30	41.1	3
14	90	94	93	93	60	52	40.4	3
15	67	100	83	23	12	25	27.9	2
16	100	84	85	34	27	24	41.0	3
17	100	91	93	37	27	25	35.2	3
18	100	95	96	42	24	48	36.3	3
19	67	100	71	11	7	10	13.4	2
20	N/A	92	92	19	12	21	39.3	3
21	100	71	75	17	8	48	35.2	3
22	100	100	100	9	7	13	24.2	2
23	N/A	100	100	3	2	3	10.0	1
Total	92	94	92	671	410	489	524.6	45

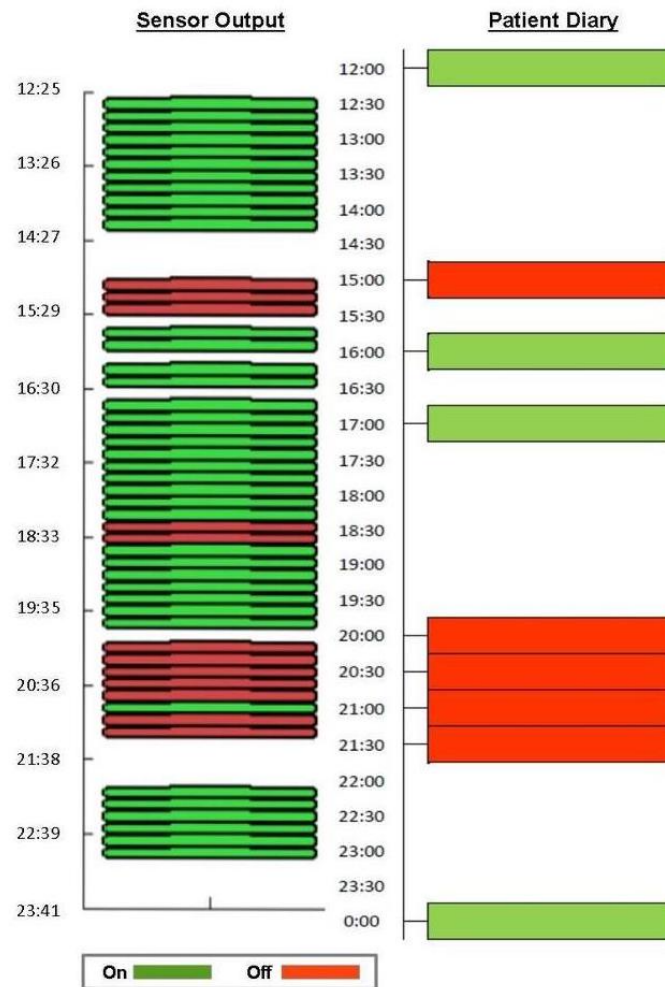
^aN/A: not applicable.

Evaluation Outcomes

The mean monitoring time was 23 hours per patient. During that time, a sensor produced 671 conclusive results (On or Off classifications or detections) for all patients, which corresponded to 22.8 results per patient and 1.3 On or Off classifications per hour and patient. From all the sensor detections, only 410 had a corresponding record in the patients' diaries with which they could be compared. The sensor's raw PPV, calculated by comparing the total of sensor readings with the total of patients'

records, was 89.3% (95% CI 85.8%-92.1%), the row NPV was 92% (95% CI 88.9%-94.4%). [Table 2](#) shows the PPV and NPV for each individual patient. The mean of PPV and NPV for all the patients were 92% (95% CI 87.33%-97.3%) and 94% (95% CI 90.71%-97.1%), respectively. The average classification accuracy was 92.20%. Patients' individual accuracies are also shown in [Table 2](#).

[Figure 3](#) shows an example of comparison between the outcomes of the algorithm and the data recorded in a patient's diary.

Figure 3. Comparison between the outcomes of the algorithm and the data recorded in a patient's diary.

Discussion

Principal Findings

Our results evidenced that the tested algorithm accurately detected motor fluctuations in patients with advanced PD. Additionally, as the experimental work was neither carried out in a controlled environment nor observed by researchers, the results might be extrapolated to the clinical practice. Experiments were conducted under real conditions of use and the data provided by the sensor were compared with the most extensively used standard in the clinical practice that is, the patients' diaries. Given the limitations of this standard, we used it only in patients who were able to recognize their motor state and additionally provided telephonic reminders to reinforce its use. Note that previous calibration or adaptation of the algorithm to individual users was not necessary; instead, a self-calibration method was used, which avoided the need of conducting previous tests with the patients.

Comparison With Earlier Evidence

As far as we know, only 2 research studies have been attempted to detect the On and Off-motor states under real conditions using inertial sensors. In one of these studies, the commercially available device Kinetigraph, a bracelet with an accelerometer, was found to detect bradykinesia and dyskinesia [17] and to

classify fluctuating patients versus controls [25] with an acceptable accuracy. However, the device and its algorithms offered global results (over a certain period of time) and could not make hourly determinations of the motor state with good accuracy (correlation was .4 in a comparison with patients' diaries) [13]. Therefore, though it might be useful to evaluate whether a patient's time in Off-state is reduced (or not) by the medication in the medium term, it would not be useful to determine the times of the day when the patients are in Off-state with accuracy enough as to fine-tune therapeutic regimens. In the second study, Hoff et al used multichannel accelerometry, previously validated for the detection of hypokinesia, bradykinesia, and tremor. However, their measurements showed limited sensitivity (0.60-0.71) and specificity (0.66-0.76) for motor fluctuations in individual PD patients (the authors did not provide the percentage of classification accuracy) [14]. Keijsers et al used 6 sensors located on different parts of the body to detect motor fluctuations, although their experiment was conducted in laboratory instead of real conditions [15]. These authors analyzed the whole inertial signal produced over the 3 hours of the experiment (not only those moments when the algorithm produces an output as in our research); in such circumstances, sensitivity and specificity correspond to PPV and NPV, respectively. They found acceptable sensitivity and specificity for detection of the motor state through measurements of bradykinesia on the wrist (sensitivity 0.71-0.74; specificity

0.78) and leg (sensitivity 0.78; specificity 0.82). They did not use sensors on the waist but used one on the chest, which showed high accuracy (sensitivity 0.96; specificity 0.95) by measuring a thoracic tremor which was found to be greater in the Off-state than in the On-state, even in patients with nontremors PD. This finding is, however, difficult to interpret; and, as far as we know, it has not been reproduced in subsequent studies (including an attempt made by our team; not published).

Although, up to our knowledge, no further studies aimed at detecting the motor state have been published, other authors have tried to detect bradykinesia, which is related to the Off-state [6,26,27]. Most of such studies have been conducted in a laboratory or a clinic (controlled environment) in conditions of restricted activity or asking the patients to perform certain maneuvers, so that their results can hardly be directly extrapolated to the clinical practice. Salarian et al [7] allowed their subjects free activity for 3 hours (although inside a clinic instead of their own environment) and found a good correlation (Spearman rank correlation, $\rho=0.7$) between the data from 2 Physilog sensors placed on the forearms and the bradykinesia item of the UPDRS. Tzallas et al [8] tested 5 sensors composed of accelerometers and gyroscopes and located on limbs and trunk in a real environment. Their algorithms showed a moderate accuracy (74.5% classification accuracy) for detection of bradykinesia as compared with the records made by the patients or their relatives.

Limitations

Our algorithm requires the occurrence of movement (gait or choreoic dyskinesia) to be able to determine the motor phase. Thus, it does not continuously provide data; and there are time slots in which the motor state remains unknown. Therefore, undetected Off-periods are probable to occur, which would reduce the system's sensitivity to detect Off-periods. In this experiment, we were unable to measure sensitivity (the number of detected Off-periods out of the total actually occurring Off-periods) because the chosen gold standard does not record all the Off-periods either (the patient may forget or fail to record some of them). However, we found high predictive value and accuracy, which means that whenever the sensor makes a determination, it is often correct. The time during which detections are not possible is an obvious limitation of this system. However, to see it in perspective, the sensor provides more information than the patient's diary (which is the best method known to date). For example, the sensor in this study collected 37% more valid data (On-Off detections) than the patients' diaries. Furthermore, patients may fail to complete the

diary time records for several consecutive days because it is an arduous task and they often give up [5]. Note that, in our study, 6 patients voluntarily stopped data recording before the third day, due to the inconvenience of filling the diary (results not shown).

The results of validation studies of new monitoring systems for PD should be interpreted with caution, due to the limitations of the reference standards currently used [28]. Methods based on new technologies may be better than traditional methods such as a patient's diary. Thus, outcome differences between both approaches may be more probably due to limitations of the standard than to poor validity of new technology methods. We postulate that, in this case, our aim should not be creating technologies as effective as traditional standards but overcoming these standards. Therefore, although concurrent validation studies are necessary (validation by comparison with a standard), prospective validation studies are needed, where the utility of new technologies to achieve better clinical control is demonstrated or ruled out.

In this study, we used patients' diaries as the reference standard because no better alternative is currently available for long-term monitoring patients in their natural environment. However, it should be taken into account that patients recruited for this study were able to recognize their motor state well and received telephone reminders to complete the diary. In the clinical practice, many patients cannot actually recognize their motor state or fail to record it in the diary, all of which reduces the accuracy of the diary method and supports the development of automatic detection methods.

As previously reported [22], our system was able to detect dyskinesia and consequently, to distinguish between On-state with dyskinesia (which may reflect excessive dopaminergic stimulation) and On-state without dyskinesia (which indicates optimal stimulation). In this study, however, such a distinction was not validated because, given the experimental design (prolonged monitoring without direct observation), preparing a good standard to verify the presence of dyskinesia was not possible; dyskinesia involves involuntary movements of which patients often remain unaware.

Conclusions

In conclusion, the kinematic sensor and the algorithm validated in this study constitute an accurate and useful tool for monitoring and recording motor fluctuations in patients with moderate-advanced PD in the outpatient setting.

Acknowledgments

We would like to thank Dr Antonio Yuste Marco, Ms Dolors Camacho, Ms Esther Valldosera Dorado, and Ms Natalia Gonzalo León for help with research management and administration. This study has been funded by Instituto de Salud Carlos III through the projects DTS15/00209 & PI12/03028 (cofunded by European Regional Development Fund, "Investing in your future").

Authors' Contributions

ARM conceived and designed the study and drafted the first version of the manuscript. CPL, AS, DRM, and AC contributed to the study design and performed the algorithmic work. They contributed to and approved the final version of the manuscript. EDM

performed the field work and approved the final version of the manuscript. JHV, AB, AM, RA, and DP contributed to the study design and recruitment. In addition, they contributed to and approved the final version of the manuscript.

Conflicts of Interest

ARM, AS, CPL, and AC are shareholders of Sense4Care, which is a spin-off company that may commercialize the results of this research device in the near future. These authors declare that the possible commercialization of the product is a research outcome, with the design, analysis, interpretation of the results, or the conclusions not being affected by commercial interests.

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Abbreviations

- FN:** false negatives
- FP:** false positives
- NPV:** negative predictive value
- PD:** Parkinson disease
- PPV:** positive predictive value
- SVM:** support vector machine
- TN:** true negatives
- TP:** true positives
- UPDRS:** Unified Parkinson's Disease Rating Scale

Edited by G Eysenbach; submitted 03.07.17; peer-reviewed by R Dorsey, M Albert, B Cole; comments to author 23.11.17; revised version received 29.01.18; accepted 31.01.18; published 25.04.18.

Please cite as:

Rodríguez-Molinero A, Pérez-López C, Samà A, de Mingo E, Rodríguez-Martín D, Hernández-Vara J, Bayés À, Moral A, Álvarez R, Pérez-Martínez DA, Català A

A Kinematic Sensor and Algorithm to Detect Motor Fluctuations in Parkinson Disease: Validation Study Under Real Conditions of Use

JMIR Rehabil Assist Technol 2018;5(1):e8

URL: <http://rehab.jmir.org/2018/1/e8/>

doi:[10.2196/rehab.8335](https://doi.org/10.2196/rehab.8335)

PMID:[29695377](https://pubmed.ncbi.nlm.nih.gov/29695377/)

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Original Paper

Patients Using an Online Forum for Reporting Progress When Engaging With a Six-Week Exercise Program for Knee Conditioning: Feasibility Study

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Abstract

Background: The use of electronic health (eHealth) and Web-based resources for patients with knee pain is expanding. Padlet is an online noticeboard that can facilitate patient interaction by posting virtual “sticky notes.”

Objective: The primary aim of this study was to determine feasibility of patients in a 6-week knee exercise program using Padlet as an online forum for self-reporting on outcome progression.

Methods: Undergraduate manual therapy students were recruited as part of a 6-week study into knee conditioning. Participants were encouraged to post maximum effort readings from quadriceps and gluteal home exercises captured from standard bathroom scales on a bespoke Padlet. Experience and progression reporting were encouraged. Posted data were analyzed for association between engagement, entry frequency, and participant characteristics. Individual data facilitated single-subject, multiple-baseline analysis using statistical process control. Experiential narrative was analyzed thematically.

Results: Nineteen participants were recruited (47%, 9/19 female); ages ranged from 19 to 53 years. Twelve individuals (63%) opted to engage with the forum (range 4-40 entries), with five (42%) reporting across all 6 weeks. Gender did not influence reporting (odds ratio [OR] 0.76, 95% CI 0.06-6.93). No significant difference manifested between body mass index and engagement $P=.46$; age and entry frequency did not correlate ($R^2=.054$, 95% CI -0.42 to 0.51 , $P=.83$). Statistically significant conditioning profiles arose in single participants. Themes of pain, mitigation, and response were inducted from the experiences posted.

Conclusions: Patients will engage with an online forum for reporting progress when undertaking exercise programs. In contrast to related literature, no significant association was found with reporting and gender, age, or body mass index. Individual posted data allowed multiple-baseline analysis and experiential induction from participants. Conditioning responses were evident on visual inspection. The importance of individualized visual data to patients and the role of forums in monitoring patients' progress in symptomatic knee pain populations need further consideration.

(*JMIR Rehabil Assist Technol* 2018;5(1):e9) doi:[10.2196/rehab.8567](https://doi.org/10.2196/rehab.8567)

KEYWORDS

eHealth; social media; exercise therapy; rehabilitation

Introduction

The use of Web-based resources and eHealth apps for patients with knee pain is an area of expansion [1,2]. The term eHealth encompasses technology delivered through computer, hand-held tablet, or mobile phone that supports patients and practitioners in decision making, coping strategies, treatment approaches, or functional improvement [3]. There are a range of knee conditions such as osteoarthritis, arthroplasty, and cruciate ligament tears that are being informed by patient decision aids, electronic patient-reported outcomes, and biofeedback software [4-6]. Positive effects are noted across a range of conditions including knee osteoarthritis, but further work is required on determining suitable interactions between patients and these eHealth measures [7,8].

The cost of developing and delivering eHealth resources is considered to be offset by the ease of patient accessibility [9]. The lack of quality studies and the heterogeneous nature of conditions supported by eHealth prevent full unequivocal endorsement of the cost-effectiveness of technology-driven approaches [10,11]. The expedient delivery and low-cost development afforded by Web 2.0 apps may facilitate further access to eHealth [12] and wider health information technology [13], including patient-reported health records [14]. The Web 2.0 platform has increased participation through social media and the sharing of experience due to the ease of posting materials such as video files and online forums [15]. This latest generation of Internet development is seen as providing a collaborative medium for knowledge generation and dissemination [16]. This aligns to the potential interactive nature of eHealth programs that has been reported to facilitate health care engagement [17].

Educational research and pedagogic practice have been fruitful areas of exploration around Web 2.0 apps [18]. The option to motivate learners in ever more expansive ways of engagement adds to the wider participation aspirations of higher education [19]. There are a range of tools that allow for students to engage in learning and feedback in the Web 2.0 toolset that may have applicability in eHealth [18,20,21]. These tools have been deployed to support chronic conditions in older adults with regards to education and self-management; the pedagogue/student relationship transformed to clinician/patient with the shared aim of empowerment [22]. The exposure to the range of eHealth has been seen to bridge gender and age differences, but there is a suggestion that gender influences engagement with Web 2.0 apps [23]. Online social interaction has also been explored with respect to weight management facilitated through discussion boards; attrition rates are reportedly high in this area and little change is noted in body mass index (BMI) as a common outcome measure [24]. High BMI has been seen to be associated with higher attrition rates.

Padlet is a Web 2.0 online noticeboard that can be used to facilitate participant interaction by posting of multimedia files as virtual "sticky notes" with mediation by an administrator [25]. The scope for using this resource as an eHealth app has been investigated with some success in terms of engaging surgeons or clinicians to discuss cases in a forum setting [12]. The initial disadvantages described around mobile access have

been addressed with the latest software release [26]. There is potential that this platform could facilitate an online health community; online health communities can be used to share patient and clinical experiences while disseminating expert-moderated knowledge [27]. These communities have the potential to allow patients to report progress and responses that are normally qualitative in nature [28]. With the range of biofeedback devices now available, the sharing of quantitative data to monitor patient progress and motivation via Web 2.0 apps has potential to influence compliance [29]. The use of the Padlet Web 2.0 platform to facilitate a patient-led, clinician-moderated online forum around knee conditioning exercises with biofeedback data has not been explored. The potential to use this type of forum for participant-specific primary data gathering is also an area requiring further investigation.

The aim of this study was to determine the feasibility of patients engaging with an online forum to report progress using biofeedback as part of a 6-week exercise program to improve knee function.

The primary objective was to facilitate a moderated, online community and explore participant characteristics that reportedly influence engagement, with a view to answer the following research question: is there a difference in reporting progress in an online forum based on gender, age, and BMI. A secondary objective was to ascertain if sufficient individual data were reported to complete a multiple-baseline case study for participants in the study. A tertiary objective was to establish if sufficient qualitative data were posted to allow induction of descriptive themes.

Methods

Design

This was a mixed-methods, quasi-experimental feasibility study with an integrated single-case, multiple-baseline, ABCD analysis and descriptive thematic summary.

Participants

As part of a parallel study into the effects of biofeedback on knee function, participants were recruited from current year 1 to 4 undergraduate students in the osteopathy program at the European School of Osteopathy and year 2 undergraduates in the sports therapy program at the University of Kent. Recruitment took place from August 2016 to January 2017, and student participants were invited to take part in the study via email and notices placed around campus. The inclusion criteria were male and female adult students who had daily access to bathroom scales, permitted receipt of reminders via text message, and had online access via any suitable device. The exclusion criteria were if they were suffering with bilateral knee or hip pain, undertook recurrent high-intensity physical training, or had an underlying metabolic disorder or neuromuscular condition.

Online Forum Development

The Padlet Web 2.0 app (Padlet Co, Sunnyvale, CA, USA) was used to develop the forum for posting of participant data; the

Padlet platform facilitates multiple users sharing information and resources in a discrete environment. From the main site page, accessed via a personalized user and password, the “+make a Padlet” option was selected and a freeform option for the forum was selected as demonstrated in [Figure 1](#).

As users were encouraged to share information and experiences. The posts were not anonymized, but oversight of the activity was conducted by the lead researchers on the study (PB, KH). A code of conduct was posted on the webpage to ensure acceptable standards of behavior were adopted. The details of this can be viewed in [Textbox 1](#). Padlet also operates its own policy for reporting and removing inappropriate content in addition to user-defined practice available on their website.

Procedure

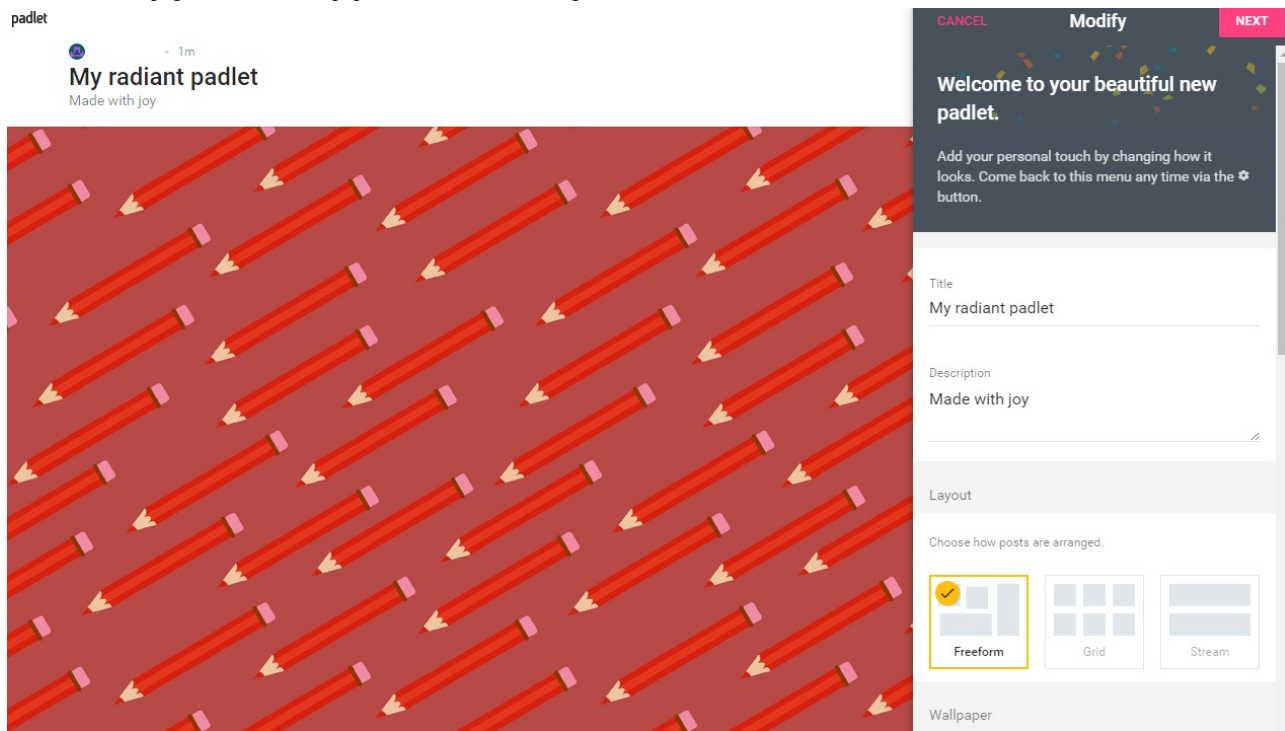
The following characteristic data were collected at baseline: height (cm), weight (kg), waist circumference (cm), BMI (kg/m²), activity levels (11-point numerical rating scale), age, and gender. Participants were inducted into a knee program consisting of staged repetitions of a seated clamshell exercise (an adaptation from Distefano et al [30]) and a short arc quadriceps extension ([Figure 2](#)). The clamshell required

participants to abduct the hip, contracting gluteals as hard as possible against the resistance of bathroom scales supported against a wall. The short arc quadriceps exercise required the participant to begin with a flexed knee over a foam roller (or equivalent bolster support) resting on bathroom scales positioned on a stable surface. The exercise was completed by contracting the quadriceps to extend the leg through the shortened range, registering contraction force on the scales beneath the roller. Both required a 5-second contraction and 2-second relaxation phase.

Both exercises were repeated in sets of 12 and on both legs with a 60-second relaxation phase between sets. The progression phases are depicted in [Table 1](#).

Participants were sent text reminders on the days they were required to perform the exercises. The text messages included a hyperlink to the bespoke Padlet forum with instructions detailing their exercise and video guidance materials (see [Multimedia Appendix 1](#)). Participants were also requested to post readings of their maximum effort in kilograms, obtained from the bathroom scales, onto the online forum after each exercise session.

Figure 1. Creation page for Padlet wallpaper is indicative of background themes that can be customized.



Textbox 1. Code of conduct displayed on Padlet.

The use of this moderated forum is to: provide information to study participants; allow a medium for recording progress; facilitate sharing of experiences during the course of the study. The exchanges should remain respectful and courteous at all times. Banter is encouraged but the study moderators policing activity will ensure any offensive or inappropriate comments or images are removed.

Participants that persist in posting such material will be asked to withdraw from the study.

Figure 2. Seated clamshell and short-arc quadriceps exercise.**Table 1.** Exercise progression details for participants.

Week	Exercise progression	Phase
Weeks 1 and 2	Maintain 2 sets of 12 repetitions every other day	Phase A
Weeks 3 and 4	Maintain 3 sets of 12 repetitions every other day	Phase B
Week 5	Maintain 4 sets of 12 repetitions every other day	Phase C
Week 6	Maintain 5 sets of 12 repetitions every other day	Phase D

Outcome Measures

The primary outcome measure was the number of recorded entries detailing progression with the exercise schedule. A secondary outcome measure was the maximum voluntary contraction reading as captured from the bathroom scales from each exercise session. This was provided by the participants over all stages of engagement within the study.

Ethics

The study protocol was submitted to and approved by the Research Ethics Committees of the European School of Osteopathy and the School of Sport and Exercise Sciences, University of Kent, as part of a larger study exploring the use of biofeedback in a knee conditioning program.

Statistical Analysis

The Padlet postings were exported to a spreadsheet and aligned to participant baseline data. Summary and inferential statistics were calculated using Excel version 16 (Microsoft Corporation, Redmond, WA, USA) and Analyse-it version 4.65.3 (Analyse-it Software, Ltd, Leeds, UK). The numbers of recorded entries and BMI were assessed for distribution and equality of variance; gender group relationships and differences in reporting were explored using odds ratios with 95% confidence intervals and the Mann-Whitney *U* test. Physical characteristics (BMI) and reporting differences were also explored using the Student *t* test. Correlation between age and recording of entries was explored using the Spearman test; statistical significance was set at $P < .05$. Entries entered against one date were considered a single entry so multiple data added under a single date were only counted once. Discrete nominal values were derived from this in terms of binary (yes/no) indication of engagement with the forum to allow proportional analysis of association.

The staged recordings of maximum voluntary isometric contractions were extracted from the forum-recorded entries

and three consistent datasets were analyzed using a multiple-baseline [31], ABCD case study [32] approach aligned to four (one baseline and three progressive) stages of exercise. A statistical process control (SPC) visual analysis [33] was applied to the resultant line graphs with means and standard deviations calculated from phase A baseline data. Statistical significance was regarded as two consecutive data points outside ± 2 standard deviations in phases B, C, or D. Linear trend lines were added to indicate direction of individual progress. Finally, open-forum comments were analyzed within a descriptive thematic framework [34] and summarized in relation to the source participants.

Results

Baseline Characteristics

A total of 19 participants were recruited. The group was 47% female (9/19); age ranged from 19 to 53 years (mean 32.79, SD 10.78 years) and BMI ranged between 16.63 and 33.83 kg/m² (mean 25.02, SD 4.39 kg/m²); eight individuals (42%) were over the desired 25 kg/m². Mean height was 173.47 (SD 10.06) cm, mean weight was 75.65 (SD 16.20) kg, and median waist circumference was 84.0 (IQR 12.7) cm. Participant's mean activity rating was 4.42 (SD 1.30) and the median number of Padlet entries was 8 (IQR 16).

Primary Outcome Measure

Twelve individuals (63%) opted to engage with the Padlet forum with entry frequency ranging from 4 to 40. Follow-up on the seven who did not report outcomes elicited four replies; time constraints (n=3) and technophobia (n=1) were cited as reasons for nonresponse. All individuals that initially reported outcomes went on to complete the exercise program regardless of dropout from the forum. The depiction of the finalized notice board entries can be viewed in [Figure 3](#).

Figure 3. Bespoke Padlet forum with participant and moderator posts.

Inferential analysis of the influences on reporting by gender and age showed no statistical significance. The odds for male and female responders demonstrated that gender was not a factor in this sample for engaging with the forum activity (OR 0.76, 95% CI 0.06-6.93). There was no significant difference between genders and entry frequency ($P=.97$) or BMI and engagement ($P=.46$). Age and entry frequency also showed no significant correlation ($R^2=.054$, 95% CI -0.42 to 0.51 , $P=.83$).

Secondary Outcome Measure

Consistent data were reported across all 6 weeks of the study by five of the 12 participants who engaged with the forum (58% attrition rate); three were selected for SPC analysis due to their staggered recruitment dates. The multiple-baseline analysis demonstrated the training effects of participants undertaking the staged exercises and the duration of their engagement with the short arc extension quadriceps exercise.

A progressive conditioning response is demonstrated in Figure 4 with the three line graphs; significant events are depicted in

two of three SPC analyses. The first (SPC1) incurs two consecutive data points outside the upper 2 standard deviation threshold at the end of phase D; SPC3 demonstrates a range of significant improvements in reported muscle strength during phase B and D of the study.

Qualitative Data

Six participants (50%, 6/12) provided limited commentary during their engagement with the online forum; examples are presented in Table 2 that demonstrate themes of pain, mitigation, and response. These participants were representative of the gender (40% female) and age (mean 31, SD 10) of this study’s demographics.

The individuals provided reflection on their experiences and progress in response to the exercises (female, age 22). The mitigating effects of pain were commonly reported in response to perceived decline in performance and reporting (male, age 29). A stoic sense of perseverance was interpreted from the commentary with an adaptation of technical approach when required (female, age 21; male, age 41).

Figure 4. Multiple-baseline analyses of single participant data with statistical thresholds and linear trend lines. SPC: statistical process control.

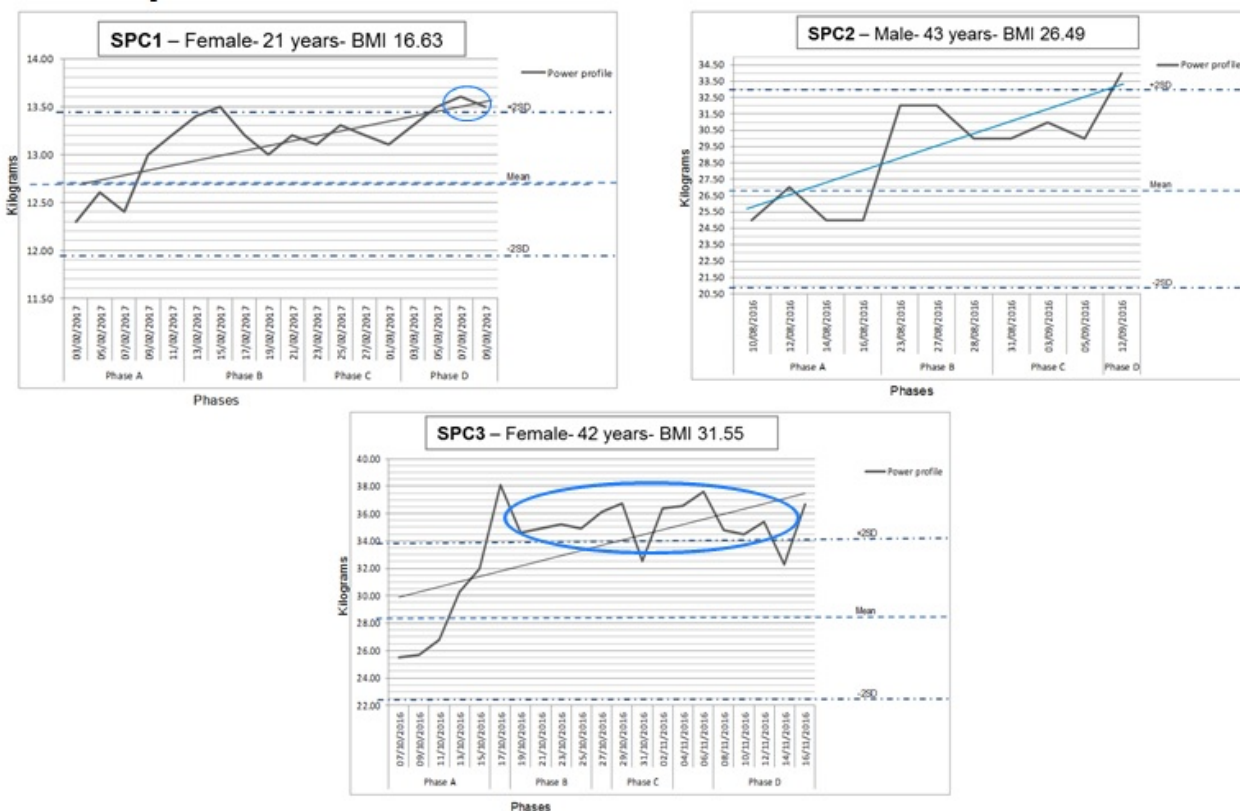


Table 2. Illustrative quotes from online forum.

Participant	Theme	Quote
Female, age 22	Mitigation	“Been getting more hypermobile in the last few days, which shows in the results”
Male, age 41	Response	“Feedback is good, I push harder”
	Mitigation/pain	“I changed how I was bracing myself and used a cushion on the scales for the glute exercise so it hurts less”
Female, age 21	Mitigation	“Get a cold, feeling weak but the exercises are fine”
Male, age 42	Mitigation	“A bit weaker over the last couple of days because of flu”
Male, age 29	Pain	“I had an injury while climbing...it’s painful”

Discussion

The primary aim of this study was to determine the feasibility of patients using an online forum for reporting progress when engaging with a 6-week exercise program for managing knee pain. No statistically significant difference was found in reporting progress based on gender, age, or BMI. It was possible to use individuals' posted progress data to complete a multiple-baseline case study for a selection of participants in the study. Participants were willing to engage in limited discussion posts during their progression on the program.

Posting to the forum was initially at a moderate level and attrition rates were comparable with other studies exploring engagement with online discussion boards. The 58% reported in this study is in the range of the 12 studies exceeding the 20% attrition rate in the review of Williams et al [24]. Within the scope of behavioral change in eHealth, the range of 41% to 84% attrition is reported in large randomized controlled trials [35]. The consistency of participants' reports within this study, facilitating individualized progression data, may be indicative of the stable core user remnant that prevails after initial early dropouts [36]. Further exploration of the benefits of self-reporting with the incentive of producing individual activity profiles is warranted, particularly within the scope of affordable technology and activity tracking [37].

Exercise adherence has been identified as a major contributor to exercise efficacy [38]. Participants that made initial engagement with recording their outcomes online committed to the 6-week program irrespective of report attrition. The access to the video instructions through the forum may have influenced this behavior because these media have been seen to improve exercise adherence [39,40]. The growth in interactive video technology may facilitate this further; real-time remote motion capture of patients, tracking, and analyzing movement, with feedback relayed direct from a therapist may be the panacea in this field [41]. There are implications for these types of systems in terms of sensitivity of personal data [42] and developing suitably secure software architecture is an ongoing challenge within the Web 2.0 milieu [43,44]. The integration of body sensor network information into this cloud computing platform and the volume of wearable devices (eg, FitBit, MOOV, Nike+) that can contribute to these biofeedback networks elicits a complex array of data [45]. This potentially lacks meaning or context for patients; the findings of this study demonstrate a simple solution to this complexity.

Age and social media engagement have been reported as conflicting characteristics in studies engaging eHealth with usage mediated by generation. Although engagement activity profiles may differ, those older than 65 years are comparable to those younger than 30 years in terms of the proportions reporting the use of the Internet for health-related information (53% and 56%, respectively) [46]. The age range in this study crossed Generations X and Y, but lacked engagement with senior citizens. Those older than 65 years are motivated to engage with eHealth and increased Internet use as a vital connection with the wider world, offsetting age-related functional changes [47] and physical inactivity [48]. Age was

not seen as predictive of engagement in this study, but there is a suggestion that socioeconomic status is an overt influence on Internet use in relation to subjective health [49]. The sample in this study were drawn from undergraduate cohorts but the age span of 19 to 53 years indicates funding sources and social status could not be directly inferred and was not sought at the time of participation.

Gender and BMI may indicate a barrier to information technology use in adolescents and practitioners [50-52], but reported disparities in adoption of Internet-based health correspond more with lower income, educational attainment, ethnic background, and those for whom English is not their native language [53]. Gender and BMI influence on engagement was equivocal in terms of the odds reported in this study; the student sample here may be more consumer-driven, aligned to recent shifts in UK higher education with strong emphasis on student choice and experience and less on gender-based decisions [49]. The shifting engagement in this study's student participants may be tempered by self-determination and personal preference. Electronic media use has been reported as a risk factor for higher BMI, particularly within the adolescent female population [54]. Conversely, targeted eHealth solutions for weight management in young women suffer from poor uptake and user satisfaction ratings [55]. Activity and diet modification via specialized apps may offer an improved engagement profile around personal weight management in adults [56,57]. Similarly, perceived pressures reported by other health care undergraduates [58] may be applicable to this study and mitigated engagement. Time availability and pressures of course deadlines are also reported as inhibitors to activity-related eHealth [59]. The potential addictive impact of technology and reduced academic performance reported in other studies [60] may have been seen as prohibitive in this study's sample. Exploration of technology reliance and side effects on prolonged eHealth use is a conflicting relationship that warrants further exploration.

The provision of individualized single-case data fed back to patients contributes to the ideal of personalized, preventive health care planning [61]. The ability for patients to report on their own progress with clinical home-based outcomes has been reported as vital to integrated electronic medical records [62]. The biofeedback information in this study could provide further complementary data to wearable devices [45,63]; this potentially negotiates the pathway between consumer mass adoption and practitioner caution in this developing area [64]. This study demonstrates that patients can have direct access to personal analytics and potentially aid in the management of ongoing conditions. The growing demand to use single-case analyses to inform effect size and meta-evidence [65-67] demands that "big data" from individual patients be used more constructively, particularly the patient-accessible visual analytics afforded within these designs [68].

This study's sample reported experiences around pain, mitigation, and responsiveness and this was within a recruitment strategy of asymptomatic participants. Subjective and objective pain measures have been widely explored in knee condition sufferers [69,70]. Qualitative data intimates that patients' outcomes and pain management should be considered on an individual basis [71] with online forums providing the

validation, support, and resources as required [28]. The sample in this study described mitigating effects of pain in relation to the exercise task orientation. This contrasts with young symptomatic individuals that report the burden of musculoskeletal pain on quality of life and future prospects; the need for digital technologies to provide accessible, evidence-based resources is seen as vital in connecting these people with support from peers and health professionals [72]. The individuals in this study were potentially engaging from a sense of duty and felt compelled to offer mitigation when compliance wavered. There is suggestion that compelling pain management programs may only arise with a population that perceives the need for individualized care, particularly if that population feels disenfranchised [73].

Limitations of this study include selection bias with a convenience sample of undergraduate students. Only those prepared to commit to the program were included indicating that participants had an underlying motivation toward exercise. All participants were asymptomatic implicating the diversity in compliance; attrition could be further mitigated with a motivated symptomatic patient population. The extension to engage with people older than 65 years in future studies would allow the development of this type of online health community in condition-specific scenarios. Socioeconomic status was not captured by this study and this is seen as a key influence on access and engagement in the field of eHealth; such barriers to

engagement have to be explored further. This study was able to demonstrate that a low-cost solution to developing an online health community is feasible and that individualized, patient-centric data can be produced from reporting biofeedback data on an online forum. Future research should look to investigate discordance between attitudes to technology-assisted health care, the importance of individualized visual data to patients, and the role of forums in monitoring patient engagement and progress in symptomatic populations.

Patients can engage with an online forum for reporting progress when complying with exercise programs for managing knee pain. No significant influence was found on reporting progress in an online forum based on gender, age, or BMI. It was possible to use individual posted progress data to complete a multiple-baseline case study for a selection of participants in the study. Participants were willing to engage in limited discussion posts during their progression on the program. The parochial nature of the sample is a limitation; future work in the area should look to address discordance between attitudes to technology-assisted health care, the importance of individualized visual data to patients, and the role of forums in monitoring patient engagement and progress in symptomatic knee pain populations. Socioeconomic background and other barriers to accessing these community forums need to be considered in this exploration.

Acknowledgments

The authors would like to thank Hannah Epps and Lee Thompson for their assistance in the recruitment of participants for this study.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Powerpoint presentation of study.

[[PPTX File, 5MB - rehab_v5i1e9_app1.pptx](#)]

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Abbreviations

BMI: body mass index

SPC: statistical process control

Edited by G Eysenbach; submitted 30.07.17; peer-reviewed by G Petrič, M Merolli, D Nault; comments to author 23.11.17; revised version received 26.02.18; accepted 16.03.18; published 26.04.18.

Please cite as:

Bright P, Hambly K

Patients Using an Online Forum for Reporting Progress When Engaging With a Six-Week Exercise Program for Knee Conditioning: Feasibility Study

JMIR Rehabil Assist Technol 2018;5(1):e9

URL: <http://rehab.jmir.org/2018/1/e9/>

doi: [10.2196/rehab.8567](https://doi.org/10.2196/rehab.8567)

PMID: [29699967](https://pubmed.ncbi.nlm.nih.gov/29699967/)

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Original Paper

Adapting the Wii Fit Balance Board to Enable Active Video Game Play by Wheelchair Users: User-Centered Design and Usability Evaluation

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Abstract

Background: Active video game (AVG) playing, also known as “exergaming,” is increasingly employed to promote physical activity across all age groups. The Wii Fit Balance Board is a popular gaming controller for AVGs and is used in a variety of settings. However, the commercial off-the-shelf (OTS) design poses several limitations. It is inaccessible to wheelchair users, does not support the use of stabilization assistive devices, and requires the ability to shift the center of balance (COB) in all directions to fully engage in game play.

Objective: The aim of this study was to design an adapted version of the Wii Fit Balance Board to overcome the identified limitations and to evaluate the usability of the newly designed adapted Wii Fit Balance Board in persons with mobility impairments.

Methods: In a previous study, 16 participants tried the OTS version of the Wii Fit Balance Board. On the basis of observed limitations, a team of engineers developed and adapted the design of the Wii Fit Balance Board, which was then subjected to multiple iterations of user feedback and design tweaks. On design completion, we recruited a new pool of participants with mobility impairments for a larger study. During their first visit, we assessed lower-extremity function using selected mobility tasks from the International Classification of Functioning, Disability and Health. During a subsequent session, participants played 2 sets of games on both the OTS and adapted versions of the Wii Fit Balance Board. Order of controller version played first was randomized. After participants played each version, we administered the System Usability Scale (SUS) to examine the participants’ perceived usability.

Results: The adapted version of the Wii Fit Balance Board resulting from the user-centered design approach met the needs of a variety of users. The adapted controller (1) allowed manual wheelchair users to engage in game play, which was previously not possible; (2) included Americans with Disabilities Act-compliant handrails as part of the controller, enabling stable and safe game play; and (3) included a sensitivity control feature, allowing users to fine-tune the controller to match the users’ range of COB motion. More than half the sample could not use the OTS version of the Wii Fit Balance Board, while all participants were able to use the adapted version. All participants rated the adapted Wii Fit Balance Board at a minimum as “good,” while those who could not use the OTS Wii Fit Balance Board rated the adapted Wii Fit Balance Board as “excellent.” We found a significant negative correlation between lower-extremity function and differences between OTS and adapted SUS scores, indicating that as lower-extremity function decreased, participants perceived the adapted Wii Fit Balance Board as more usable.

Conclusions: This study demonstrated a successful adaptation of a widely used AVG controller. The adapted controller’s potential to increase physical activity levels among people with mobility impairments will be evaluated in a subsequent trial.

Trial Registration: ClinicalTrials.gov NCT02994199; <https://clinicaltrials.gov/ct2/show/NCT02994199> (Archived by WebCite at <http://www.webcitation.org/6xWTyiJWf>)

(*JMIR Rehabil Assist Technol* 2018;5(1):e2) doi:[10.2196/rehab.8003](https://doi.org/10.2196/rehab.8003)

KEYWORDS

sedentary lifestyle; video games; active video gaming; Wii Fit; equipment design; physical activity; exercise; wheelchairs; physical disability; rehabilitation; usability

Introduction

Active video games (AVGs), or exergames, are video games that require players to perform substantial body movement for game play, unlike conventional video games, which use remote control push buttons or joysticks. Video game controllers are peripheral devices through which users interact with gaming environments. There are multiple commercially available gaming consoles, and they include a variety of game controllers. Nintendo Wii is a popular gaming console and can connect to the Nintendo Wii Fit Balance Board game controller (Nintendo of America Inc, Redmond, WA, USA). The Wii Fit Balance Board can be used with a variety of AVGs that focus on improving balance, strength, flexibility, endurance, and overall fitness.

AVGs using various consoles have been demonstrated to successfully promote increased physical activity levels among a variety of age groups [1-6], and to increase physical activity and improve balance and mobility among people with physical disabilities [7-16]. The Wii Fit Balance Board has been used for a variety of outcomes (such as balance training, gait training, physical fitness, and range of motion) and with various populations, such as those with multiple sclerosis, Parkinson disease, incomplete spinal cord injury, and after a stroke [7,8,10-13,17-28]. However, due to accessibility barriers of the Wii Fit Balance Board, none of the studies have included individuals who use a wheelchair as their primary mode of mobility or individuals with complete spinal cord injury. Studies have noted concerns such as lack of safety, intimidation, and worries about falling for individuals with more severe symptoms and less functional ability [19,28].

The limited research has focused on increasing the accessibility of standard video games, with an emphasis on visual disabilities [29-32]. However, little if any research has examined the accessibility of controllers for AVG play or, more specifically, balance board gaming controllers.

Limitations of the Wii Fit Balance Board

The need to design an adapted version of the Wii Fit Balance Board was motivated by an earlier study conducted by our research team [12] and recommendations from the literature [33]. The previous study involved participants with mobility impairments (N=16) attempting to play 4 AVGs on each of 3 gaming systems. All sessions were video recorded, and study staff noted the barriers faced by the participants in using the various controllers. Based on a review of video recordings and study notes [12], the most limiting features of the off-the-shelf (OTS) Wii Fit Balance Board for successful AVG play by participants with mobility impairments were the following: (1) the Wii Fit Balance Board was completely inaccessible to wheelchair users, (2) it had a small platform area (49.5 cm wide by 30.5 cm deep), (3) it was incompatible with the use of stabilization assistance devices (ie, walker, cane), (4) it required a full range of center-of-balance (COB) motion for responsive game play, and (5) it required the ability to shift the center of gravity in all directions (ie, full range of trunk motion).

As noted, the biggest limitation of the OTS Wii Fit Balance Board is that it requires participants to be able to stand, thus making the system completely inaccessible to wheelchair users (Figure 1). In addition, given the small size of the platform, it can only accommodate a stance that is no more than shoulder-width apart for most people. Because the board uses load cells to detect the player's weight and COB shifts, all of the player's weight must bear on the top of the platform. This limitation makes the board less responsive to those who require the use of stabilization assistance devices (eg, cane, walker) that bear on the floor around the platform. Furthermore, to achieve success, many games require that players have a full range of trunk motion.

Study Objectives

The aims of this study were to (1) adapt the Wii Fit Balance Board to improve accessibility, and (2) evaluate the usability of the OTS and adapted Wii Fit Balance Board in persons with physical disabilities, specifically mobility impairments.

Figure 1. Commercial off-the-shelf Wii Fit Balance Board.



Methods

Adaptation of the Wii Fit Balance Board

Adaptations to Improve Accessibility

We presented the above-identified limitations to our engineering design team. We proposed a variety of solutions, and finally decided to make the following mechanical and electrical adaptations to increase the level of accessibility: (1) construct a larger platform area (101.6 cm wide by 96.5 cm deep), (2) build in lateral stabilization supports (ie, handrails), (3) adjust the sensitivity for COB response, and (4) add an accessible wheelchair ramp compliant with the Americans with Disabilities Act (ADA). We selected these adaptations not only to enable wheelchair users to access the Wii Fit Balance Board, but also to make it a universal device with enhanced safety for all users.

Product Development

We deconstructed the OTS Wii Fit Balance Board so that the electrical components could be reconfigured and integrated into the new form factor and electrical design of the platform. As [Figure 2](#) shows, we removed the bottom cover of the board to access the core electrical components: the electronic control unit (ECU), the battery housing with built-in sync button, the 4 load cells, and the power button. The 4 load cells, wired directly to the ECU, detect the weight and COB of the player. The sync button enclosed in the battery housing enables the user to initiate a Bluetooth link between the board and a Wii system. The power button triggers the ECU to power up and establish a Bluetooth link to the Wii system and to begin transmission of weight and COB data.

We focused the mechanical redesign ([Figure 3](#)) on providing a larger platform for players to use in both seated and standing positions. To facilitate wheelchair users, we designed the usable space on the platform to be 91.5 cm by 91.5 cm, with the load cells placed at each of the 4 corners. To frame the platform, we used 1-inch t-slot aluminum extrusions, with 2 transparent acrylic sheets (45.7 cm by 91.5 cm by 1.27 cm) for the platform's surface. To provide the user with an alignment grid, the acrylic sheets were laser etched and edge lit with a variable-color light-emitting diode (LED) strip. This alignment grid provided a guide for proper positioning of a seated player. This alignment is crucial for successful game play, as any major offset to one side of the board causes the player to experience a proportional bias, thereby negatively affecting accurate manipulation of the system.

We purchased an OTS modular ADA-compliant ramp to provide safe access to the top of the platform at a height of 6.35 cm. We designed transparent acrylic roll-off guards to prevent a player using a wheelchair from inadvertently rolling off the front or back of the platform. The front guard had an adjustable hinge that allowed for customized positioning of the guard so as to not interfere with the player's wheelchair footrests, which can vary widely from one wheelchair configuration to another. The back guard was removable and was dropped into the rear guard slot after the player had positioned himself or herself onto the platform, and was tethered in place with the provided elastic bands.

We integrated ADA-compliant, adjustable-height handrails ([Figure 3](#)) into the design to provide lateral stability and additional leverage for players both in seated and in standing positions. The handrails were firmly anchored directly into the

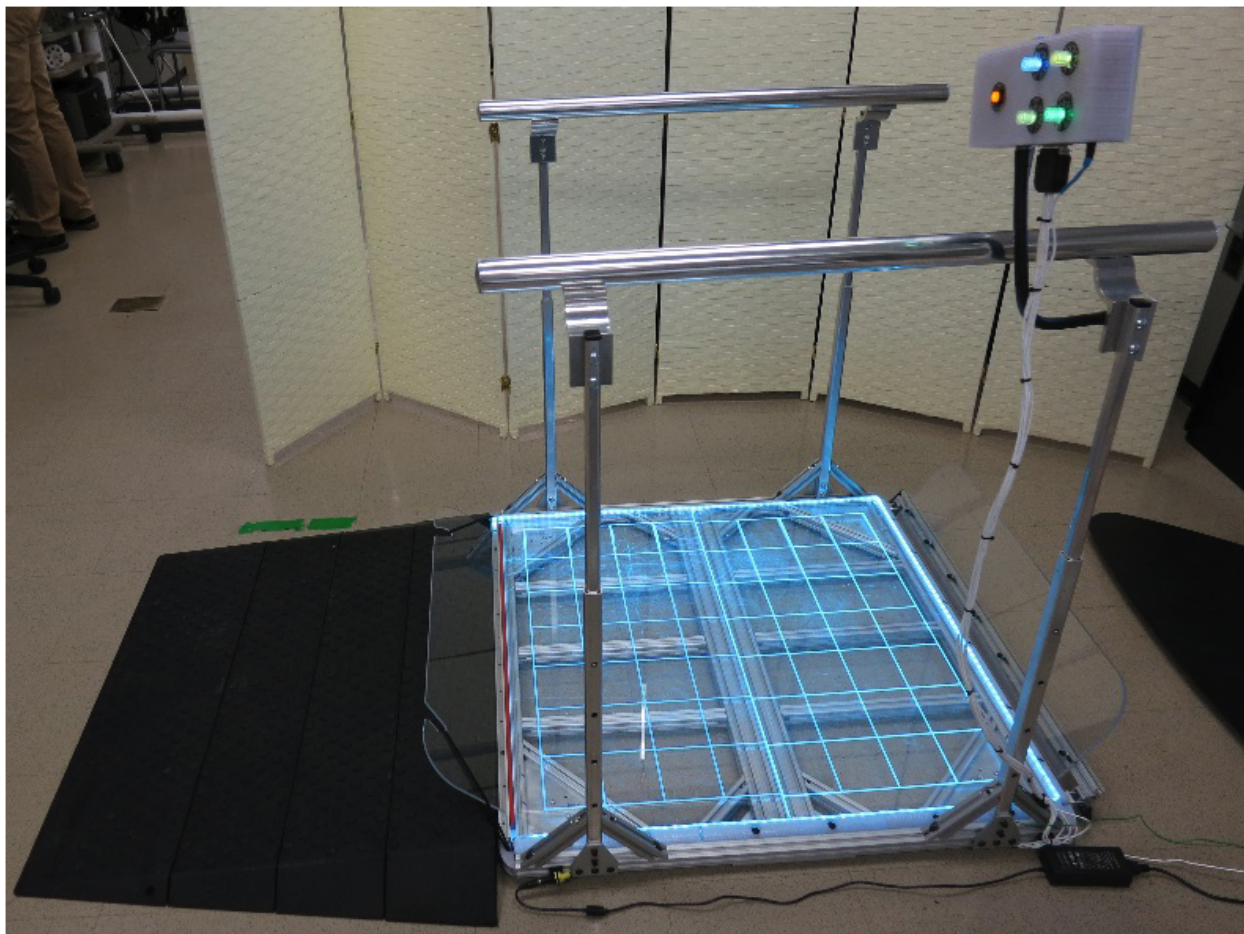
platform frame to ensure all of the player's weight and COB would be accurately captured. The handrails featured 4 telescoping vertical support members that allowed the handrails to be set at different heights (between 62.2 cm and 94 cm), which are within height requirements for ADA-compliant

handrails. The rails themselves consisted of 2 ADA-compliant 1.25-inch polished aluminum rails with end caps and ADA-compliant brackets that ensured a continuous grip along the entire length of the rails.

Figure 2. Wii Fit Balance Board electrical components.



Figure 3. Adapted Wii Fit Balance Board with added ramp, adjustable-height handrails, and control box mounted on the right-side handle.



All of the t-slot aluminum extrusions were held together with a combination of t-slot anchors and strategically located bracing plates (Figure 4) to provide the most rigid platform possible. Rigidity is an important feature for use of a low-profile platform that incorporates load cells, because all of the player's weight must pass through the load cells to the floor for an accurate COB to be calculated, thereby requiring that no part of the frame can deflect under a load such that it contacts the floor. As with the OTS Wii Fit Balance Board, we designed the platform to work best with players who have a gross weight (ie, player plus wheelchair) of less than 150 kg (330 lb).

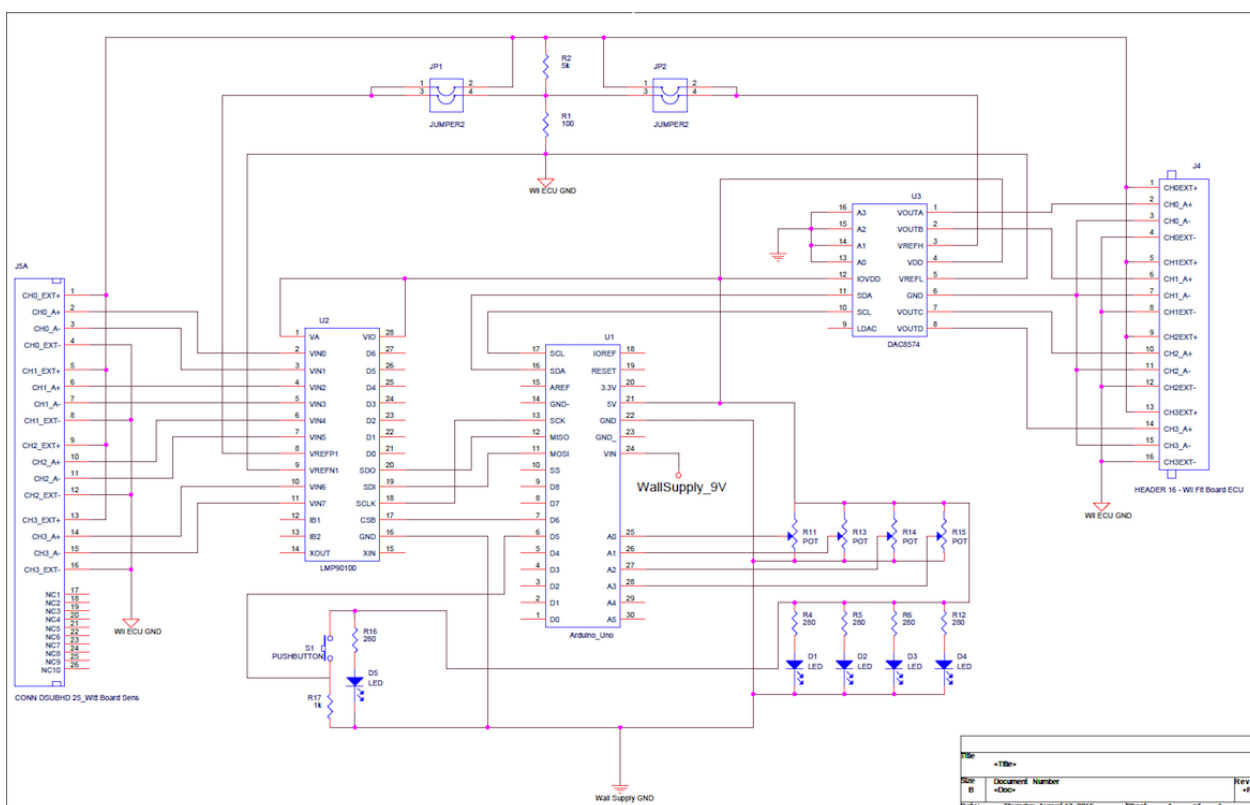
The electrical redesign (Figure 5) required that the voltage readings from the load cells be captured, analyzed, manipulated, and retransmitted to the Wii Fit Balance Board ECU. The redesign provided full control over the data coming from the load cells and consequently allowed for complex functions, such as increased or decreased sensitivity to COB shifts and inclusion of a "jump" button, to be implemented in the firmware algorithm. The electrical components required to accomplish the desired implementation included a 4-channel Texas Instruments LMP09100 analog front-end integrated circuit

(Texas Instruments Incorporated, Dallas, TX, USA), an Arduino Uno microcontroller (Arduino, San Jose, CA, USA), and a 4-channel Texas Instruments digital-to-analog converter. The analog front-end integrated circuit provided a 4-channel 24-bit analog-to-digital converter with associated hardware filtering to deliver precision digital measurements of the load cell voltages to the microcontroller over a 4-wire serial peripheral interface bus. The 4-channel 16-bit converter allowed the microcontroller to precisely control (over an interintegrated circuit bus) the manipulated load cell voltages presented to the Wii Fit Balance Board ECU for processing of the COB (and eventual transmission to the Wii system). The microcontroller executed the firmware algorithm that controlled all aspects of the adapted Wii Fit Balance Board, which primarily required the acquisition, manipulation, and simulation of the load cell data at approximately 47 Hz. The Wii Fit Balance Board ECU's 3.3-V voltage supply was used as the excitation voltage source for the load cells, and a voltage divider was used to scale the 3.3-V full-scale 16-bit digital-to-analog converter voltage down to the 0- to 15-mV range for presentation to the ECU for COB calculation.

Figure 4. Bottom view of the adapted Wii Fit Balance Board braced for rigidity.



Figure 5. Custom electronics schematic for the adapted Wii Fit Balance Board enabling voltage readings from the load cells to be captured, analyzed, manipulated, and retransmitted to the electronic control unit.



We also included in the electrical redesign a control box mounted on a flexible arm that was attached to the right-side handrail (Figure 3). This box housed all of the board’s required electronics and had 4 illuminated dials, 2 illuminated push buttons, and the Bluetooth sync button. A dial labeled “Sensitivity” allowed the user to adjust the balance board sensitivity to shifts in COB. With the dial positioned at 12 o’clock, the sensitivity was at a nominal setting, meaning it was approximately the same as it would be for an OTS Wii Fit Balance Board. With the dial positioned at approximately 7 o’clock, the sensitivity was twice that of the nominal, meaning that any shift in the player’s COB would be greatly exaggerated. With the dial set at approximately 5 o’clock, the sensitivity was zero, meaning that the COB was locked in the neutral or center position. The dial could be set anywhere in between these values in real time during game play. The 2 dials on the lower half of the control box were used to adjust color and brightness on the LED alignment grid strip. The top right unlabeled dial allowed for the player to freeze the output of the platform to allow for more time to position themselves correctly on top of the platform during the in-game calibration sequences. The push button labeled “Jump” allowed the player to perform a jump action in the game without requiring the player to physically jump in place. The blue push button located on the top of the box toggled the Wii Fit Balance Board ECU power and Bluetooth connection.

In accordance with user-centered design principles [34], we focused this project on usability throughout the entire development process. To allow for this continual, systematic evaluation of usability, we developed the adapted controller

iteratively and incrementally, sought input from stakeholders at regular intervals, built and refined multiple prototypes incrementally, and involved a multidisciplinary team.

Usability Testing

Design and Setting

All research study procedures were approved by the University of Alabama’s Institutional Review Board. The trial is registered with ClinicalTrials.gov (NCT02994199). Data collection took place at Lakeshore Foundation (Birmingham, Alabama, USA) Exercise and Sport Science Laboratory, which houses a variety of equipment dedicated to comprehensive health promotion and sport science research. For the purposes of this study, participants came to the laboratory for 3 visits. Our protocol article described the study procedures in detail [30].

Participants

We included participants (age 10 to 60 years) in the study if they had a confirmed diagnosis of lower-extremity mobility limitation (eg, spina bifida, cerebral palsy, muscular dystrophy, 1 year following spinal cord injury, multiple sclerosis, stroke, or limb loss) with partial or full use of their upper extremities and use of an assistive device (eg, cane, walker, or wheelchair) or problems with gait, balance, or coordination. Participants were excluded if they had an unstable cardiovascular condition, a visual impairment that interferes with playing video games (eg, complete blindness; inability to read game commands on a 52-inch television screen from a distance of 10 feet), or weighed over 150 kg (330 lb) including their assistive device. Following distribution of a flyer at a large health and wellness

facility for people with disabilities, the project recruitment coordinator answered calls from or met with interested individuals. At that time, the recruitment coordinator reviewed the inclusion and exclusion criteria with them using a screening form to determine whether they were eligible to participate.

Measures

We quantitatively evaluated usability of the OTS and adapted versions of the Wii Fit Balance Board using the System Usability Scale (SUS) [35]. The SUS is a simple, 10-item Likert scale, giving a global view of subjective assessments of usability. Various studies have shown that the SUS is a highly robust and versatile tool for usability professionals [36]. The SUS produces a score ranging from 0 to 100, which can be compared with the reported average SUS score of 68, to produce normalized percentile scores [37]. The SUS is generally used after the respondent has had an opportunity to use the system being evaluated, but before any debriefing or discussion takes place [35].

We also recorded each participant's physical function assessment, health history, video game play history, and assistive device use. For assessment of physical function, each participant performed a series of upper- and lower-body functional movement tasks from the *International Classification of Functioning, Disability and Health* (ICF) [38,39]. Participants completed each task individually and were scored by research staff according to the level of difficulty exhibited in completing the task. As defined in the ICF manual, the scoring was as follows: 0=no difficulty, 1=mild difficulty, 2=moderate difficulty, 3=severe difficulty, and 4=complete difficulty. Two trained research staff independently scored each participant and then reviewed the scores together, if needed, until they reached a consensus for the final score. Video recordings were available for any significant discrepancies. For this project, we added the scores from 10 specific ICF tasks, which assessed lower-extremity function and trunk control, together to create a composite score (ranging from 0 to 40) that we included in the analyses. The individual ICF mobility activities were Squatting, Sitting, Standing, Bending, Shifting the body's center of gravity, Kicking, Walking short distances, Walking other (marching in place), Running, and Jumping. A low score indicated higher functional ability.

Sample Size

The literature suggests that a sample size of 20 is sufficient for detecting usability issues as measured with the SUS [40]. To

determine usability of the adapted Wii Fit Balance Board, we asked a random subset of participants ($n=25$) from our larger study [41] to complete the SUS.

Data Analysis

We computed participants' SUS scores for the OTS and adapted versions of the Wii Fit Balance Board according to the scale's scoring rubric. Following computation of the scores, we conducted a paired-samples t test (IBM SPSS Statistics 22.0, IBM Corporation) to compare the usability scores of the Wii Fit Balance Board with and without adaptation. We also computed the Pearson correlation coefficient between the adapted Wii Fit Balance Board SUS scores and the participant's lower-extremity function and trunk control score.

Results

[Multimedia Appendix 1](#) presents the participants' ($n=25$) characteristics. The mean age of the participants was 40.16 (SD 14.5) years, with slightly over half of the sample ($n=14$) being male. They had a variety of conditions: multiple sclerosis ($n=6$), spinal cord injury ($n=5$), cerebral palsy ($n=4$), stroke ($n=3$), and various other physical impairments ($n=7$). The primary mode of mobility was manual wheelchair ($n=9$), no assistive aid ($n=11$), walker ($n=2$), and cane, leg brace, and prosthetic leg each used by 1 participant. A total of 15 participants had prior AVG experience, with only 2 having had prior experience with the Wii Fit Balance Board. [Figure 6](#) shows a participant on the modified Wii Fit Balance Board and [Multimedia Appendix 2](#) presents a video of participants using the Wii Fit Balance Board.

Among the sample, half of the participants ($n=13$), all assistive aid users, could not use the OTS version of the Wii Fit Balance Board. The mean SUS score for the OTS Wii Fit Balance Board among the participants who could use it ($n=12$) was 66.88 (SD 20.14). All participants ($n=25$) were able to use the adapted version of the Wii Fit Balance Board, resulting in a mean SUS score of 71.7 (SD 18.03). The mean SUS score for the adapted Wii Fit Balance Board among the participants who could use the OTS version ($n=12$) was 67.08 (SD 21.76), whereas the mean was 75.96 (SD 13.24) among the participants ($n=13$) who could not use the OTS version. [Table 1](#) shows participants' individual SUS scores for the OTS and adapted versions of the Wii Fit Balance Board.

We found a significant Pearson correlation ($r=.692$, $P<.001$) between the difference in SUS scores (OTS, adapted) and the physical function scores.

Figure 6. Wheelchair user using adapted Wii Fit Balance Board.



Table 1. System Usability Scale (SUS) scores for each participant.

Participant ID	OTS ^a Wii Fit Balance Board SUS score	Adapted Wii Fit Balance Board SUS score
1	75	75
2	57.5	62.5
3	0	77.5
4	50	37.5
5	100	37.5
6	100	100
7	60	82.5
8	42.5	70
9	50	55
10	57.5	100
11	0	62.5
12	0	97.5
13	0	75
14	0	100
15	0	70
16	0	65
17	0	70
18	92.5	45
19	0	55
20	55	57.5
21	0	70
22	62.5	82.5
23	0	90
24	0	75
25	0	80

^aOTS: off-the-shelf.

Discussion

Principal Findings

A first step in determining a system's success or failure is to evaluate its usability [33]. SUS computed scores range from 0 to 100, but do not equate to percentages. As a way to interpret SUS scores, Bangor et al established an adjective rating scale to correspond to the computed scores [36]. Based on the adjective scale, the adapted Wii Fit Balance Board's score of 71.7 among all participants translates to "good" and belongs to the acceptable range of SUS scores. Additionally, among participants who could not use the OTS Wii Fit Balance Board, the adapted Wii Fit Balance Board had a mean SUS score of 75.96, which translates to "excellent". For those who could use it, the SUS score for the OTS Wii Fit Balance Board was 66.88 and translates to "good".

The results of this study demonstrate that employing user-centered design principles can increase accessibility and safety of AVG controllers, resulting in increased usability,

especially for individuals who require an assistive aid for mobility. The increased usability of the adapted Wii Fit Balance Board is the result of a user-driven design, where users provided initial feedback to help in the design of the first prototype. Subsequent user feedback at multiple levels throughout the design process resulted in a highly usable product. The most significant benefit offered by the adapted Wii Fit Balance Board is that it doubled the number of the users able to engage in AVG play on the Wii Fit Balance Board, and adaptation of the Wii Fit Balance Board was rated as excellent. Furthermore, the strong correlation between the difference in usability scores and physical function score suggests that the Wii Fit Balance Board adaptations were increasingly useful (highly usable) for participants with a stronger need (ie, increased lower-extremity function and trunk control limitations).

We observed a few exceptions to the generally positive rating of the adapted Wii Fit Balance Board. For instance, 1 participant (ID #18), who did not use an assistive aid, demonstrated high physical function and had prior experience with the Wii Fit Balance Board, rated usability of the OTS version higher than

that of the adapted board. Similarly, another participant (ID #5) scored usability of the OTS Wii Fit Balance Board much higher than the adapted version. This large difference in perception of usability is perhaps explained by the fact that the participant had previously played AVGs using the Wii Fit Balance Board and perceived her game play performance using the OTS controller as proficient given her high level of lower-extremity function with use of a prosthetic leg. This participant likely perceived the adapted board as having little value and perhaps viewed it as an unnecessary adaptation. Had the participant conducted the trials without her prosthetic leg, however, we would expect that she would have rated the usability of the adapted board more highly. As noted in one study, individuals with unilateral transtibial amputation who used a custom-fit prosthetic leg were able to perform similarly to individuals without amputation on a variety of physical performance measures [42].

This study aimed to evaluate the usability of the adapted Wii Fit Balance Board; however, generalizability of the results is limited by the fact that a large variety of users, with different types of impairments and assistive aids, were included in the sample. A further stratified study, evaluating the usability of the device qualitatively and quantitatively within selected population groups, such as those with specific degrees of mobility impairment or using an assistive aid, would help identify a much more precise level of usability for this adapted gaming controller. Furthermore, the prototype evaluated in this study was based on the commercial Wii Fit Balance Board and thus was limited to a maximum weight of user and wheelchair (if needed) to 150 kg (330 lb).

One addition to the adapted Wii Fit Balance Board that we did not evaluate in the context of this study was a button to adjust the sensitivity of the controller. This addition was based on the range of movements required for various games, from extreme whole-body movements to very limited and controlled small-segment (eg, hand) movements. The sensitivity control was introduced to counter these requirements and enable participants with limited functional movement to successfully engage in AVG play. Further investigation should include evaluation of this feature and its effect on usability of the system.

Individuals with disabilities experience high rates of secondary conditions, with lack of physical activity being an important contributing factor [43,44]. Participation in AVGs has been shown to increase physical activity in people with disabilities

[1-5,17,18]. Our study successfully designed, engineered, and evaluated the removal of the access barrier to a widely used gaming controller (Wii Fit Balance Board), thereby enabling users with a range of physical function to play a variety of games that can be controlled through the Wii Fit Balance Board.

To date, several studies have examined usability of AVG controllers with a focus on older adult populations most often playing researcher-developed games [45,46]. Our study was unique, in that it evaluated the usability of a mainstream AVG controller (Wii Fit Balance Board), redesigned with major hardware adaptations to enhance the accessibility, safety, and user experience for individuals with impaired mobility during play of commercially available games. The results demonstrated that application of user-centered design principles to the adaptation of gaming controllers can result in acceptable and usable AVG controllers for a wide range of individuals with varying physical disabilities. Future efforts should be directed toward user-centered design and adaptation of other OTS AVG controllers with subsequent evaluation of usability and acceptability. It is important that all AVG controllers be designed universally, or be adapted, to meet the needs of people with various physical disabilities and provide them with equal opportunities to engage in AVG play. Although the results of this study demonstrated the usability of the adapted Wii Fit Balance Board, its effect on the level of physical activity and other important fitness and health outcomes is an important next step. We are engaged in a preliminary study to evaluate energy expenditure during AVG play on the adapted Wii Fit Balance Board in persons with physical disabilities, specifically those with mobility impairments.

Conclusions

This study demonstrated a successful adaptation of the Wii Fit Balance Board, thereby enabling AVG play as an option for individuals with mobility impairments. Evaluation of the usability of the OTS and adapted versions of the Wii Fit Balance Board showed that users with various impairments, including those who use a wheelchair for mobility, were able to engage in AVG play using the Wii Fit Balance Board as a result of the adaptation. Additionally, results suggest that, the less lower-extremity function and trunk control participants have, the more highly they rate the usability of the adapted Wii Fit Balance Board. Future studies should consider adaptation of other available AVG controllers following a similar user-centered design approach.

Acknowledgments

The contents of this article were developed under a grant from the US National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90RE5009-01-00). NIDILRR is a Center within the Administration for Community Living (ACL), US Department of Health and Human Services (HHS). The contents of this article do not necessarily represent the policy of NIDILRR, ACL, or HHS, and the reader should not assume endorsement by the US Federal Government. Thanks to the following research staff for their assistance with this project: Brandon Kane, Justin McCroskey, and Whitney Neal. Thanks to the following team members of the Engineering and Innovative Technology Department, University of Alabama at Birmingham, for their assistance with the design: Rafael Correa, Larry Frost, and BJ Herrington.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Participant characteristics (Table).

[[PDF File \(Adobe PDF File\), 41KB - rehab_v5i1e2_app1.pdf](#)]

Multimedia Appendix 2

Participants using the adapted Wii Fit Balance Board (Video).

[[AVI File, 6MB - rehab_v5i1e2_app2.avi](#)]

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Abbreviations

ADA: Americans with Disabilities Act

AVG: active video game

COB: center of balance

ECU: electronic control unit

ICF: International Classification of Functioning, Disability and Health

LED: light-emitting diode

OTS: off-the-shelf

SUS: System Usability Scale

Edited by G Eysenbach; submitted 31.05.17; peer-reviewed by K Ferrar, S Hiremath, K Ng; comments to author 03.07.17; revised version received 24.10.17; accepted 17.01.18; published 06.03.18.

Please cite as:

Thirumalai M, Kirkland WB, Misko SR, Padalabalanarayanan S, Malone LA

Adapting the Wii Fit Balance Board to Enable Active Video Game Play by Wheelchair Users: User-Centered Design and Usability Evaluation

JMIR Rehabil Assist Technol 2018;5(1):e2

URL: <http://rehab.jmir.org/2018/1/e2/>

doi: [10.2196/rehab.8003](https://doi.org/10.2196/rehab.8003)

PMID: [29510972](https://pubmed.ncbi.nlm.nih.gov/29510972/)

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Original Paper

Perceptions of Existing Wearable Robotic Devices for Upper Extremity and Suggestions for Their Development: Findings From Therapists and People With Stroke

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Abstract

Background: Advances in wearable robotic technologies have increased the potential of these devices for rehabilitation and as assistive devices. However, the utilization of these devices is still limited and there are questions regarding how well these devices address users' (therapists and patients) needs.

Objective: The aims of this study were to (1) describe users' perceptions about existing wearable robotic devices for the upper extremity; (2) identify if there is a need to develop new devices for the upper extremity and the desired features; and (3) explore obstacles that would influence the utilization of these new devices.

Methods: Focus groups were held to collect data. Data were analyzed thematically.

Results: A total of 16 participants took part in the focus group discussions. Our analysis identified three main themes: (1) "They exist, but..." described participants' perceptions about existing devices for upper extremity; (2) "Indeed, we need more, can we have it all?" reflected participants' desire to have new devices for the upper extremity and revealed heterogeneity among different participants; and (3) "Bumps on the road" identified challenges that the participants felt needed to be taken into consideration during the development of these devices.

Conclusions: This study resonates with previous research that has highlighted the importance of involving end users in the design process. The study suggests that having a single solution for stroke rehabilitation or assistance could be challenging or even impossible, and thus, engineers should clearly identify the targeted stroke population needs before the design of any device for the upper extremity.

(*JMIR Rehabil Assist Technol* 2018;5(1):e12) doi:[10.2196/rehab.9535](https://doi.org/10.2196/rehab.9535)

KEYWORDS

qualitative research; focus group; wearable devices; rehabilitation; upper extremity

Introduction

Traditional, hospital-based stroke rehabilitation can be labor-intensive and expensive. In the United States alone, the direct and indirect cost for stroke rehabilitation is about US \$36.5 billion per year [1]. From 2012 to 2030, the total direct annual stroke-related medical costs are expected to increase from US \$71.55 billion to US \$184.13 billion [2]. Furthermore, outcomes from rehabilitation are inconsistent across individuals, and recovery is hard to predict. Given these uncertainties, numerous technological approaches have been tested in an effort to improve rehabilitation outcomes and reduce the cost of stroke rehabilitation [3]. In recent years, interest has grown in the use of wearable robotic devices (ie, devices worn by human operators, whether to supplement the function of a limb or to replace it and thus enhance a person's motion or physical abilities [4]) that aim to restore mobility in stroke population [5-16]. However, many of these devices have been developed from a technology-centered perspective, where engineers develop systems needed to provide upper extremity rehabilitation or assistance with little user input [17]. Moreover, designers are either unaware of the needs of users with different capabilities, or do not know how to accommodate their needs into the design cycle [18]. The lack of involvement of end users in the design process results in a failure to gain users' acceptance and approval [19].

Given the multiple factors that affect a user's decisions to use or adopt different types of devices and technologies in the clinical practice, it has been recommended that users should be involved throughout the design process; this approach is known as user-centered design. This approach is intended to help designers identify relevant aspects and different factors that should inform their design choices [20]. User-centered design has emerged in the last 30 years as an alternative approach to traditional engineering effort [21]. The purpose of user-centered design approach is to serve the user and not just the use of a specific technology. Additionally, it is an iterative process with an ultimate goal to develop usable systems and thus prompt their clinical utilization [22]. Unfortunately, little research has been conducted to explore and understand users' perceptions and their viewpoints regarding these devices and technologies [23-26].

Given the uncertainties about the utility of existing devices for the upper extremities and the desire to develop better ones, we conducted a study with three main objectives:

1. Explore the users' perceptions of existing devices and technologies for upper extremities and thus identify reasons that would affect whether they would use or not use these devices.
2. Investigate whether there is a need to develop new devices.
3. Identify different factors that would limit the utilization of any future devices for the upper extremities.

Methods

Setting, Participants, and Recruitment

The exploratory nature of this study lends itself to qualitative methods. Focus group discussions were the primary method of data collection for this study [27]. Focus groups have advantages over other data collection tools such as one-to-one interviews and surveys, as they accommodate large number of people having common interests in a specific topic [28] and enable the collection of information in a short time [29]. We have reported the study using the consolidated criteria for reporting qualitative research [30]. The study was approved by local universities and health authorities ethical review boards (REB: # 2012s0527, BREB #: H16-01085, and VCHRI: # V16-01085).

The study took place in the province of British Columbia, Canada. In this jurisdiction, there is very limited public funding available for assistive technologies (eg, disability benefits or basic medical disability plan), so most people need to rely on personal finances or extended health insurance benefits to obtain these devices [31]. Two groups of participants were invited to participate in the study. The first group was for people with stroke who had ongoing upper limb mobility problems and had experience with or interest in robotic devices. The second group was for occupational therapists and physical therapists who had at least 1 year of professional experience working with either seniors or people with stroke or were interested in robotic devices. Participants with stroke were recruited through distribution of advertisements to community centers and local supportive groups (eg, local stroke clubs). Therapists were recruited through email distribution of a letter of initial contact and posted advertisements. All participants provided informed consent. The second author knew some of the therapists who participated in the study casually as members of the same discipline.

Data Collection

The second author, an occupational therapist who has extensive experience with individuals with neurological disorders and focus group facilitation, moderated the focus groups. During focus group interviews, participants were led through a series of questions following an interview guide that was developed after extensive discussions and review with qualitative research experts with experience in conducting focus groups. The focus group interview guide went through multiple revision cycles to make sure that the questions would be understandable by the participants ([Multimedia Appendix 1](#)). Questions probed the participants' experiences and views of current therapeutic technologies and devices used for upper extremity, desirable features for future technology designed to rehabilitate the upper limb, and perceived barriers to use of technologies and robotic devices.

The study was conducted in a local rehabilitation center where discussions included the participants and the researchers only. At the beginning of each group, the moderator introduced the purpose of the focus group, the ground rules, the process, and the objectives of the discussion. During the introduction, the moderator reiterated the purpose of the study and encouraged an open climate for all participants to express their opinions

freely. The moderator facilitated the discussion to allow the participants to enrich the conversation through interactions with each other. The first author took field notes to offer an additional perspective of the focus group findings and to provide a nuanced context of each group. The focus groups were audiorecorded and later transcribed verbatim by a research assistant. Both the first and second authors reviewed all the transcriptions to confirm the content and to identify any missing data or any discrepancies. Transcripts identified participants and researchers by numbers so that perceptions or contributions of everyone could be tracked anonymously. To further protect participants anonymity, all proper nouns (describing places or other people) were replaced with pseudonyms, and we limited the amount of personal information revealed about each participant, and we did not report quotes that might enable the participant's identity to be easily inferred (eg, if the situation or event was very unique).

Data Analysis

Transcripts and filed notes were analyzed thematically through a process outlined by Braun and Clarke [32]. This involved becoming familiar with the data, generating initial codes, searching for themes, reviewing themes, and defining and naming themes. The first two authors used Microsoft Excel to initially code interview transcripts, observation notes, and debriefing, following data collection sessions independently

and then worked collaboratively to develop an initial coding guide, which was then applied to all of the data and eventually amalgamated into subthemes and themes.

We used two different strategies to promote trustworthiness: triangulation and reflexivity. Triangulation of participants involved the inclusion of people with stroke and clinicians. There was also triangulation of researchers as noted above. Field observation notes and debriefing following data collection sessions between the first two authors were used to facilitate reflexivity [33]. We were interested in developing new devices for upper extremity, so that may have prejudiced the researchers against existing devices. To guard against this, we tried to probe for positive features of existing technologies.

Results

We conducted four focus groups from September 2016 to October 2016: one for people with stroke and three for therapists. The focus group for people with stroke included 8 participants and lasted for 90 min. The three focus groups for therapists included 8 participants (2-3 each), and each lasted for almost 45 min. [Tables 1](#) and [2](#) show the demographic characteristics of people with stroke and therapists who joined the focus groups interviews, respectively. Our analysis of the interview data and field notes identified three main themes and 11 subthemes as described in [Textbox 1](#) and detailed below.

Table 1. Demographic characteristics of participants (people with stroke, n=8).

Characteristics	n (%)
Gender	
Female	1 (13)
Male	7 (87)
Age in years	
50-60	1 (13)
61-70	5 (62)
>70	2 (25)
Stroke duration in years	
<5	1 (13)
5-10	3 (37)
>10	4 (50)
Handedness	
Right	8 (100)
Affected hand	
Right	3 (38)
Left	5 (62)

Table 2. Demographic characteristics of participants (therapists, n=8, all females).

Characteristics	n (%)
Age in years	
30-40	4 (50)
40-50	2 (25)
50-60	2 (25)
Profession	
Physiotherapist	4 (50)
Occupational therapist	2 (25)
Rehabilitation assistant	2 (25)
Professional experience in years	
<5	1 (13)
5-10	2 (25)
11-15	3 (36)
16-20	1 (13)
>20	1 (13)

Textbox 1. Summary of main themes and subthemes.

<ol style="list-style-type: none"> 1. They exist, but... <ul style="list-style-type: none"> • Existing devices and technologies • Cost-effectiveness • Doubts on efficiency • Compromise the independence 2. Indeed, we need more. Can we have it all? <ul style="list-style-type: none"> • Assistance vs rehabilitation • Distal vs proximal • Portability vs complexity • Activation and motivation 3. Bumps on the road <ul style="list-style-type: none"> • Single solution is challenging • Ensure accessibility • Setup time and learning curve
--

Theme 1: “They Exist, but...”

The first theme described participants’ experience with existing devices and technologies for upper extremity. Subthemes described participants’ knowledge of existing devices and factors limiting their utilization.

All participants had knowledge about existing passive or nonrobotic devices for upper extremity. For example, one participant with stroke indicated that sometimes he used slings for stabilization. Another participant with stroke mentioned a device used for wrist and fingers extension to decrease spasticity:

The [Saebo] is a manual device for the hand with springs on it, looks like a glove. After exercising the fingers, turn the fingers on.

A therapist described using passive devices to decrease spasticity, maintain range of motion, and to avoid subluxation of the shoulder:

We use resting hand splints with our stroke clients..., for...night time, helping to...maintain range and manage their spasticity and we have a couple different shoulder supports for like hemiplegic shoulders, subluxation of the shoulder.

Thus, these devices were widely known and used for different joints and different reasons.

Available active devices for upper extremity were not as popular as the passive ones. Only one stroke participant mentioned a commercially available active device for upper extremity. He stated the following:

The [Bioness] opens my hand and closes it. My hand naturally tells itself [to do this]. So this helps my hand. It's electronic.

Participants mentioned that the utilization of existing devices was limited because of many issues. Participants went through some barriers such as the initial cost, doubts on the efficacy of such devices, interfering with their activities, and compromising their independence.

All participants reported that the initial cost of any device would affect their decision to adopt it (as for therapists) or to use it (as for people with stroke). For example, one participant with stroke considered the cost of a device he had before was overpriced. Another example is a therapist who described a device developed a few years ago and was unaffordable for her clients. She stated the following:

I can recall an in service with a splint a number of years ago when they came in and showed us I would call it, sort of robotic like, where it helps them to do a certain pattern of movement. But quite expensive, we didn't really think...our clients would be able to afford it.

The cost was an important consideration not only for patients but also for therapists who could potentially act as gatekeepers to these devices. Thus, a high cost could potentially hinder the utilization of any device for upper extremity rehabilitation.

Limited evidence of clinical utility of existing upper extremity devices was considered as a barrier. For example, one participant with stroke shared his experience with a company that sells a device for the upper extremity. He stated the following:

By the way, I talked to [a company] last week...They still have not written a manual for recovery,...they still do not have clinical trials.

Another participant with stroke questioned the efficacy of rehabilitation in general. He stated the following:

I am completely paralyzed on the left side and with probably no chance to recover, I don't know what to do but robotic devices, I see this stuff on the computer and YouTube. But without [the] brain active, doesn't do any good.

These doubts about the efficacy of existing devices for upper extremity rehabilitation were considered a barrier to their utilization.

The size of upper extremity devices was a barrier, given a perception that available devices are either bulky or uncomfortable. A therapist indicated that the size of many devices was annoying for her clients, as she wanted her clients to use these devices while they are sleeping; however, there was an issue with adherence. She stated the following:

A lot of people say they don't like to wear the splint [ie, a passive device to maintain wrist or hand posture and to decrease spasticity] because it's bulky...People don't wear these devices because the Velcro catches on their sheets.

Thus, the size of upper extremity devices was a limiting factor that might prevent some people from using them.

Participants were concerned about the long-term implications of device use. A stroke participant shared his experience from the acute phase of his injury and suggested that relying on assistive devices would have compromised his independence. He stated the following:

I had my stroke 9 years ago hemiplegic...I could not eat, and I could not talk... was completely paralyzed on the right side...From the beginning; I was against devices to help me, because I did not want to rely [on] high tech.

Another stroke participant shared similar experience after being discharged from the hospital, as he refused to rely on wheelchair as an assistive device. He stated the following:

When I came home back [released from the hospital] my kid brought me a wheelchair,...I said never, I would get into one of these,...I am walking around for 6 months now.

Thus, concerns about the long-term impact of these devices on participants represented a disincentive for their use among some participants.

Theme 2: “Indeed, we Need More. Can we Have it all?”

All participants identified a need to develop new devices for upper extremity. Participants with stroke mentioned personal reasons to develop new devices, as they were keen to have assistive devices to help in daily life activities (such as word processing or typing, cooking, drinking, etc). One participant with stroke indicated that she wanted devices to help in her kitchen:

Try cooking with it,...you're holding onto a bowl and not holding on very well...You're stirring well in it but it's going all over the place on the floor.

In contrast, therapists' needs were more diverse and covered larger spectrum of potential users. For example, a therapist wanted to have devices that would complement traditional therapy, such as a preparation for rehabilitation sessions to reduce the traditional therapy sessions as an adjunct to the therapy. He stated the following:

You know we're talking active rehab, prepping it for therapy sessions or for use in the therapy session. Or potentially you could still say it was part of your therapy session.

Thus, the needs were different; participants with stroke were in the favor of assistive devices, whereas therapists demonstrated a preference for therapeutic devices.

All participants with stroke suggested developing new devices for hand and fingers. To illustrate this need, one participant with

stroke demonstrated his inability to open a bottle of water without spilling the contents. Two occupational therapists supported the need to have new devices for distal control as a motivation of active engagement and for functional training:

I think there would be pros to getting the distal because maybe if they [patients] start to activate their hand more, then we'll actually see better proximal, I think that the research shows we don't just lift our arms for the sake of lifting our arm[s], I mean you're always moving your upper limbs for a purpose.

In contrast, 4 physiotherapists suggested having new devices for proximal control and stabilization; such devices would help decrease spasticity and the pain. A physiotherapist shared her thoughts about which joints considered important for upper extremity rehabilitation. She stated the following:

I think by the end of the day, the stroke will be with proximal joints more. They have a lot of pain in the shoulder because they don't move [or] do anything with those joints.

Thus, despite the perceived need to develop new devices, participants were not unanimous about which part of the upper limb should have the priority when designing new devices.

Participants had different opinions regarding the portability and ease of donning devices for upper extremity. All participants with stroke wanted new devices to be wearable and portable, like a garment. A participant with stroke emphasized the importance of having simple devices:

Ease of insertion, you know for some people they only have one arm, you don't want something really complex, you know, get it on get it off easily.

Therapist participants were in the favor of having comprehensive devices (ie, larger devices that could work across multiple joints) for the upper extremity. A therapist participant acknowledged that comprehensive devices would be more complicated; however, they would accommodate a broader spectrum of movements for functional training:

If you're going to have something as a multi-joint, that would be awesome from a reach pattern perspective but then the complexity of the device, could be [too] much.

Thus, portability and easiness of donning devices for upper extremity were critical issues for stroke participants, as they could facilitate their independence; they were less critical issues for therapists.

Participants had different opinions regarding which type of signals would be the best to control or trigger devices for the upper extremity. On one hand, there was considerable variation in the methods of activation preferred by participants with stroke, and no one approach dominated. A stroke participant suggested a novel method to control a wearable hand device only by looking at the device:

I want to be able to just look at the hand and put those two fingers together.

On the other hand, therapists had more specific suggestions about signals that could be used to control or trigger these devices for distal or proximal joints. For example, a therapist suggested using biosignals to activate these devices to augment relearning movement patterns:

Brain activity would be cool, actually having them [patients] like think about the movement; it seems smart for somebody who had a stroke, which would be a good idea. EMG [electromyography] maybe if they're showing small amounts of muscle activity, so then they [patients] might then back learn the pattern more, and with that help for further activation.

One therapist shared her experience with an exoskeleton used for lower extremity. She suggested having new devices that provide active engagement and thus provide more motivation. She stated the following:

You can see how they get really happy when they can do something with the help of something, like for example, when I see the clients working with the robotic thing for walking, hope comes, so they can be more motivated to do it.

Thus, developing devices that would provide active training may have positive psychological impacts in that success in training might motivate patients to practice more.

Theme 3: Bumps on the Road

In addition to the issues participants perceived above about existing devices for the upper extremity, participants identified other issues and concerns that would hinder the utilization of any newly developed devices. These concerns varied from the difficulty finding a single design that would fit every one, users' should be able to have the accessibility to such new devices, and finally, the way to set up and use these device should be as simple as possible.

All participants reflected that finding a single design is challenging, as it is difficult to identify a universal design that would work for all users. This concern was illustrated by one participant with stroke, who stated the following:

Everyone has their own situation...We're talking about different things for different situations...there isn't one size fits all.

Likewise, one therapist indicated that it is not clear which population would most likely use a robotic device, as there are many parameters involved, and it is difficult to decide on which joint should be the focus as it depends on client needs:

Yeah it is very client dependent. If I try to think of the spectrum of my clients, it would be very difficult to say one.

Two stroke participants reported that sometimes there were some tools or devices that would benefit them; however, they did not get access to these tools. One participant with stroke explained the following:

Access to the tool you're using [...] might be an issue. They are not located anywhere you can use them. [People] might know about new devices or

technologies; however, they are not available to every patient to use them.

Likewise, three therapists identified a concern about accessibility from a different point of view. One therapist illustrated that without financial support from a third party (eg, governments and insurance companies), the accessibility for any new developed devices would be limited:

I think without [...] extended benefits, without insurance companies maybe buying into that, I think [only] relatively small grouping of clients would be able to afford it.

Thus, having the accessibility to the right tools for rehabilitation or assistance was one of the concerns that would limit the utilization of any new device.

All therapists reported that the setup time was a concern when adopting new devices. A therapist reported that the setup time should not be more than 10 min:

Oh gosh no, I would say 10 minutes max for me...and then every 6 months, you still [got to] be able to do it in 10 minutes.

Another therapist acknowledged that using new devices is a learning process:

I think something with the exoskeleton [for the lower extremity] I noticed for initially, I know it takes some learning and it gets a little bit better but initially they [users] seem to perceptually have a really hard time with what exactly is going on in the exoskeleton.

Thus, setup time or complicated training requirements could limit adoption of new devices.

Discussion

Principal Findings

The objectives of this study were to explore users' perceptions about existing wearable robotic devices for upper extremity, to identify if there was a need to design and develop new devices for upper extremity, and to describe different factors that might affect the design of new devices and thus the required features for these devices. Earlier studies have investigated user's perception regarding specific robotic devices for upper extremity [34]; however, to the best of our knowledge, this is the first study to explore users' perceptions regarding wearable robotic devices for the upper extremity generally, rather than being limited to a specific device. The study findings describe the perspectives of therapists and people with stroke who had previous experience with different upper extremity devices.

Theme 1: "They Exist, but..."

The awareness that participants had about assistive technologies or devices is not surprising given previous research by Hughes et al [35] that found 92% of health care professionals had accessed information on assistive technologies, with 59% of them using assistive technologies or devices in their clinical practice, whereas 41% of patients and care givers had accessed information, with 44% of them using assistive technologies or devices. People with stroke showed more knowledge of existing

devices for assistance over therapeutic devices, as their main goal is to perform their daily life activities independently. Therapists showed more knowledge of existing therapeutic devices, as their main goal is to help people with neurological disorders to recover if possible. Although there is little evidence that passive devices (eg, splints and slings) improve motor function, reduce spasticity, or prevent contractures in the upper extremity [36], participants indicated that these interventions are still relatively common and had limited awareness of active devices for upper extremity, which have been recommended as an alternative [37]. The popularity of passive devices over active devices for the upper extremity reflects a tension between research evidence and the clinical practice, which appears ongoing as reported by Hughes et al [35].

The acceptability of novel interventions such as robotic devices requires careful weighing of the perceived benefits with the potential costs, which is described as the cost-effectiveness trade-off [38]. Currently, there is a critical need for more experimental research that provides evidence about the efficacy of these devices [32] and better information about actual costs involved. For example, although participants in this study were concerned about the cost of these interventions, a study by Wagner et al [31] found no statistical difference between robotic rehabilitation cost and usual care cost. Ultimately, without a better understanding of the effectiveness of these devices and their cost to implement into practice, people with stroke and clinicians who work with them will be unable to make accurate determinations of their cost-effectiveness.

Concerns about not regaining functional independence is a barrier that may limit the utilization of wearable robotic devices for the upper extremity. Although there is controversy about how independence should be defined [38,39], stroke participants in our study suggested depending on assistive devices would be stigmatizing. This finding is congruent with previous research done by Silvers [40] that concluded that people feel stigmatized by devices that signal loss of function. Similarly, Luborsky indicated that people with stroke may not choose to adopt new technologies that allow independent mobility if this makes them feel more visibly disabled [41].

Theme 2: "Indeed, we Need More. Can we Have it all?"

This study reveals the existence of a strong desire to develop new devices for upper extremities. Interestingly, each set of participants (eg, people with stroke and therapists.) had their own reasons to have new devices for upper extremity. In general, therapists would like to have devices that complement the traditional therapy; this finding supports the study carried out by Hughes et al [35] where the authors concluded that robot-assisted movement therapy should only be used as an adjunct to conventional therapy to minimize unwanted compensatory movements. Despite recent efforts to reduce compensatory movements using automated feedback, Valdés et al [42], our finding emphasizes concerns about the unsupervised use of these devices by therapists, which may also reflect fears that robotic devices could reduce their role during rehabilitation.

Another tension that emerged in this study was related to concerns about portability vs complexity. People with stroke wanted these devices to be as simple as possible and allow users to don and doff them without assistance. Research conducted by Colleen O'Brien Cherry et al [43] was congruent with our finding that users (people with stroke) wanted to have a device that is easy to wear and to use. The preference for therapists for a more complex device that covers a broader spectrum of patients is understandable given the heterogeneous populations they serve.

Our findings emphasize a desire for active devices that provide motivation. Acknowledging that active devices required control signals to be actuated, people with stroke suggested having simple control mechanisms (eg, the device could be triggered and moved by visual cues). Unlike verbal or auditory signals, this mechanism would draw less public attention to the user. In contrast, because the therapists were more interested in neuroplasticity augmentation, they preferred to use biosignals such as electroencephalography and electromyography to control such active devices. The simplicity of the active assistive devices that people with stroke are asking for might reflect concerns about the likeliness of recovery; thus, they may want devices to help in their daily activities regardless of any recovery goals. This variability in goal setting is congruent with previous studies by Lawler et al [44] and Dowsell et al [45] that concluded that recovery goals are relative, variable, and individually based.

Theme 3: Bumps on the Road

In this study, some barriers were identified that would hamper the development of new devices for upper extremity and could potentially hinder their adoption. The heterogeneity of users represents a challenge for device development. Although the heterogeneity among the participants with stroke might be anticipated given that their needs and expectations from the assistive devices are diverse, the existence of such heterogeneity among occupational and physical therapists is interesting. These differences could be related to the different role they have in rehabilitation settings, as there may be more of a focus on hand function among occupational therapists [46,47]. Given these heterogeneities, finding a single solution that is accepted by the majority of the users' may not be possible.

The ease of access to commercially available technologies or technologies under development is a crucial barrier. Limited accessibility to available resources for rehabilitation or assistance technologies would slow down their adoption. This finding is congruent with a study by Hughes et al [35] that concluded that lack of information and access to assistive devices are the main reasons for their lack of adoption. Lack of funding for upper limb assistive technologies has previously been identified as an issue that hampers their development [33].

Ease of doffing and donning and setup time affect the acceptance for any new device for upper extremity. On the basis of the findings of our study, ease of application and setup times appear to be important considerations for device development. Our finding contradicted a study by Liu et al [48] where the authors concluded that therapists' effort expectancy was not a salient factor when adopting new technologies or devices. However, our findings are congruent with a study by Hughes et al [35] where the authors found that when developing a new device for the upper extremity, ease of setup and use was the most important factor identified by health care professionals and the second factor identified by the patients and their caregivers. Thus, for any future design of assistive devices for upper extremity, it is important to insure the ease of donning the device and setup time are considered.

Limitations

Given the exploratory nature of this study, a number of limitations need to be acknowledged. There may be some issues with transferability given the nature of the study sample, which included 16 participants in total (8 people with stroke and 8 therapists) from one site. Although focus groups are more efficient than individual interviews, they have their own limitations, especially with heterogeneous groups. Moreover, despite efforts that were made to hear from everyone, some participant voices dominated the discussion. Furthermore, given time constraints within the focus groups, it was not always possible to clearly delineate the cause of all users' concerns.

Conclusions and Future Work

This exploratory study investigated perspectives from two different populations (ie, people with stroke and therapists) regarding available wearable robotic devices for the upper extremity. Participants with stroke had more knowledge about passive devices over active ones despite equivocal evidence about the efficacy of passive devices, whereas therapists had more knowledge about existing therapeutic devices. In general, participants' experiences with available robotic devices for upper extremity were not positive because of multiple issues that included concerns about cost-effectiveness and concerns about the potential long-term loss of independence. Although participants supported the need to develop new robotic devices for the upper extremity, their needs were diverse.

This research lays the groundwork for a variety of future studies. This could include studies with a larger sample of participants representing more diverse age ranges, geographical locations, and patients with different neurological disorders (such as spinal cord injury or cerebral palsy patients) which could add to our study findings. Furthermore, future studies could investigate whether the gap between users' current activity levels and their desired activity levels influences their preferences regarding new robotic devices.

Acknowledgments

This study was supported by the Natural Sciences and Engineering Research Council of Canada (NSERC) and the Canadian Institutes of Health Research (CHIR). The authors would like to acknowledge the participants for their time and valuable contributions in this research study. WBM was supported by a CIHR new investigator award.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Focus Group Interview Guide.

[\[PDF File \(Adobe PDF File\), 58KB - rehab_v5i1e12_app1.pdf\]](#)

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Edited by G Eysenbach; submitted 29.11.17; peer-reviewed by ML Bird, R Matthew; comments to author 01.02.18; revised version received 13.03.18; accepted 16.03.18; published 15.05.18.

Please cite as:

Elnady A, Mortenson WB, Menon C

Perceptions of Existing Wearable Robotic Devices for Upper Extremity and Suggestions for Their Development: Findings From Therapists and People With Stroke

JMIR Rehabil Assist Technol 2018;5(1):e12

URL: <http://rehab.jmir.org/2018/1/e12/>

doi: [10.2196/rehab.9535](https://doi.org/10.2196/rehab.9535)

PMID: [29764799](https://pubmed.ncbi.nlm.nih.gov/29764799/)

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Review

Person-Generated Health Data in Simulated Rehabilitation Using Kinect for Stroke: Literature Review

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Abstract

Background: Person- or patient-generated health data (PGHD) are health, wellness, and clinical data that people generate, record, and analyze for themselves. There is potential for PGHD to improve the efficiency and effectiveness of simulated rehabilitation technologies for stroke. Simulated rehabilitation is a type of telerehabilitation that uses computer technologies and interfaces to allow the real-time simulation of rehabilitation activities or a rehabilitation environment. A leading technology for simulated rehabilitation is Microsoft's Kinect, a video-based technology that uses infrared to track a user's body movements.

Objective: This review attempts to understand to what extent Kinect-based stroke rehabilitation systems (K-SRS) have used PGHD and to what benefit.

Methods: The review is conducted in two parts. In part 1, aspects of relevance for PGHD were searched for in existing systematic reviews on K-SRS. The following databases were searched: IEEE Xplore, Association of Computing Machinery Digital Library, PubMed, Biomed Central, Cochrane Library, and Campbell Collaboration. In part 2, original research papers that presented or used K-SRS were reviewed in terms of (1) types of PGHD, (2) patient access to PGHD, (3) PGHD use, and (4) effects of PGHD use. The search was conducted in the same databases as part 1 except Cochrane and Campbell Collaboration. Reference lists on K-SRS of the reviews found in part 1 were also included in the search for part 2. There was no date restriction. The search was closed in June 2017. The quality of the papers was not assessed, as it was not deemed critical to understanding PGHD access and use in studies that used K-SRS.

Results: In part 1, 192 papers were identified, and after assessment only 3 papers were included. Part 1 showed that previous reviews focused on technical effectiveness of K-SRS with some attention on clinical effectiveness. None of those reviews reported on home-based implementation or PGHD use. In part 2, 163 papers were identified and after assessment, 41 papers were included. Part 2 showed that there is a gap in understanding how PGHD use may affect patients using K-SRS and a lack of patient participation in the design of such systems.

Conclusions: This paper calls specifically for further studies of K-SRS—and for studies of technologies that allow patients to generate their own health data in general—to pay more attention to how patients' own use of their data may influence their care processes and outcomes. Future studies that trial the effectiveness of K-SRS outside the clinic should also explore how patients and carers use PGHD in home rehabilitation programs.

(*JMIR Rehabil Assist Technol* 2018;5(1):e11) doi:[10.2196/rehab.9123](https://doi.org/10.2196/rehab.9123)

KEYWORDS

health care information systems; Kinect; patient-generated health data; person-generated health data; review; simulated rehabilitation; stroke; stroke rehabilitation; video games; virtual rehabilitation

Introduction

Understanding the Effects of Person-Generated Health Data

Person- or patient-generated health data (PGHD) are health, wellness, and clinical data that people generate, record, and analyze for themselves [1]. Examples of technologies that support PGHD include online health journals, activity-tracking devices or mobile apps, networked health data-gathering devices such as weighing scales, and simulated rehabilitation technologies. However, PGHD integration into clinical use is hampered by the lack of theoretical foundation, strategies, and data models [1]. The availability of PGHD technologies has been increasing, and so has their adoption. However, implementation and evaluation research has not kept up.

PGHD's effects on the health of the individual have yet to be demonstrated or defined. It is known that when patients understand their illness, they may become active problem solvers and improve their health behavior; for example, it has been suggested that people will stop smoking when they personally see the connection between activity and illness [2]. Moreover, patients' use of PGHD has been suggested to improve health management coordination between them and their health care providers and treatment teams, assist patients in self-managing their care, engage patients, and increase the social support they receive and their sense of social connectedness [3-8].

In particular, PGHD may make home-based health care more efficient and effective. If not only clinicians but also patients are able to access health data generated from the use of home-based health care technologies, this may improve patients' engagement in their own care and optimize their use of clinical supervision, thus contributing to more effective outcomes across the health system overall [7,9,10].

PGHD may be especially relevant and accessible to patients who use a particular form of home-based health care, simulated rehabilitation systems. Simulated rehabilitation is a type of telerehabilitation that uses computer technologies and interfaces to allow the real-time simulation of rehabilitation activities or a rehabilitation environment [11]. Users interact with the simulation through multiple sensory channels [12-14].

Person-Generated Health Data Use Case: Simulated Rehabilitation After Stroke

One important PGHD use case may be in home-based poststroke rehabilitation that uses body-tracking simulated rehabilitation technologies [15]. Stroke is an important application area for rehabilitation systems because of the burden and complexity of the care required. It is a leading cause of death and disability across the globe and accounts for 46.6 million disability-adjusted life years [16,17]. Stroke patient motor function recovery is a long and complicated process, requiring patients to undergo extensive rehabilitation therapy that involves frequent, regular movement exercises matched to their impairments [18,19]. Regular rehabilitation exercises, especially in the first few weeks poststroke, are essential in helping patients recover and reduce long-term impact on their quality of life. However, clinical

rehabilitation can be costly and may not be readily available for some patients [20].

More practical and convenient rehabilitation options for patients are needed. Access to an effective home-based rehabilitation program is important in a patient's journey to recovery. Moreover, patients recovering after a stroke may prefer home-based rehabilitation rather than traveling to a clinic [20]. However, patient compliance with home-based exercise programs may be weak, in part due to the perceived monotony of exercises as well as lack of guidance in completing them [21-23]. The small number of successful trials reporting home-based exercises for stroke are also personnel intensive [20], indicating that therapists' close involvement remains necessary.

The potential benefit of simulated rehabilitation systems poststroke has been documented in select systematic reviews [12-14,24]. This form of rehabilitation can provide simulation of activities of daily living [24]. At the same time, it can allow the treating therapist a semicontrolled, consistent format for observing and documenting patient performance and progress [24] and for assessing any performance changes [13]. There is potential to decrease rehabilitation costs while increasing accessibility to rehabilitation exercises for patients in areas where there is a dearth of rehabilitation services [21-23]. Since these systems are interactive, many of them gamified, they add enjoyability to exercises, help motivate patients, and encourage adherence to the rehabilitation tasks [24]. As such, they are seen as optimizing the benefits of conventional therapy [12].

Implementing PGHD technologies might further optimize these systems. Simulated setups employ various hardware and software technologies including a range of off-the-shelf technologies [25] to set tasks (which in rehabilitation are often a form of physical exercise), facilitate the accomplishing of tasks, and—crucially for the relevance of PGHD—record the user's performance [26,27]. Using PGHD tools, performance data could be made accessible to the patient at home and, in Internet-connected settings, could be shared online (in rehabilitation, typically with the therapist) [27].

Use Case System of Choice: Microsoft Kinect

Microsoft's Kinect is a video-based technology that uses infrared to track a user's body movements. It has been suggested as a leading technology for simulated rehabilitation [26] for several reasons: it has good movement range and demands, which helps in rehabilitation; it has been shown to be reliable and accurate; and it demonstrates consistent performance in tracking user movements [28-30]. Also, it is a relatively affordable product that is available to consumers for home entertainment. These factors have led to its adoption for patient therapy in cerebral palsy [31], assessment of foot posture [32], and cardiovascular diseases [33].

Kinect has been used extensively in simulated rehabilitation systems for stroke. Commercial examples used by physical therapists with stroke patients include Limbs Alive and Jintronix. However, little is known about how effectively such systems may facilitate not only clinical data use by therapists but also PGHD use by patients themselves. There is no clear body of

evidence about the impact the patient’s experience using PGHD could have on their overall experience of rehabilitation in such systems.

Objectives of This Review

There is potential to realize greater engagement, efficiency, and effectiveness benefits of Kinect-based stroke rehabilitation systems (K-SRS) deployed in patient’s homes under clinical supervision by allowing each patient to access their own PGHD from the system. Hence, the objective of this review is to answer the questions: To what extent do K-SRS enable PGHD? And to what effect?

Methods

The literature review was conducted following the guidelines of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement [34], as appropriate to our objectives.

The review is structured in 2 parts:

1. Analysis of existing systematic reviews of K-SRS [25,27,29]. This reveals which aspects of relevance for PGHD have been prioritized by previous studies.
2. Systematic review of the use of PGHD in existing K-SRS.

Part 1: Analysis of Systematic Reviews

An exhaustive search strategy (Multimedia Appendix 1) resulted in 3 systematic reviews. Figure 1 illustrates this search process. The inclusion criteria include articles written in English, systematic or literature reviews, reviews of systems that used

Kinect, and systems for stroke rehabilitation. The exclusion criteria include reviews for nonstroke rehabilitation purposes (eg, assess Kinect’s gesture recognition) or broad scoping reviews that primarily take inventory of a suite of technology-based rehabilitation systems. The content of each systematic review was analyzed based on (1) method for analysis vis-à-vis objectives; (2) focus on use of patient-generated health data, including feedback given to users or patients; (3) the extent to which the systems included in the review are usable at home, including the challenges and recommendations for implementing at home; and (4) the effectiveness of the systems in the review based on patient outcomes as well as technological limitations that may affect those outcomes.

Part 2: Review of Person-Generated Health Data Use in Kinect-Based Stroke Rehabilitation Systems

An exhaustive search strategy (Multimedia Appendix 2) resulted in 41 original research reports for review. Figure 2 illustrates this search process. The inclusion criteria include those full papers written in English that present rehabilitation systems for stroke using Kinect. Exclusion criteria include white papers or systematic or literature reviews, primary purpose of study not being rehabilitation or primary disease case not being stroke, or not using Kinect in any way. Based on our objectives, content of the included papers was primarily analyzed using the following questions: (1) What types of data did patients generate? (2) Did they have access to their PGHD, and if yes in what form? (3) How were these data used by patients, clinicians, developers, and researchers? (4) What effects were observed from PGHD use?

Figure 1. Search process for part 1.

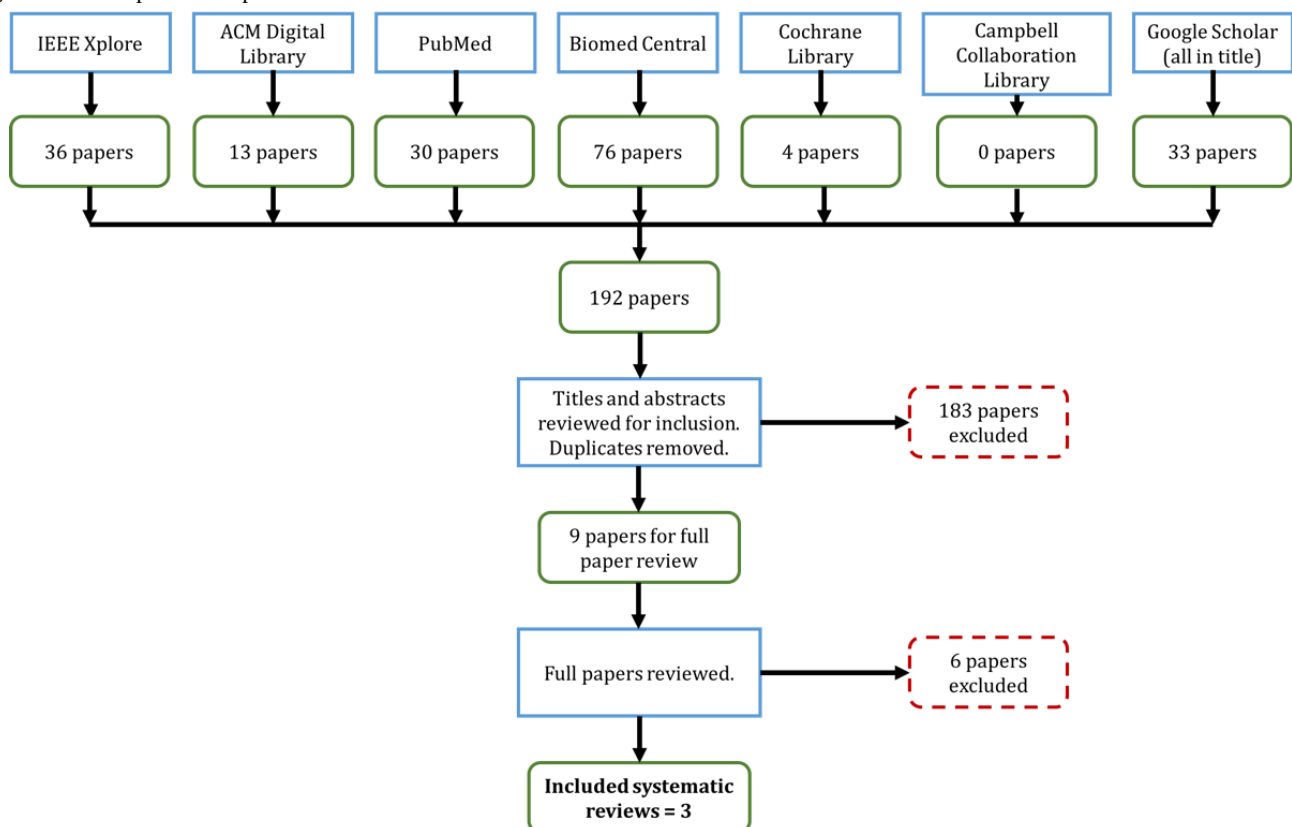
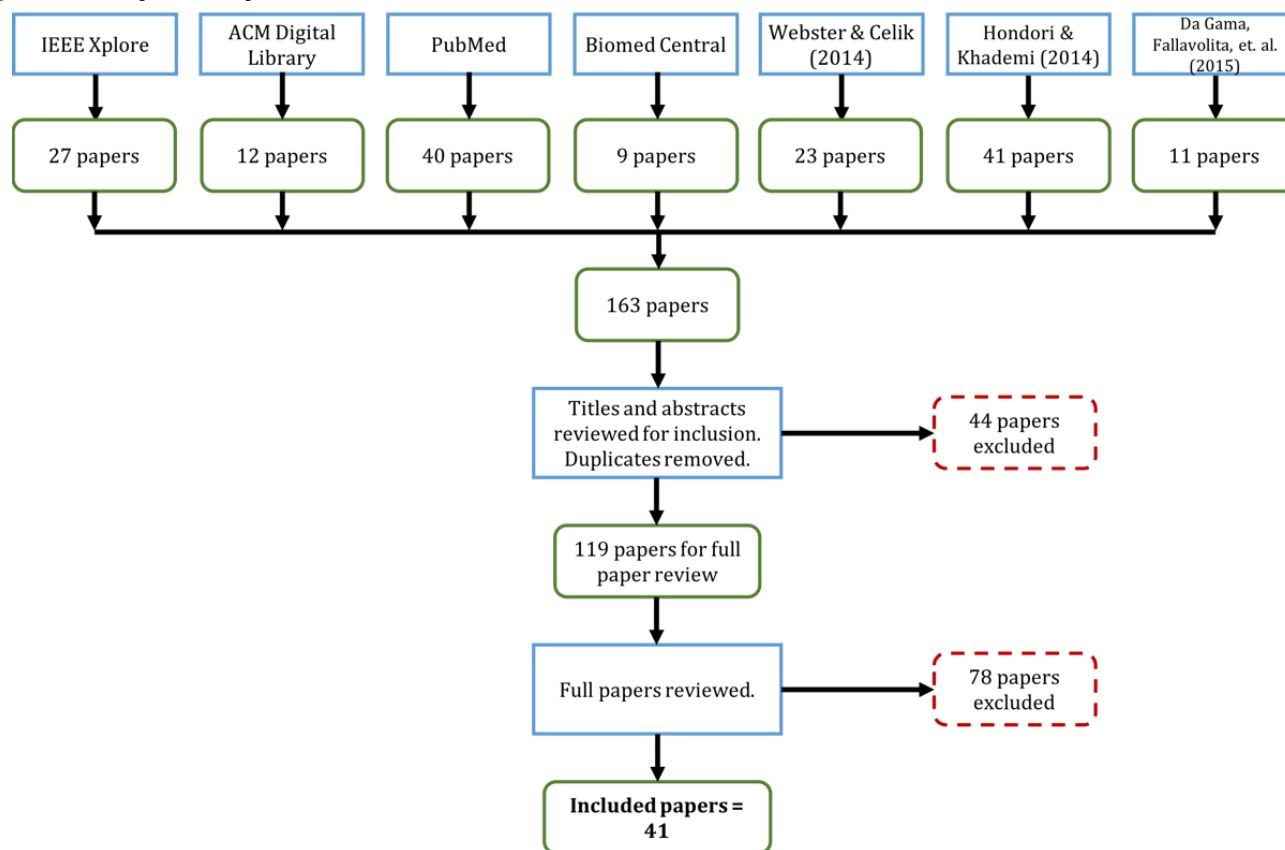


Figure 2. Search process for part 2.



Results

Part 1 highlights gaps in information collected in previous systematic reviews of K-SRS, particularly the use of PGHD and home use of K-SRS. Moreover, it shows that previous reviews mainly provided technical descriptions of K-SRS, while suggesting that more studies are needed to ascertain their clinical effectiveness. Part 2 of this review addresses the PGHD use gap.

Part 1: Analysis of Systematic Reviews of Kinect-Based Stroke Rehabilitation Systems

The objectives, methods, and structure of each systematic review are detailed in Table A (Multimedia Appendix 3). A summary of these systematic reviews vis-à-vis the themes of interest can be found in Table B (Multimedia Appendix 4).

Review of Person-Generated Health Data Use

None of the 3 systematic reviews examined the literature on use or management of patient-generated data, although system feedback methods were briefly described. Webster et al [26], however, noted the need for future research to look into the data-gathering potential of Kinect and provide proper feedback to patients, especially when they fail to accomplish a task. Hondori et al [25] focused on describing the technical and technological aspects and features of Kinect and other body-tracking technologies. Da Gama et al [27] were more comprehensive in their analysis and presentation of papers.

Review of Home Use

None of the reviews included a home usability criterion. However, Hondori et al [25] noted the need to assess Kinect's safety and efficacy when implemented at home. Moreover, Da Gama et al [27] briefly noted some challenges that can be encountered in a home implementation, such as space and lighting conditions. These authors recommended future studies into the effects and benefits of a home-based implementation. How patients might interact with their data outside of clinical settings is a significant gap in our understanding, particularly because K-SRS are touted as beneficial and advantageous for home use [35].

Review of Effectiveness

These 3 reviews confirmed the accuracy and reliability of Kinect when used for poststroke rehabilitation, particularly for providing and tracking movement exercises. They also highlighted Kinect's weaknesses, including occlusion and inability to track fine motor movement such as those including fingers, and suggested that Kinect should be focused only on the whole hand or be used with other technologies such as sensors. Webster et al [26] noted that Kinect may not be suitable for patients with extremely severe impairments because they are only capable of performing minute movements.

All reviews noted that more work is needed to verify the clinical effectiveness of K-SRS and describe their possible benefits for patients. Webster et al [26] discussed the potential physical and mental benefits of K-SRS (ie, faster and better supported rehabilitation and increased enjoyability of exercises and motivation due to the highly interactive interfaces). Kinect-based

systems can also extend guidance and correction of patient movements. Moreover, exercises can be tailored to the needs of patients. Hondori et al [25] found that patients preferred Kinect over other off-the-shelf, consumer body-tracking devices, Kinect-based systems can assist in improving balance, and they have the potential to improve functional ability of patients. Da Gama et al [27] echoed the findings of Webster et al [26] that enjoyability increased motivation.

Part 2: Person-Generated Health Data Use in Kinect-Based Stroke Rehabilitation Systems

Part 1 highlighted gaps in information collected in previous systematic reviews of K-SRS, particularly the use of PGHD and home use of K-SRS. Moreover, it showed that previous reviews mainly provided technical descriptions of K-SRS, while suggesting that more studies are needed to ascertain their clinical effectiveness. Part 2 of this review addresses the PGHD use gap.

Article Types

To assist future studies in assessing the clinical effectiveness of K-SRS, papers are categorized as either clinical- or technical-focused. Clinical-focused papers prioritize the clinical effectiveness, feasibility, or safety of K-SRS. They include cohort studies (n=2), case reports (n=2), and randomized controlled trials (n=5). Technically oriented papers prioritize the design, development, and evaluation of the systems. They include a survey (n=1), proofs of concept (n=5), development of an app (n=17) or platform (n=6), and assessment of reliability and precision (n=3). The list of papers categorized according to their clinical or technical type is in [Multimedia Appendix 5](#) (Tables C and D).

Participants

Health Status

Nearly half of the papers (17/41, 42%) recruited only stroke patients [22,35-50], 15% (6/41) recruited only healthy participants [51-56], and 17% (7/41) recruited both patients and healthy participants [23,30,57-61]. One paper recruited participants for a requirements-gathering phase but no details were provided regarding their health status and demographics [62], and 20% (8/41) of papers did not recruit any participants [63-70]. Both study protocols will be recruiting patients [71,72].

Demographics

While 33% (11/33) of papers with subjects did not report ages [45-47,52-54,56,59,60,62,70], there was considerable variation in the ages of both patients and subjects in those that did. For papers that recruited patients, the combined mean age was 59.2 (SD 19.6) years. For papers that recruited healthy subjects, combined standard deviation (39.9 years) was greater than the combined mean (37.3 years), indicative of how spread out the age ranges were. While 38% (9/24) of papers with patients did not record gender [23,44-47,57,59,60,70], the majority of patients in those that did were male and 2 had an equal distribution [39,48]. Meanwhile, 54% (7/13) of papers with healthy subjects did not record gender [52,53,55-57,59,60]; the majority of patients in those that did were male. None had more females, and only 1 had an equal distribution [54].

Stroke Details

Only 12% (5/41) of papers recorded the stroke types of patients [38,40-42,49], and of those all patients had infarct or ischemic strokes except for one, which had 10 ischemic and 5 hemorrhagic patients [49]. More than a quarter (11/41, 27%) of papers recorded hemiparetic side of patients [23,36-42,48-50], and the majority of recorded hemiparesis was the right side (7/11, 64%). Only 20% (8/41) of papers recorded the duration poststroke of the patients at the time of the study [22,37-41,49,50]. The combined standard deviation (25.2 months) was greater than the combined mean (12.8 months), indicating the wide range of duration poststroke.

Outcome Measures

Outcome measures are documented and categorized to give an overview of how clinical, technical, and home use aspects, if any, were assessed in the literature. The measures were categorized as either measures of patient activity, balance, motor function, and quality of life or measures of system usability or other technical aspects. Most papers used multiple measures under different categories. Activity outcome measures assessed the ability of patients to perform activities (ie, exercise tasks and activities of daily living). Balance measures assessed the balance ability of patients, motor function measures assessed physical function capabilities, and quality of life measures assessed the quality of physiological and psychological well-being of patients. System usability measures assessed the usability of Kinect-based systems. Other technical measures, variables, or methods assessed the accuracy, design, and reliability of the K-SRS used. [Multimedia Appendix 6](#) shows the measures categorized (Tables E-J) and ranked according to studies that used them.

Person-Generated Health Data

This section focuses on the data generated by patients and other study participants (such as healthy volunteers) through their use of K-SRS. Study descriptions of the papers can be found in [Multimedia Appendix 7](#).

What Data Did People Generate by Using a Kinect-Based Stroke Rehabilitation System?

The types of data generated by patients when using a K-SRS can be broadly categorized as human performance data or system variable data. These PGHD were, in most cases, not provided to patients as feedback. The types of feedback provided to patients are described in the next section. Human performance data (n=25) are those used to indicate movement or exercise performance of the individual [22,36-40,42,45-48,52,53,57,59,60,62,64-67,69-72]. Most of these data were generated directly from the Kinect sensor; others were from different sensors such as accelerometers. System variable data (n=20) were unsynthesized to indicate system or patient performance [23,30,35,39,41,44,49,50,53-56,58,60,61,63,67-69,71]. These types of data were used to evaluate a system's accuracy, feasibility, reliability, and effectiveness. Many papers generated such data directly from Kinect-based systems (n=12) [23,30,39,41,44,49,55,56,61,63,68,69]. Ten papers generated data from other sensors [35,50,53,56,58,60,61,67,69,71] such as an inertial wrist strap, 6 papers reported both performance

and variable data [39,53,60,67,69,71], and 2 papers did not report data from individuals' use of the rehabilitation systems [43,51]. For more detailed descriptions of these data, please see [Multimedia Appendix 7](#) (Table K).

How Did People Have Access to Their Data?

People were provided with various forms of feedback, but in no cases did they access their complete data, data similar to those seen by their attending clinicians, from the K-SRS. For example, while clinicians may see a patient's calculated reaching distance, patients would only see game task scores. It is unknown why this is so; of the 33 papers that provided feedback, only 11 papers provided reasons for giving any feedback at all. These included following good game design for a better user experience [67,70], guiding movements [49,56,60,61,69,70], reducing user errors [35,60,63], and assisting users in meeting exercise goals [35,46,50]. [Figures 3 and 4](#) show sample clinician views, while [Figure 5](#) shows a sample patient view after an exercise illustrating one of the systems in use [71,72].

The types of feedback provided can be categorized as guidance, progress, or task scores. Guidance feedback (n=19) is in the form of visual and auditory information, intended to facilitate performing an exercise or task. In 13 papers, patients were guided in performing a task through a visual interface [44,45,49,52,53,60-62,64,67,70-72]; in 1 paper, through auditory feedback [30]; and in 5 papers, through both visual and auditory guidance [23,35,54,56,66]. Progress feedback (n=4) tracked patient progress in terms of number of exercises or tasks completed or to be completed [42,46,63,65]. Task score feedback (n=10) was in the form of game scores provided as-is, without any interpretation of the user's performance. These

papers simply provided people with their scores at the end of a task execution [22,37-39,47,50,55,57,59,69]; 8 papers did not describe provision of feedback or any other mode of patient access to their data [36,40,41,43,48,51,58,68]. For more detailed descriptions of these data, please see [Appendix 7](#) (Table L).

Who Else Used the Data and for What Purposes?

Use of PGHD can be categorized based on the purpose of use, which was for patient benefit, comparison of effects, assessment of K-SRS, or evaluation of other technologies. For patient-benefit use papers, 63% (12/19) were in the form of therapists using the data to prescribe or tailor rehabilitation to individual patient needs [23,46-49,58,65-67,69,70,72]. Comparison papers used PGHD for researchers to study the different effects of a K-SRS in different groups of people [57,72]. Use of K-SRS assessment research (n=13) was done to study system effectiveness, feasibility, accuracy, or reliability [22,23,30,41,42,44,45,50,54-56,61,71]. PGHD use for evaluation of other technologies employed the generated data to assess other technologies used in their K-SRS [35,40]; 5 papers used data for 2 purposes [23,35,56,61,72] and 10 papers did not describe use of PGHD [36-38,43,51,53,59,60,62,63]. For more detailed descriptions of PGHD use, please see [Appendix 7](#) (Table M).

What Effects Were Reported From People's Use of Their Own Data?

Only 1 paper [22] described any effects on a patient from using PGHD. This paper observed that when the patient was provided with her performance scores daily she remembered them and was motivated to improve the next day.

Figure 3. Clinician view: patient-generated health data outcomes summary.

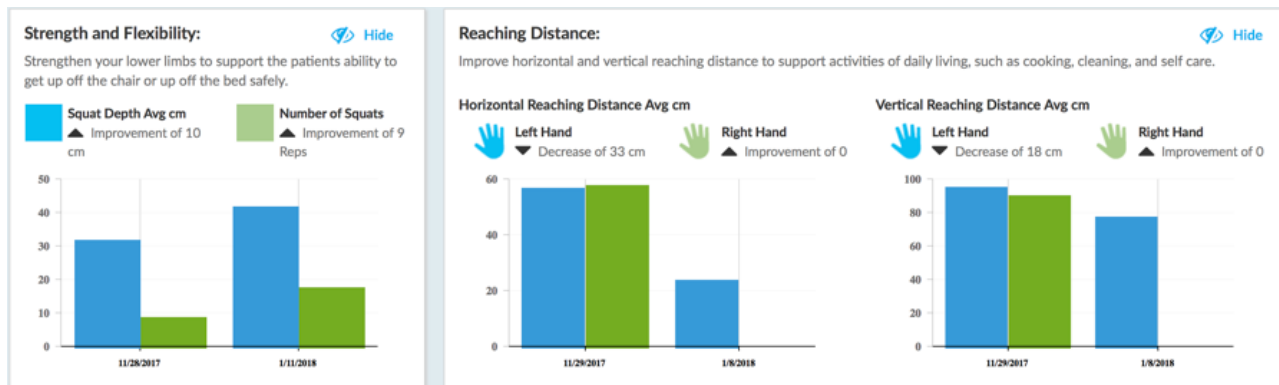
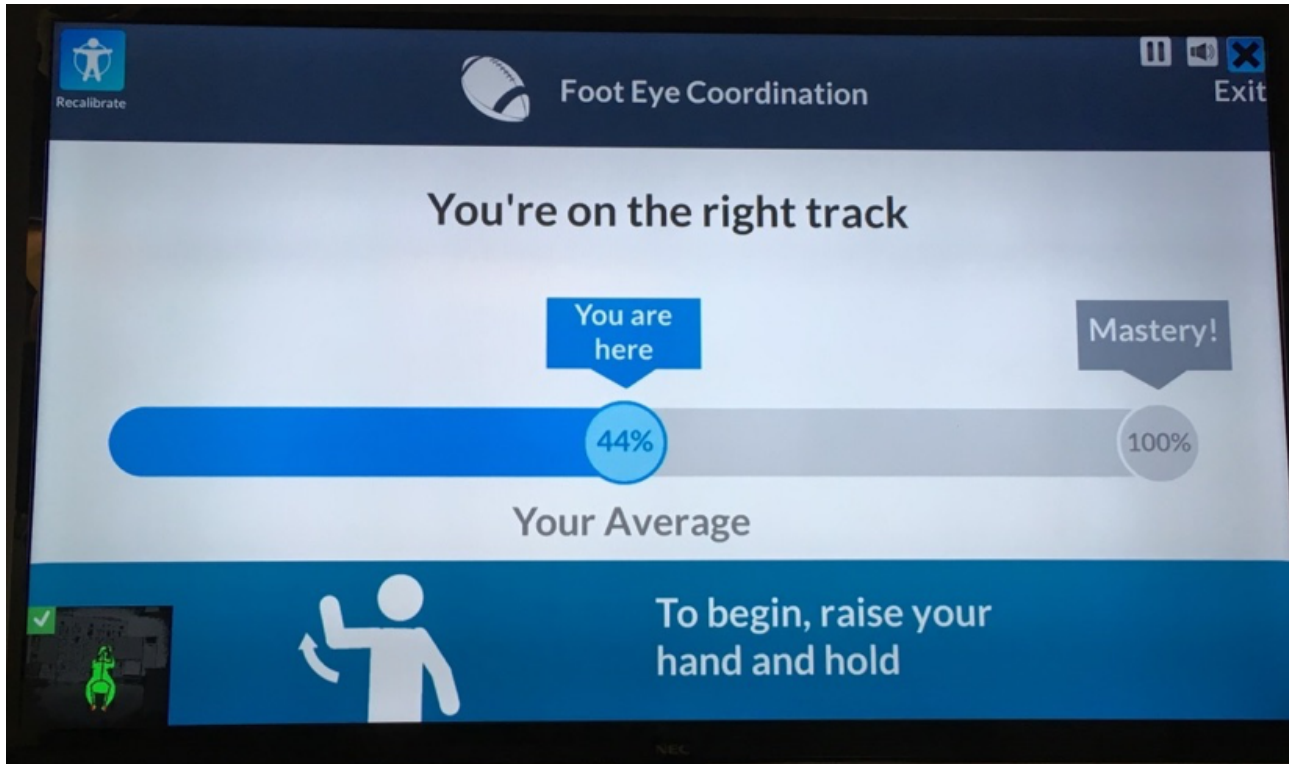


Figure 4. Clinician view: detailed patient performance data.

Activities Exercises Assessments	Reaching Distance Calibration Bilateral Coordination	Horizontal Avg	Left Hand	56 cm	56 cm	23 cm	--
			Right Hand	57 cm	57 cm	--	--
		Vertical Avg	Left Hand	94 cm	94 cm	76 cm	--
			Right Hand	89 cm	89 cm	--	--
		# Tasks Performed		38 of 40	--	--	--
		# Tasks Successfully Completed		34 of 38	--	--	--
		Time Standing		02:40	--	--	--

Figure 5. Patient view: sample postexercise game score.



Discussion

Principal Findings

No prior systematic reviews have examined the literature for evidence about use or management of the patient health data that K-SRS users generate. In our own review of the K-SRS literature, we found that while more than three-quarters of the papers used PGHD in some way, only 1 described the effects of PGHD use [22]. Moreover, the fact that use was mainly for technical evaluation and secondarily for clinicians to prescribe exercises shows that patient participation was not a priority in the design of K-SRS. Additional evidence of this can be found in the data access provided to patients, which was mainly in the form of feedback to provide guidance. The focus of data provision has been to prescribe tasks and guide patients to perform movements rather than to allow patients to access and make sense of their own performance data. This represents a missed opportunity from the literature to engage poststroke patients in their own health care, as it has been shown that when patients have direct access to their PGHD they become more engaged and improve their health outcomes [7,9,10,73]. The lack of patient access to data also suggests that patient-centered design was not part of developing these Kinect-based systems [74], a key consideration in a modern participatory health paradigm. This factor could overlook PGHD and undermine the rehabilitation experience of patients [75].

The use of data overwhelmingly for technological development and assessment is clearly shown by 78% (32/41) of papers having a technical primary objective. Even if we acknowledge that it is necessary to assess the accuracy and reliability of Kinect-based systems, this technical focus confirms the finding of Webster et al [26] that this field of rehabilitation is still in its

infancy. This presents an opportunity and challenge to evaluate clinical outcomes [25-27] (eg, effectiveness and safety of such systems), a challenge that only a few papers have taken up [36-39,49,50,57,71,72].

The focus of existing K-SRS papers was on upper extremities. It is interesting that while Kinect has the ability to track the whole body, only upper extremity software is described [25]. None of the papers in this review used lower extremity outcome measures.

Results of this review show that there is insufficient attention given to PGHD from K-SRS. While most studies provide some form of feedback, they do not allow patients to actively engage with data about their own rehabilitation, nor do the papers try to understand the health behavior impact of providing data access to patients.

Limitations

While most papers described the data types collected in their papers and available feedback, often they were glossed over in the descriptions and discussion. As mentioned previously, this shows a lack of attention to PGHD and to health data management generally in K-SRS papers. The lack of documentation may also have limited the details into PGHD this review gathered (ie, some other benefit of PGHD may have occurred but was not documented or described). As such, while this review attempted to provide a snapshot of the PGHD types, access, and benefits, it may be incomplete. In short the lack of attention given to PGHD in the papers confirms the need for papers to pay attention to the PGHD of their K-SRS but also limits the PGHD evidence obtained. Due to time constraints, the authors of the papers reviewed were not directly contacted for more information on the PGHD they have given patients.

With regard to patients recruited, the majority of patients had infarct or ischemic type of stroke, and patients were not separated based on their stroke type. Given that there is some evidence that hemorrhagic patients benefit from rehabilitative therapies faster than infarct and ischemic patients [76], this could produce some stroke-type bias in the effectiveness results, where results derived largely from infarct patients are generalized for hemorrhagic patients as well.

Conclusions

Reviewing current K-SRS literature through the lens of PGHD showed that there is a significant gap in our understanding of what it may contribute to the experience of patients who use K-SRS. Most papers provide some feedback but do not allow

patients to engage with all of their PGHD (eg, for self-management of their health journey). This provides further evidence of the need for studies that contribute to the theoretical foundation of PGHD use [1]. It is also indicative of the need for future researchers of technology-based rehabilitation to consider PGHD and patient access to information in their system design and implementation. Improving our understanding of the effects of using PGHD could help in designing systems where the benefits of PGHD access are made available to patients. This paper calls for future studies on K-SRS—and studies that have the potential for generating patient health data in general—to pay more attention to how those data may influence the process of care.

Acknowledgments

The primary author would like to acknowledge the support of his organizational sponsor, Newman College (University of Melbourne). A sincere thank you also goes to Bernd Ploderer and Luis Eduardo Cofré Lizama for their assistance in the initial conceptualization of this review.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Search strategy for part 1: analysis of systematic reviews.

[[PDF File \(Adobe PDF File\), 286KB - rehab_v5i1e11_app1.pdf](#)]

Multimedia Appendix 2

Search strategy for part 2: review of person-generated health data use in Kinect-based stroke rehabilitation systems.

[[PDF File \(Adobe PDF File\), 329KB - rehab_v5i1e11_app2.pdf](#)]

Multimedia Appendix 3

Objectives, methods, and structure of existing systematic reviews.

[[PDF File \(Adobe PDF File\), 30KB - rehab_v5i1e11_app3.pdf](#)]

Multimedia Appendix 4

Analysis of person-generated health data, home use, and effectiveness in existing systematic reviews.

[[PDF File \(Adobe PDF File\), 15KB - rehab_v5i1e11_app4.pdf](#)]

Multimedia Appendix 5

Types of papers.

[[PDF File \(Adobe PDF File\), 35KB - rehab_v5i1e11_app5.pdf](#)]

Multimedia Appendix 6

Outcome measures.

[[PDF File \(Adobe PDF File\), 34KB - rehab_v5i1e11_app6.pdf](#)]

Multimedia Appendix 7

Review of person-generated health data.

[PDF File (Adobe PDF File), 38KB - [rehab_v5i1e11_app7.pdf](#)]

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Abbreviations

K-SRS: Kinect-based stroke rehabilitation systems

PGHD: person-generated health data

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

Edited by G Eysenbach; submitted 13.10.17; peer-reviewed by S Woods, E Broadbent; comments to author 30.11.17; revised version received 14.02.18; accepted 15.02.18; published 08.05.18.

Please cite as:

Dimaguila GL, Gray K, Merolli M

Person-Generated Health Data in Simulated Rehabilitation Using Kinect for Stroke: Literature Review

JMIR Rehabil Assist Technol 2018;5(1):e11

URL: <http://rehab.jmir.org/2018/1/e11/>

doi: [10.2196/rehab.9123](https://doi.org/10.2196/rehab.9123)

PMID: [29739739](https://pubmed.ncbi.nlm.nih.gov/29739739/)

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Review

Evolution of Cognitive Rehabilitation After Stroke From Traditional Techniques to Smart and Personalized Home-Based Information and Communication Technology Systems: Literature Review

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Abstract

Background: Neurological patients after stroke usually present cognitive deficits that cause dependencies in their daily living. These deficits mainly affect the performance of some of their daily activities. For that reason, stroke patients need long-term processes for their cognitive rehabilitation. Considering that classical techniques are focused on acting as guides and are dependent on help from therapists, significant efforts are being made to improve current methodologies and to use eHealth and Web-based architectures to implement information and communication technology (ICT) systems that achieve reliable, personalized, and home-based platforms to increase efficiency and level of attractiveness for patients and carers.

Objective: The goal of this work was to provide an overview of the practices implemented for the assessment of stroke patients and cognitive rehabilitation. This study puts together traditional methods and the most recent personalized platforms based on ICT technologies and Internet of Things.

Methods: A literature review has been distributed to a multidisciplinary team of researchers from engineering, psychology, and sport science fields. The systematic review has been focused on published scientific research, other European projects, and the most current innovative large-scale initiatives in the area. A total of 3469 results were retrieved from Web of Science, 284 studies from *Journal of Medical Internet Research*, and 15 European research projects from Community Research and Development Information Service from the last 15 years were reviewed for classification and selection regarding their relevance.

Results: A total of 7 relevant studies on the screening of stroke patients have been presented with 6 additional methods for the analysis of kinematics and 9 studies on the execution of goal-oriented activities. Meanwhile, the classical methods to provide cognitive rehabilitation have been classified in the 5 main techniques implemented. Finally, the review has been finalized with the selection of 8 different ICT-based approaches found in scientific-technical studies, 9 European projects funded by the European Commission that offer eHealth architectures, and other large-scale activities such as smart houses and the initiative City4Age.

Conclusions: Stroke is one of the main causes that most negatively affect countries in the socioeconomic aspect. The design of new ICT-based systems should provide 4 main features for an efficient and personalized cognitive rehabilitation: support in the execution of complex daily tasks, automatic error detection, home-based performance, and accessibility. Only 33% of the European projects presented fulfilled those requirements at the same time. For this reason, current and future large-scale initiatives

focused on eHealth and smart environments should try to solve this situation by providing more complete and sophisticated platforms.

(*JMIR Rehabil Assist Technol* 2018;5(1):e4) doi:[10.2196/rehab.8548](https://doi.org/10.2196/rehab.8548)

KEYWORDS

cognition; rehabilitation; stroke; eHealth; activities of daily living; delivery of health care

Introduction

General Framework

Imagine if people rejuvenated as time went by, such as Benjamin Button in the F Scott Fitzgerald's tale—a man who was an elder at birth and died with the appearance of a baby. Instead, human abilities deteriorate as they become older. Life expectancy at birth in Europe is increasing steadily [1], and by 2050, it is expected that 27% of the population will be older than 65 years [2]. Although this is a very positive outcome of the progress of medical care and the general improvement of our lives, it also imposes the great challenge of maintaining the overall (mainly cognitive) well-being of the aging population to sustain their functional capability, prolong their independent living, and reduce the risk of institutionalization.

Although aging involves several components, deterioration in cognitive abilities does not always appear due to aging, but rather, it often appears following a stroke. The risk of suffering a stroke duplicates in people aged above 65 years [3]. According to the statistical office of the European Union and the World Health Organization, the main causes of death in Europe in the last 15 years are heart attacks and strokes. Notably, in 2015, almost 6.24 million deaths were caused by stroke incidents [4].

Regarding those stroke survivors, as many as 68% of stroke patients meet the criteria for apraxia and action disorganization syndrome [5]. This deterioration usually makes people unable to remember their partial or full activities of daily living (ADL), and sometimes they even forget the complete execution of sequential actions. This means that this group of citizens is more dependent on caregivers and health care systems and they find it difficult to live independently [6]. Additionally, there are 2 other main syndromes derived from a stroke: hemiparesis and neglect.

With the objective of assisting the cognitive rehabilitation of stroke survivors, the traditional methodologies used to support the movements of the user act as a guide to be followed, and generally, they depend on the help of therapists. Currently, health care services are using centrally directed general guidelines which have very limited effect.

To address this issue at the cutting edge, some research and commercial home-based information and communication technology (ICT) systems (ie, MavHome, the Gloucester “Smart House,” ORCATECH, A2E2), mobile apps (ie, Garmin Connect, Endomondo, Newolo, Runtastic Results, Fitbit Trainer, Alfred), and Web-based strategies [7] have introduced more interactive approaches to health management and cognitive training by monitoring user activities and recommend actions.

The objective of this study was to provide an identification of the effective assessment of rehabilitation practices for cognitive disorders from a traditional perspective to a more technological one by presenting the most recent advanced eHealth systems and projects to not only maintain but also improve the cognitive status of both elderly people and stroke patients in their daily living.

Moreover, this study encompasses the concepts and manifestations in the execution of daily tasks of the main and most common stroke-related syndromes mentioned before, which can cause deficits in the execution of daily activities. They are presented in a broader context considering their influence in a high percentage of stroke survivors.

Apraxia

It is thought that Hugo Liepmann presented the first description of apraxia as a distinct neuropsychological syndrome in the 19th century [8]. Liepmann's theory showed deficient motor control at the heart of an apraxic impairment, and he defended the idea that some patients are not able to convert the image of an intended action into appropriate motor command even though they have the clear concept of what they want to do. Additionally, he considered apraxia as associated with left brain damage (LBD) after comparing studies with patient groups with left and right brain damages [8].

One of the most accepted definitions of apraxia is as follows: apraxia is a “disorder of skilled movement not caused by weakness, akinesia, differentiation, abnormal tone or posture, movement disorders (such as tremors or chorea), intellectual deterioration, poor comprehension, or uncooperativeness” [9]. This definition supports Liepmann's idea of a disturbance at the interface between cognition and motor control, although some clinical manifestations make more emphasis in 3 main domains of human actions, namely, imitation of gestures, the performance of communicative gestures, and the use of objects.

The consequences of cognitive disorders in these domains have been studied mainly in specific activities which involve the use of tools and multistep tasks (see sections Action Disorganization Syndrome, Neglect, and Hemiparesis for details).

One of the main consequences of apraxia is the misuse of common everyday objects, for example, forks to eat soap, cutting paper with closed scissors, biting on the toothbrush when cleaning teeth, pressing knives into the loaf without moving it, or closing a paper punch on top of the sheet without inserting it. Although some apraxic patients present right-sided hemiplegia and their errors may be associated with the paralysis of the nondominant left hand, there is evidence of their pathological nature when observing the behavior of healthy

people when manipulating objects with the nondominant hand [10,11].

The errors that appear when manipulating single tools, and those which are detectable in explicit testing, are probable to arise in the execution of multistep tasks also. However, there is a classification of specific errors associated with multistep tasks. The most relevant are as follows (see [11-14] for a more extensive classification):

- Misallocation: a correct action performed with the wrong recipient
- The omission of some steps
- Toying: the act of touching or briefly lifting objects not followed by goal-oriented manipulations
- Perplexity: hesitation before starting an action or failure when proceeding with an action

Action Disorganization Syndrome

Action disorganization syndrome (ADS) is a neuropsychological disorder after a brain injury. Schwartz and colleagues were the first in providing a description [15]. The main characteristic of ADS is the high presence of cognitive errors when carrying out daily activities, such as preparing hot drinks, grooming, and dressing. However, these are not caused by a motor deficit [16]. On the basis of the study of Schwarz et al [15], ADS patients usually execute actions in the wrong sequence or select the wrong objects.

According to the studies presented in [15], 5 error types are considered to be common [17] and summarized in Table 1.

On the basis of different case studies with ADS patients, some errors are found to be more frequent in specific patients than others. In addition, thanks to these studies, it can be revealed that those patients who present high error rates commit more omission errors [18-20].

Hemiparesis

It is found that 80% of stroke survivors suffer from hemiparesis. The main consequence of this disease is usually the weakness or inability to execute movements in one side of the patient's body. This inability can be centered in the user's hands, facial muscles, arms, or even legs, leading to significant difficulty when carrying out their ADL [21].

When users present weaknesses in the body segments mentioned before, it is very probable that they will suffer from loss of balance due to muscle fatigue, coordination for walking, coordination when manipulating objects, and dexterity in achieving accuracy.

Table 1. Common error types based on studies by Cooper and Shallice [17].

Error	Explanation
Omission	Missing steps
Anticipation	Performance of actions in the wrong sequence
Quality errors	Action is carried out inappropriately
Object substitution	Misuse of objects
Place substitution	Movement of objects to wrong destinations

Obviously, the part of the body that experiences the inability depends on the part of the brain where the stroke happens. So, when an injury occurs on the left side of the brain, it usually results in deficits in right-sided components and vice versa.

Neglect

Neglect is one of the consequences derived from a brain accident, typical of the left hemiplegic patient, that is, one who has suffered damage to the right hemisphere of the brain. It is often also recognized as unilateral spatial agnosia, hemi-inattention, or hemispacial neglect.

Neglect is a disorder of attention to space, especially with respect to space on the left. Neglect often appears as a problem exclusively visual in nature, because the difficulties of the left hemiplegic patient in orienting his or her eyes toward the visual field of the left are evident, especially during the first weeks following the stroke.

Neglect or hemi-inattention often represents an aspect that is not valued in terms of rehabilitation with due dedication but rather is defined as a phenomenon that in most cases resolves spontaneously after a few months following stroke.

However, neglect is not attributed to a problem in the ability to see but it is a problem related to attention. Already in 1874, Hughlings Jackson hypothesized that the right hemisphere was directly involved in perception and in relation to the outside world, and almost 100 years later, the neuropsychologist AR Lurija confirmed his perceptive peculiarities [22]. But even today, in contrast to the treatment of left hemiplegia, neglect is not taken into account because it is considered as an aspect that, in addition to being reduced spontaneously in most cases, is an element outside of the traditional motor re-education in hemiplegia.

Studies About the Influences of Stroke in Activities of Daily Living

ADL comprises activities of basic self-care such as washing, grooming, and dressing, besides preparing drinks and food. The execution of these tasks involves sequences of more basic actions with manipulation of environmental objects directed at some desired end goal.

Table 2 shows a summary of some review of the literature on psychological studies of the production of sequential action in ADL tasks. They have generally been quite helpful to identify the nature of the errors committed by the patients with brain damage [15,19,23] or by healthy individuals, caused by different factors [24].

Table 2. Summary of previous studies of activities of daily living (ADL) tasks.

Institution and reference	ADL task	User
Philadelphia, United States [24]	Preparation of coffee	Neurologically healthy adults
University of Birmingham [16,25]	Preparation of tea, wrapping of a gift, preparation of a sandwich of cheese, and brushing teeth	Patients with action disorganization syndrome (ADS) and controls
University of Oxford [26]	Preparation of tea	Semantic dementia patient; ADS patient
University of Toronto, Canada [27]	Washing hands	Older adults with dementia
University of Nottingham [28]	Preparation of a hot drink	Stroke patients
University of London [29]	Preparation of coffee and tea	Neurologically healthy adults
Technical University of Munich [30,31]	Preparation of tea	Chronic stroke patients

Once these studies are analyzed, the main thought is that a strong correlation exists between those impairments in the execution of ADL and apraxia scores. The functional independence measure provides a rough evaluation of the performance of ADL at home or at hospitals, and this score was used to establish a correlation between outcome and apraxia [32]. A similar approach, the physical self-maintenance scale, is also used to measure the percentage of assistance by caregivers.

Methods

Areas Involved in the Review

Taking into account the behavior of stroke patients and with the purpose of providing a complete report on the evolution of methodologies for their screening and techniques of cognitive rehabilitation, a literature review was carried out by a multidisciplinary team of researchers from engineering, sports science, and psychology fields.

Criteria

First of all, regarding the traditional methods for the individual evaluation of stroke patients as well as for providing cognitive rehabilitation after the screening, some material has been used from the results generated in some European projects that the authors collaborated in. In addition, a deep review of additional bibliography has been carried out. This additional review was designed using a systematic protocol to interpret and analyze the most relevant research [33,34]. For that purpose, 2 main questions were put on the table:

- Are the current methodologies for cognitive rehabilitation effective enough to improve health status and independence during the rehabilitation phase?
- Is the workload of the therapists in current rehabilitation techniques worthwhile based on the slow improvement of the cognitive abilities of patients?

Second, taking into account the negative answers to those questions, 2 additional ones were proposed:

- What types of technology are adequate and used nowadays to design a smart ICT-based system that would interact with stroke patients?
- How well could those technologies be received by end users, their families and carers, as well as health professionals?

Then, a new search of those actual ICT-based approaches or research projects that provide cognitive rehabilitation was done. For that purpose, using relevant keywords such as “cognitive rehabilitation,” “personalized health care,” and “stroke,” an extensive review of Web of Science and other sources (IEEE Xplore, *Journal of Medical Internet Research*) for research studies and Community Research and Development Information Service (CORDIS) [35] for research projects has been done. For example, 3469 results were retrieved from Web of Science focusing on cognitive rehabilitation after stroke (from 2012 onward), 284 results from *Journal of Medical Internet Research*, and 15 research projects from CORDIS were reviewed for classification and selection.

Finally, special attention was paid to the following features to classify the ICT-based approaches:

- Do they provide a home-based rehabilitation?
- Do they assist in the execution of complex ADL tasks?
- Do they present automatic error recognition?
- Are they accessible?

Results

Classification of Studies

Taking into account the review methodology described above, the material presented in this section focuses on (1) relevant classical techniques for the individual assessment of patients who suffer from cognitive disorders; (2) traditional methods to provide cognitive rehabilitation after screening; and, finally, (3) the most recent proof of concepts, projects, and innovative actions that provide smart interactive ICT systems, which implement the concept of eHealth to maintain the cognitive status of users while providing novel ways of rehabilitation.

Individual Assessment of Stroke Patients

Some of the most important aspects taking into account the traditional techniques for assessment of stroke patients and cognitive rehabilitation are related to the following:

- The analysis of the manipulation of single tools, which demonstrates the existence of performance deficits even in the execution of simple activities
- The importance of the use of kinematics as a quantitative approach to analyze the performance of an action with tool use

- The fact that many goal-directed movements (ie, pointing) are impaired even in the hand ipsilateral to the lesion

Analysis of Tool Use

Testing the use of actual tools with real target objects has been mandatory to analyze the ability of stroke patients in interacting with objects in their daily living. Table 3 shows a summary of the main publications and tests carried out in this matter.

Analysis of Kinematics When Manipulating Tools

The temporal and spatial features of the movements are subspects in some of the scoring methods, but the assessment is very rough. Nevertheless, there are other tests focused on these specific aspects, which monitored user movements in 3D

space by using the adequate methodology for analyzing kinematics (Table 4).

Execution of Goal-Directed Movements

Bearing in mind that the studies that consider the recording of user movements during tool use are relatively rare in patients who suffer from left brain damage (LBD) or right brain damage (RBD), there is a great number of research on the kinematics of more basic goal-directed movements such as pointing, aiming to targets, or grasping neutral objects.

As indicated in Table 5, these tests noted specific deficits in patients with LBD versus patients with RBD, more dynamic aspects of movement following damage to the motor-dominant left hemisphere, and movement initiation and movement accuracy following damage to the right hemisphere.

Table 3. Summary of reports on the assessment of performance deficits when using objects in stroke patients. LBD: left brain damage.

Reference	Objects used	Result	Type of scoring
Liepmann [8]	Comb, brush, hammer	Errors in 25% of “dyspraxics” (N=42)	Right or wrong
De Renzi and Luchelli [36]	Common-use objects	All of them made errors	Major or minor or no error
McDonald et al [37]	Cup, key, fan, scissors	17 LBD patients: no differentiation from other task modes	Right or wrong
Buxbaum et al [38]	Common-use objects	Single case: fewer errors during use	Grasp, trajectory, amplitude, and timing
Westwood et al [39]	Hammer, saw, spectacles	Object use deficit: 37 LBD patients (43%); 50 right brain damage patients (18%)	Performance accuracy from composite scores
Goldenberg et al [40]	Glass, apple, electric bulb, squeezer	10 LBD patients: more errors in the use of actual tools	The presence of feature for grasping and movement
Randerath et al [41]	Hammer, ladle	25 LBD patients: errors in almost all conditions	The presence of features: grasp, movement execution, direction, space

Table 4. Summary of reports about the analysis of 3D movement kinematics when manipulating objects. LBD: left brain damage ; RBD: right brain damage.

Reference	Task	Result
Clark et al [42]	Slicing bread	3 LBD patients: imprecise plane of motion and trajectory shape
Poizner et al [43]	Slicing bread	3 LBD patients: impaired joint coordination
Laimgruber, et al [44]	Grasping a glass	19 LBD patients + 10 RBD patients: prolonged adjustment phase RBD: slowed velocity
Hermsdörfer et al [45]	Sawing	9 LBD patients: velocity deficits
Hermsdörfer et al [46]	Hammering	23 LBD patients: prolonged reaction time, slowed velocity. 10 RBD patients: prolonged reaction time
Hermsdörfer et al [47]	Scooping	23 LBD patients: reduced amplitude, reduced hand roll 9 RBD patients: no deficits

Table 5. Summary of studies on deficits during goal-directed movements with the ipsilesional hand. LBD: left brain damage; RBD: right brain damage.

Reference	Task	Result in patients
Hermsdörfer et al [48]	Grasping	LBD: acceleration deficits RBD: adjustment deficits
Hermsdörfer et al [49]	Grasping and placing	LBD: slowed movement, awkward hand rotation RBD: prolonged reaction time, slowed movement, hand placement errors
Schaefer et al [50]	Shoulder or elbow aiming	LBD: reduced acceleration amplitude RBD: reduced acceleration duration
Tretriluxana et al [51]	Grasping	LBD: deficient scaling of grasp preshaping RBD: weak transport-grasp coordination
Schaefer et al [52]	Shoulder or elbow aiming	LBD: impaired multijoint coordination RBD: decreased final accuracy
Schaefer et al [53]	Visuomotor adaptation	LBD: initial direction adaptation impaired RBD: final adjustment impaired
Haaland et al [54]	Elbow aiming movements	LBD + paresis: reduced amplitude modulation
Mutha et al [55]	Visuomotor adaptation	LBD + apraxia: impaired
Mutha et al [56]	Visuomotor adaptation	LBD parietal damage: impaired

Traditional Methodologies to Support Cognitive Rehabilitation

The implementation of intelligent environments to provide a rehabilitation platform is something relatively new, which many researchers are focusing their efforts on. In fact, later in the study, the most important work exploring this topic will be presented.

Once a general view of how to assess the level of severity of stroke patients, as well as to screen them, has been presented, the main traditional techniques to provide cognitive rehabilitation in their daily living are summarized. As derived

from the reading of this subsection, classical techniques are not especially based on the use of smart technology, which means high workload for therapists and clinicians along with long and frequent patient visits to the hospitals or rehabilitation centers.

Table 6 shows a summary of different approaches that provide cognitive rehabilitation once the corresponding stroke patients have been screened. The majority of the methods presented try to improve ADL performance and to increase the independence of the patients. For example, the execution of a task can be improved by the personalized feedback prompted to the patients [26] and by breaking the task down into basic actions [57].

Table 6. Traditional approaches for cognitive rehabilitation after stroke. ADL: activities of daily living.

Approach	Description	Result
Strategy training approach [58]	Internal and external compensatory strategies	Strategy training groups improve patients' dexterity
Errorless learning [11]	Manipulation of limbs during ADL Simultaneous performance of ADL with therapist or examiner	Significant improvement on trained activities
Variety of approaches [57]	Pictorial representation of the goals and subgoals, written commands	No significant effects on trained tasks
Verbalization strategy [26]	Patient taught a poem based on the steps of making a cup of tea	Weak training effects across sessions and no transfer to untrained tasks or objects
Error monitoring and detection; task training action intervention [59]	Pictorial descriptions of objects Video presentation of the task, from a patient's perspective	Better performance on the Naturalistic Action Test

Information and Communication Technology–Based Personalized, Long-Term, and Continuous Cognitive Rehabilitation Systems

Considering the limitations presented in traditional techniques, these methodologies do not offer many benefits during the rehabilitation stage. For that reason, efforts have been taken in the previous years to develop systems that monitor the performance of a task and provide feedback, making it familiar, personalized, and attractive for the user. Successful execution of rehabilitation tasks would increase and the use of a smart environment (even at patients' house) would improve independence in daily living and would alleviate occupational therapists' workload.

This subsection aims at describing the main research approaches and projects in the last 15 years related to providing smart

platforms or environments that support cognitive rehabilitation and even maintain the cognitive status of the elderly, empowering their active aging.

Approaches Proposed in the Literature

Table 7 shows a description of 6 main eHealth-based approaches focused on cognitive rehabilitation. They have been classified based on relevant research publications.

European Projects

There are 9 main European research projects focused on the development of prototypes based on new technologies for providing advanced cognitive rehabilitation, excluding those centered in the rehabilitation of the movement of body segments. These are explained in detail in Table 8.

Table 7. Summary of published approaches focused on information and communication technology–based solutions for cognitive rehabilitation.

Approach	Description	Result	Main feature
Remote acquisition of neuropsychological data [60]	An architecture that allows collaborative video conferencing and continuous virtual interaction with patient	Data are successfully obtained from patients who are not familiar with technology	<ul style="list-style-type: none"> • Home based • Accessible
Living Labs [61]	Interaction with real world is monitored by health care sensing	Living Labs improves independence and quality of life	<ul style="list-style-type: none"> • Home based • Monitoring of the execution of complex daily activities • Accessible
Virtual reality [62]	A virtual reality–based prototype to improve coordination skills of stroke patients	A technology-assisted solution that improves endurance abilities	<ul style="list-style-type: none"> • Home based • Automatic error detection
Noninvasive, open, and distributed architectures (RehabNet) [63]	A system based on neuroscience that provides an interactive interface for stroke rehabilitation	Patients with high spasticity had better control by using a regular glove	<ul style="list-style-type: none"> • Home based • Automatic error detection
Brain-computer interfaces [64]	Communication tool to support neuronal plasticity by activating language circuits	Aphasia patients initially had problems to use the paradigm of the visual speller	<ul style="list-style-type: none"> • Automatic error detection
Tele-stroke [65-68]	Wireless telemedicine and mobile apps: teleradiology [66]	This improves the efficiency of the usage of resources as well as the interaction with patients	<ul style="list-style-type: none"> • Home based • Monitoring of the execution of complex daily activities • Accessible
Robots [69]	A socially assistive robotic platform to propose and adopt new plans to new situations in real time	It maintains verbal and nonverbal communication with users	<ul style="list-style-type: none"> • Home based
Dashboard design [70]	Use of an interactive dashboard platform to assess upper limb movements in daily living	It improves the acquisition of users' data, engagement of patients, and coordination between clinicians	<ul style="list-style-type: none"> • Home based • Monitoring of the execution of complex daily activities • Accessible

Table 8. European research projects focused on information and communication technology–based cognitive rehabilitation.

Project	Result	Main feature
MIMICS: Multimodal Immersive Motion Rehabilitation with Interactive Cognitive Systems [71]	Immersive multimodal virtual environments for sensory motor rehabilitation	<ul style="list-style-type: none"> Monitoring of the execution of complex daily activities Accessible
COACH: Cognitive Orthosis for Assisting with Activities in the Home [72]	Smart platform to supervise elderly Alzheimer's patients	<ul style="list-style-type: none"> Home based Automatic error detection Accessible
GUIDE, Technology for Independent Living [73]	Prototype to assist stroke patients in the learning and execution of laundry and dressing tasks	<ul style="list-style-type: none"> Home based Monitoring of the execution of complex daily activities
DEM@CARE: Dementia Ambient Care: Multi-Sensing Monitoring for Intelligent Remote Management and Decision Support [74]	Adaptive human-computer interaction for neuro feedback training in dementia patients	<ul style="list-style-type: none"> Home based Accessible
CONTRAST: Remote Control Cognitive Training [75]		
COGWATCH: Cognitive Rehabilitation of Apraxia and Action Disorganisation Syndrome [76]	Information and communication technology (ICT) prototype for the cognitive rehabilitation of patients with apraxia and action disorganization syndrome in real time [77]	<ul style="list-style-type: none"> Home based Automatic error detection Monitoring of the execution of complex daily activities Accessible
VR STROKE REHAB: Virtual Reality Intervention for Stroke Rehabilitation [78]	Use of virtual reality to encourage chronic stroke patients	<ul style="list-style-type: none"> Home based
HOMER: Development of Home Rehabilitation System [79]	Open-access platform for cognitive rehabilitation, which integrates virtual reality and ICT commercial systems	<ul style="list-style-type: none"> Home based Automatic error detection Monitoring of the execution of complex daily activities Accessible
SWORD: Advanced Analytics Platform for Stroke Patients Rehabilitation [80]	Integration of current technologies into novel neuroscience-driven therapeutic methods	<ul style="list-style-type: none"> Home based Monitoring of the execution of complex daily activities Accessible
ACTIVE HANDS [81]	Multimodal platform at home to provide user feedback in daily tasks	<ul style="list-style-type: none"> Home based Monitoring of the execution of complex daily activities Automatic error detection Accessible

Other Coaching Platforms and Large-Scale Innovative Actions

Elderly people wish to live at home and independently as long as possible. Different multidisciplinary research groups are nowadays working on achieving the “smart house of the future” to suit the needs of people. For example, the Orcatech project is focused on carrying out a pilot study to determine adherence to treatment of an internet-based platform that provides mindfulness meditation [82]. The platform uses what is called a life laboratory as a resource to explore technologies that support independent living, to assess new behavioral markers, and to evaluate approaches for assessing neurological and other relevant health changes, all in the participant's home.

The Gloucester “Smart House” project for people with dementia supports this population in their ADL and focused on the cognitive aspects [83]. The smart house has all the necessary

equipment found in a conventional house but with different sensors and control panels connected to remind and help in different daily tasks and security aspects: leisure activities, bathroom flooding, cooker monitor and fire usage, falling, nighttime wandering, taking medication, and forgetting keys.

Meanwhile, “UTA's MavHome Smart House” project physically assists the elderly and individuals with cognitive disabilities by providing home capabilities that will monitor health trends and assist in the inhabitant's day-to-day activities in their own homes [84].

Finally, City4Age aims at enabling “Ambient Assisted Cities” by defining elderly-friendly city services for the active and healthy aging. The core idea is to demonstrate that “smart cities” can play a pivotal role in the early detection of mild cognitive impairment (MCI) and frailty risks and subsequent interventions by collecting data about individual behaviors in an unobtrusive way [85]. Data collected are used twofold: first, to cluster

population segments that show MCI and frailty evidence; second, to pay attention and monitor closely the population at risk already identified. When a change of behavior that may lead to a risk of MCI or frailty is detected, an intervention is provided to the user with the aim of persuading the user to reverse these changes to a positive behavior and thus reduce risks.

The City4Age project lead by Politecnico di Milano makes use of current city services (open data) and collected large amount of data about citizens, such as usage of public transports, services, and shopping, to develop useful interventions. Interventions could include ecological momentary interventions to improve the quality of life in daily living, dynamic interventions providing positive patterns of behavior change, and just-in-time interventions to assist individuals in case a higher priority intervention is required.

Discussion

Principal Findings

The material presented in this study addressed different topics relevant for the cognitive rehabilitation of stroke patients and the importance of ICT technologies as well as the implementation of eHealth and tele-rehabilitation concepts for the evolution of classical methodologies. Moreover, the concept and consequences of the most common syndromes after stroke were described along with an introduction.

From the review of the literature and regarding the assessment of the performance of stroke patients during the use of single tools for their individual screening, 7 main traditional relevant works have been presented as well as 6 examples of methods that include analysis of kinematics, and 9 focused on the performance of goal-oriented tasks.

First of all, the analysis of single tool use has emphasized the role of the left hemisphere of the brain in this type of tasks (eg, use of comb, hammer, glass) and also showed that actual task performance is generally less compromised than out-of-context performance. However, most of the tests demonstrated that a high number of patients present deficits even in the performance of seemingly simple activities. Second, the analysis of kinematics has also been considered as useful in the analysis of actual tool use. As derived from the tables presented, this kind of analysis is more sensitive than scoring systems. Finally, the results of some studies noted that the processing and interpretation of the data acquired from patients' behavior for the recognition of movements, which makes possible the determination of the success of an action, can be affected by more elementary deficits of the patients during the performance of goal-directed movements.

Meanwhile, the classical methods to provide cognitive rehabilitation once the screening of the corresponding stroke patients is done have been classified in 5 main techniques. On the basis of the analysis of the results, there is evidence that new rehabilitation technologies are needed. Among the main

reasons why new ICT systems are necessary, the following ones can be derived:

- There are a high number of stroke survivors who need long-term cognitive rehabilitation.
- Consequences and traditional rehabilitation techniques of apraxia and action disorganization syndrome reduce independence.
- The economic costs of health care are significant when dealing with rehabilitation after stroke.
- Stroke patients show improvements very slowly by using current hospital-based rehabilitation methods.
- One of the main consequences of the inadequacy of current techniques is the fact that many patients present lifelong disabilities and suffer from social exclusion.

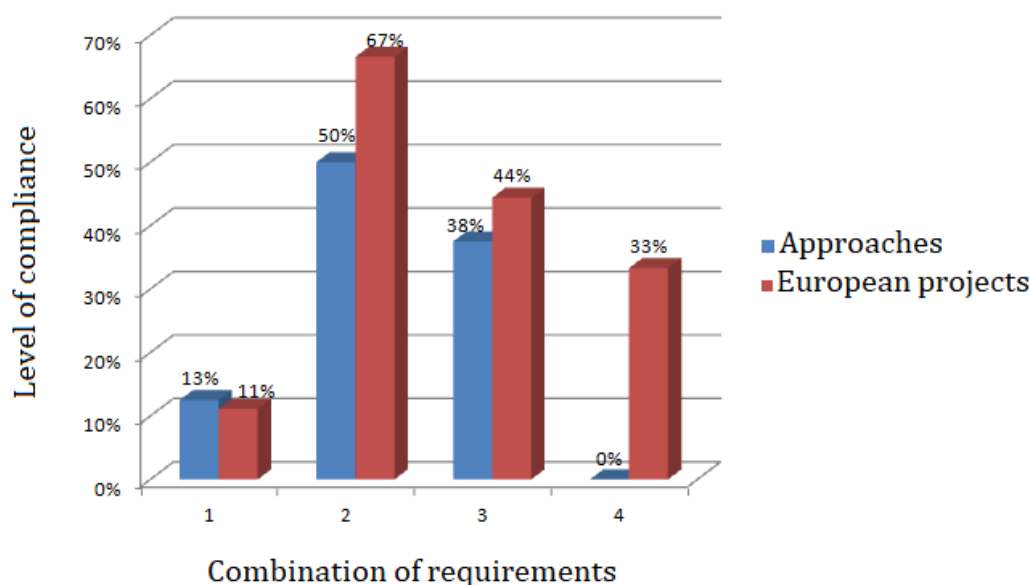
These statements are directly related to the questions proposed and indicated in the methodology. For that reason, the review has covered the main current instances of ICT-based cognitive rehabilitation systems or approaches. The study has been completed with 8 different technology-based approaches from scientific-technical literature; 9 European projects from past Framework Programs to the current Horizon 2020; and other actions such as the use of virtual coaching, 3 examples of smart houses, and the large-scale initiative City4Age. This compilation of projects has been limited to the last 15 years approximately.

Limitations of Smart Technologies for Daily Living

Although nowadays ICT-based platforms are the main interest of research for many professionals and institutions to provide cognitive rehabilitation after stroke, current research initiatives focused on providing such smart systems for coaching and maintenance of cognitive well-being should be well aware of some barriers and take them into account when designing and developing the smart environments.

In terms of user acceptance, older adults are mainly using the internet and mobile phones to keep in contact with family and friends. Although the proportion of older adults using these technologies is less than in any other age, the numbers are steadily increasing [86,87]. There are also some studies focused especially on the acceptance of users in using their mobile phones to monitor health status [88,89]. Nonetheless, assistive technologies especially for cognitive rehabilitation still need to overcome significant barriers to be adopted by older people including privacy, functionality, suitability for daily use, perceived need and usefulness, costs, accessibility, fear of dependence, lack of training, and stigmatization by using technologies specifically targeting older users ("gerontechnology") [90,91].

To deal with this issue, focus groups should be involved in the user requirements and throughout the development of the prototypes. In addition, user groups should be recruited to validate the components developed in different cycles. A user-centered approach would ensure that the usability and perception of the usefulness of the systems are maximized. Moreover, cost barriers must also be addressed by aiming to use affordable, off-the-shelf technologies.

Figure 1. Level of compliance of the approaches and European projects presented based on the requirements to fulfill.

Conclusions

Stroke has significant negative effects on the socioeconomics of countries. Considering the health budget allocated for stroke in Europe and with the goal of improving the efficacy of current rehabilitation techniques and the personal life of stroke patients, the future implementation of systems that are able to provide cognitive rehabilitation at home will have a positive impact on daily living.

Increasing the independence of stroke patients can improve their personal lives because self-confidence of patients will improve as well as their socialization with other family members and friends. It is quite important to ensure proper emotional status in patients which will make the acceptance of rehabilitation easier. Moreover, increasing the personal independence of stroke patients will have a direct implication for health care services.

From the review of current state-of-the-art ICT-based approaches for cognitive self-rehabilitation and tele-rehabilitation, the most relevant ones have been presented in this document. Figure 1 shows the level of compliance of the approaches and European projects described with the requirements mentioned in the methodology considering the following assumptions:

1. Only home-based performance
2. Home-based performance + accessibility
3. Home-based performance + accessibility + support in the execution of complex daily living tasks
4. Home-based performance + accessibility + support in the execution of complex daily living tasks + automatic error detection

By analyzing the data, it can be derived that none of the approaches found in the literature provide all the 4 features at the same time, and only 50% of them are accessible. Meanwhile, although 77% of the European projects presented are conscious of the importance of making new technologies accessible, bearing in mind the limitations of some patients, only 33% of them fulfill the 4 requisites considered as essential.

For this reason, current and future large-scale initiatives focused on smart environments should try to present all these features to users. The design and use of personalized and eHealth rehabilitation systems, which could be used for the assessment of a wide range of neurological disorders including those syndromes not presented in this study, will reduce hospitalization rates as well as the frequency of home visits by health professionals, which means a reduction in costs for the national health care services.

Acknowledgments

The research presented in this paper has been supported by the European Commission under the Cognitive Rehabilitation of Apraxia and Action Disorganisation Syndrome (CogWatch) project (7th Framework Programme), grant agreement 288912, and the Active Hands European Project, from EIT Health-Call 2015 Innovation by Ideas; this study has received funding from the RoboCity2030-III-CM project (S2013-MIT-2748), funded by Programas de Actividades I+D en la Comunidad de Madrid.

Additionally, the authors acknowledge the support and indirect contribution to this work by the members of the different consortiums involved in the European projects mentioned earlier.

Conflicts of Interest

None declared.

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Abbreviations

ADL: activities of daily living

ADS: action disorganization syndrome

CORDIS: Community Research and Development Information Service

ICT: information and communication technology

LBD: left brain damage

MCI: mild cognitive impairment

RBD: right brain damage

Edited by G Eysenbach; submitted 26.07.17; peer-reviewed by M Valero, M Danovska; comments to author 16.08.17; revised version received 11.09.17; accepted 12.09.17; published 26.03.18.

Please cite as:

Cogollor JM, Rojo-Lacal J, Hermsdörfer J, Ferre M, Arredondo Waldmeyer MT, Giachritsis C, Armstrong A, Breñosa Martinez JM, Bautista Loza DA, Sebastián JM

Evolution of Cognitive Rehabilitation After Stroke From Traditional Techniques to Smart and Personalized Home-Based Information and Communication Technology Systems: Literature Review

JMIR Rehabil Assist Technol 2018;5(1):e4

URL: <http://rehab.jmir.org/2018/1/e4/>

doi: [10.2196/rehab.8548](https://doi.org/10.2196/rehab.8548)

PMID: [29581093](https://pubmed.ncbi.nlm.nih.gov/29581093/)

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Review

Scoping Review of Dance for Adults With Fibromyalgia: What Do We Know About It?

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Abstract

Background: Fibromyalgia is a chronic disorder characterized by widespread muscular tenderness, pain, fatigue, and cognitive difficulties. Nonpharmacological treatment options, such as physical activity, are important for people with fibromyalgia. There are strong recommendations to support engagement in physical activity for symptom management among adults with fibromyalgia. Dance is a mode of physical activity that may allow individuals with fibromyalgia to improve their physical function, health, and well-being. Dance has the potential to promote improved pain processing while simultaneously providing the health and social benefits of engaging in physical activity that contributes to symptom management and overall function rehabilitation. However, we are unaware of current evidence on dance as a nonpharmacological/physical activity intervention for adults with fibromyalgia.

Objective: The aims of this study were to understand how dance is used therapeutically by individuals with fibromyalgia; to examine the extent, range and nature of research activity in the area; and to determine the value of undertaking a systematic review of interventions.

Methods: We used and adapted the Arksey and O'Malley scoping framework. The search strategy involved a comprehensive search of main health and electronic social databases, trial registries and grey literature without language limits. Pairs of reviewers independently screened and extracted data and evaluated the methodological quality of randomized control trials.

Results: Twenty-one unique records for 13 studies met inclusion criteria; the studies included mostly middle-aged women. Types of dance included were aerobic dance, belly dance, dance movement therapy, biodanza and Zumba. Intervention parameters were different among studies. Frequency varied between one to three times a week; all were done in small group settings. Studies evaluated a variety of outcomes in the symptoms, wellness, psychosocial, physical functioning, balance and fitness categories; no studies evaluated the safety or adverse events systematically which is a major weakness of the literature.

Conclusions: There are few studies in the field of dance and fibromyalgia, suggesting research is in its infancy but slowly growing. They are of European and South American origin, focusing on female participants and a limited number of dance modes. Because the body of literature is small, of low quality and highly heterogeneous, we concluded that a systematic review of interventions on dance is not warranted at this time.

(*JMIR Rehabil Assist Technol* 2018;5(1):e10033) doi:[10.2196/10033](https://doi.org/10.2196/10033)

KEYWORDS

fibromyalgia; exercise; dancing; scoping review; adult

Introduction

Background

Fibromyalgia is a chronic disorder characterized by widespread muscular tenderness, pain, fatigue and cognitive difficulties [1,2]. The diagnosis is often complex, requiring a history of typical symptoms over time and the exclusion of a somatic disease by medical examination [1]. In addition to pain, fatigue, and cognitive difficulties, individuals with fibromyalgia may experience sleep and mood disturbances, anxiety, depression, difficulty with attention and concentration, as well as a range of gastrointestinal (eg, irritable bowel syndrome) and somatosensory (eg, hyperalgesia, allodynia, paresthesia) symptoms [1]. Symptoms of fibromyalgia can affect an individual's quality of life, often negatively impacting family dynamics, productivity at work, and independence [2].

Fibromyalgia is common worldwide with the prevalence reported to be 2%-4% of the general population, and diagnosis in females outnumbering diagnosis in males [1,3]. Insights gained from research in the past several decades implicate numerous factors in its pathophysiology including changes in brain and neural structure and function, muscular physiology, hormonal factors, inflammatory markers, and genetic influences [4,5]. Individuals with fibromyalgia often experience comorbid illnesses, including musculoskeletal conditions, cardiovascular or endocrinological disorders, spondylosis/intervertebral disc disorders, interstitial cystitis bladder syndrome, chronic pelvic pain, temporomandibular joint disorder, and psychiatric disorders [6].

Physical Activity and Dance

A substantial evidence base supports the use of physical activity for individuals with fibromyalgia. The latest European League Against Rheumatism guideline stated there is a strong recommendation to support both aerobic and resistance training in symptom management for individuals with fibromyalgia [7]. Physical activity is defined as any bodily movement produced by skeletal muscles resulting in energy expenditure [8]. Dance, a genre of physical activity, can be a social experience, an artistic expression, and a leisure activity, as well as a rigorous stimulus for physical fitness. We operationalize dance as a purposeful, deliberate, and expressive motion of the body caused by contraction of the skeletal muscles [9]. Dance may include music; and although dance movements could be called "functional" (eg, bending, walking, and reaching), the goal of dance is the deliberate and purposeful expression of the body itself through movement [10].

Benefits of dance for chronic conditions can be found in the literature; for example, increased functional and cardiovascular gains, motivation for participation [11], and quality of life [12], as well as a reduction in cardiovascular mortality [13], when compared to traditional exercise training. Emotional benefits were seen after dance-based exercise participation among older individuals [14]. One specific dance-based approach common in the literature is dance movement therapy (DMT), which has been defined as the psychotherapeutic use of movement that furthers the emotional, social, cognitive, and physical integration of the individual [15]. This form of dance may include a variety

of movement methods that have a systematic treatment approach and are goal-oriented [16]. DMT has been used for conditions including cancer [16], schizophrenia [17], depression [18], dementia [19,20], and Parkinson's disease [21]. At the start of this scoping review, we were aware of two publications that include adults with fibromyalgia [22-24].

Dance contributes to the physical training of balance, coordination, strength, flexibility, aerobic capacity, bone health, and proprioception. Additionally, dance promotes increased motivation to exercise [25], attention and cognitive capacity [26], vitality [27], and positive effects on mood [28], everyday competencies, and social life [29]. Dance can also offer auditory, visual and sensory stimulation, motor learning, emotional perception, expression, and interaction. All these features make dance an "enriched environment" which stimulates the brain's plasticity [29] and suggest that dance may be worth evaluating as a component of fibromyalgia management.

Pain Processing and Social Bonding

Widespread pain and fatigue are hallmark symptoms of fibromyalgia and are known factors limiting an individual's participation in treatment [30]. During physical activity, the muscular and physiological stress on the body stimulates the release of endorphins, which contributes to the sensation of an "activity high" and, potentially, a "social high" [31]. Evidence supports that both physical pain (the unpleasant experience that is associated with actual or potential damage to tissue) and social pain (the unpleasant experience that is associated with actual or potential damage to one's sense of social connection or value) are processed with shared neural circuitry [32]. This supports the hypothesis that experiences in social and physical pain may be similar for the individual, such that individuals experiencing chronic physical pain are more likely to avoid activities for fear of inducing both social and physical pain [32,33]. Therefore, a social activity intervention may lead to improved treatment outcomes for adults with fibromyalgia by improving pain processing.

Dance is an engaging and enjoyable form of physical activity. Group or social dance facilitates social bonds, through working in synchrony (performing the same movements at the same time) [31,34]. Synchronization and physical exertion, such as through dance, independently elevate the pain threshold [31]. Moreover, dance can increase self-control, which impacts psychological health and therefore the experience of chronic pain [35]. Therefore, dance has the potential to promote improved pain processing while simultaneously providing the health and social benefits of engaging in physical activity that may contribute to symptom management for adults with fibromyalgia.

This scoping review aimed to: comprehensively examine and map the evidence related to dance in adults (ie, 18 years or older) with diagnosed fibromyalgia; to examine the extent, range and nature of research activity in the area; and to determine the value of undertaking a systematic review of interventions. Definitions used in this review are found in the glossary (Multimedia Appendix 1).

Methods

Scoping review methodology is particularly useful for examining the breadth of the research in a specific topic area. We used and adapted the Arksey and O'Malley scoping framework [36]; adaptations (including a seventh step, knowledge dissemination, not reported in this manuscript) were driven by an intention to develop a feasible approach for reviewing the body of literature. The steps included identifying the research questions and relevant studies; selecting the studies and charting the data; collating, summarising and reporting the results; and ongoing consultation. A detailed description of these steps is outlined in our protocol [37].

The population, intervention, comparator, and outcome (PICO) criteria and the search strategy are presented in the [Multimedia Appendices 2 and 3](#) and also in our protocol [37]. Pairs of reviewers independently screened citations for inclusion, extracted data and evaluated the methodological quality of randomized control trials (RCTs) using the Cochrane Collaboration Risk of Bias Tool [38]. Conflicts were resolved by consensus and with the aid of a third reviewer if needed. Criteria used for screening, extracting and methods for quality evaluation are provided in our protocol [37].

We used frequencies and percentages to describe nominal data. We shared the findings with the researchers and patients engaged with the Cochrane Fibromyalgia and Physical Activity team led by one of the authors (JB), and we integrated all responses into this review.

Results

Identifying and Selecting Relevant Studies

The search of the databases, clinical trials registries, and citation tracking yielded 171 citations after duplicates were removed. [Figure 1](#) presents results of the literature search and flow of articles. Search of fibromyalgia association websites did not yield research reports. In total, we screened 171 publications at title and abstract phase and excluded 133 not meeting the inclusion criteria. The full-text of 34 articles and four trial registry records were screened, and 21 records (ie, unique, companion, and trial registry records) for 13 studies were included [22-24,39-56]. Of the four trial registry records, three were protocols for full-text publications [40,47,54] and one was for a study currently recruiting [48]. Five studies each published two articles for the same study, and the second publication is considered a companion article for the same study: those are Assunção Júnior [39,53] Bojner Horowitz [24,43], Carbonell-Baeza [46,56], Collado-Mateo [49,50], and Lopez Rodriguez [22,23]. Studies by Lopez Rodriguez were a pilot trial and follow up conducted consecutively; we believe these two publications have substantial overlap in their samples, and with a trial registry record [54]. A publication summary is presented in [Table 1](#).

Charting and Collating the Data

Publications were original peer-reviewed journal articles; designs were uncontrolled before and after (n=4), controlled before and after (n=2), qualitative (n=2), and RCTs (n=6). All

but one study [55], were published after 2003 (range 1997-2017; see [Figure 2](#)). Two publications were from South America and the remaining from Europe. Eleven articles were written in English, and one in Spanish. Dance interventions modes included aerobic dance, belly dance, biodanza, DMT, and Zumba. Most of these interventions included dance and another component (eg, DMT+theatre+cultural events).

Outcomes measured fell within seven domains: symptoms (ie, pain), wellness (eg, overall health), psychosocial (ie, self-image), physical function, balance, and fitness (ie, muscle strength), and other (ie, body composition). We have summarized outcomes and outcome measures in [Multimedia Appendix 4](#). No studies assessed adverse events systematically, and narrative reports were included in few instances [41,46,50,52], generally relating to an acute increase in pain (see [Multimedia Appendix 5](#)). The number of withdrawals was reported in nine studies [22,39,41,44-46,50,51,55].

We evaluated the methodological quality of five published RCTs [22,24,41,50,55] ([Figures 3 and 4](#)) to determine the value of undertaking a systematic review of interventions. Results demonstrated problems of selection, performance, detection and reporting biases. Other factors affecting study quality are assessment of a large number of outcomes, diversity on the psychometric and other outcome measures, and clinical heterogeneity.

Participants

Participants were mainly middle-aged females with a fibromyalgia diagnosis (ACR 1990, n=11; ACR 2011, n=1; unclear criteria, n=1); one study recruited males but its final sample composition was unclear [55]. The total number of participants across studies was 488 (median 36). Participant age ranged between 30 and 68 years. Duration of fibromyalgia (years since diagnosis) varied from 2 to 35 years (not reported in three studies). Participants who were taken medications needed to be on a stable course of pharmacological treatment before starting the intervention, and have no contraindications for physical activity (eg, uncontrolled hypertension). The inclusion criteria of one study specified that participants needed to meet the criteria for depression [51]; two studies specified inclusion criteria for pain levels to be between 3-8 on a visual analog scale [23,51].

Intervention and Music

Interventions were performed once (n=5), twice (n=4) or three times a week (n=2). Intensity was not specified in five studies, set as a low intensity (n=2), worded as listening to their bodies or not exceeding pain thresholds (n=2) or set at 40%-50% of oxygen consumption (VO₂; n=1). Intervention duration ranged between 50 to 120 minutes and length between 8 to 24 weeks; only two studies reported long-term follow up times (see [Table 2](#)). There was limited information about the qualifications of the instructor or the setting (group or individual). Five studies lack information on the instructor's qualifications [22-24,43,46,48,55], two mentioned a physiotherapist with experience in dance [41,45], one a student with training in dancing [39,53], one professional kinesiologist and dance teacher [49,50] and the rest made reference to "study leader."

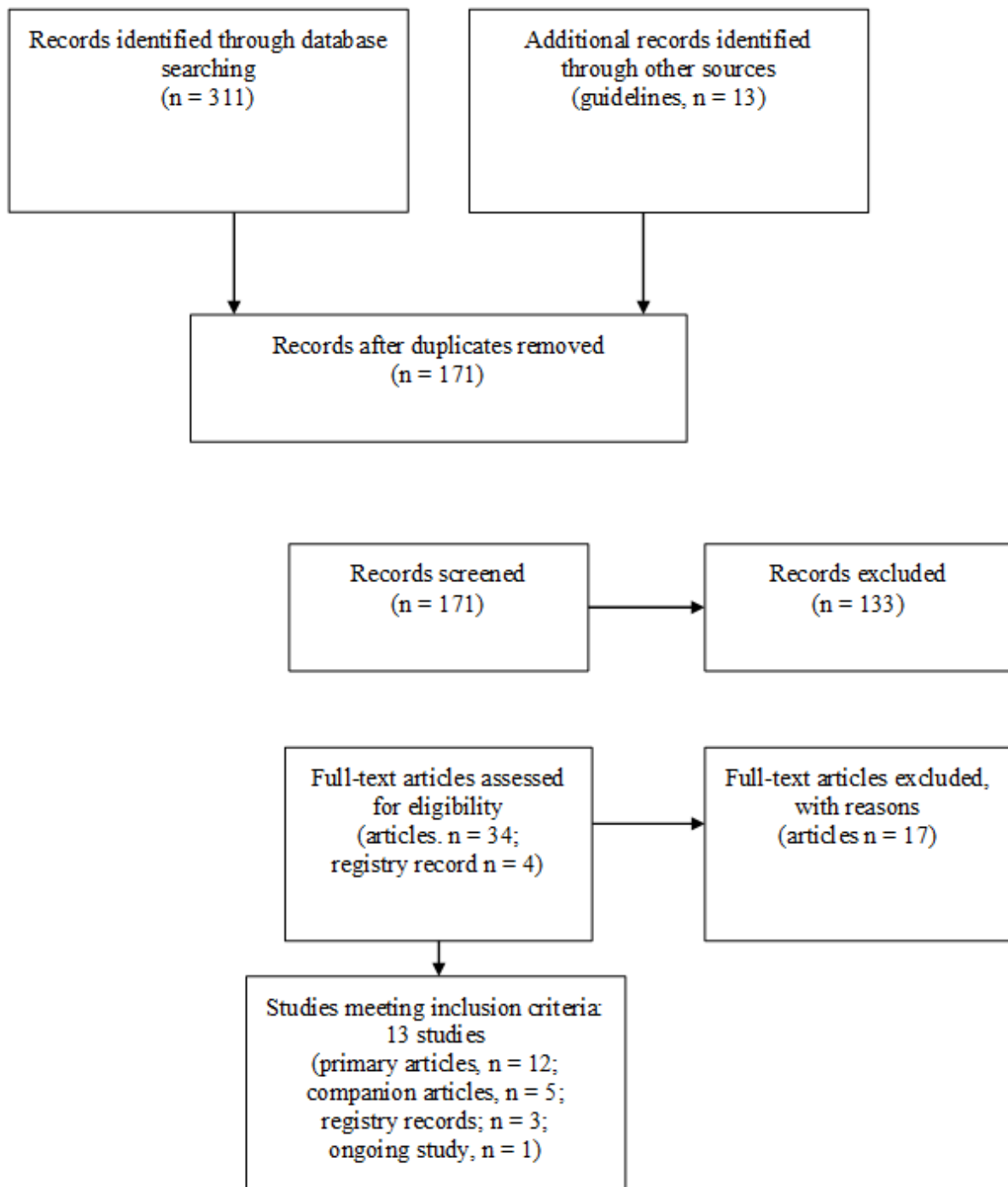
Figure 1. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram.

Table 1. Publication summary.

Characteristics	Value
Year of Publication, n (%)	
1997	1 (8)
2003-10	4 (31)
2011-17	7 (54)
Ongoing	1 (8)
Continent, n (%)	
South America	2 (15)
Europe	11 (85)
Language, n (%)	
English	12 (92)
Spanish	1 (8)
Design, n (%)	
Randomized control trial	6 (46)
Controlled before and after	2 (15)
Uncontrolled before and after	4 (31)
Grounded theory	1 (8)
Mode, n (%)	
Aerobic dance	1 (8)
Belly dance	1 (8)
Biodanza	3 (23)
Dance movement therapy	5 (38)
Zumba	2 (15)
Activity, recovery and balance	1 (8)
Type of publication, n	
Primary article	12
Companion article (published protocol or additional publication)	5
Ongoing (ie, trial registry record status recruiting)	1

We found limited information on how music was used (see [Multimedia Appendix 6](#)), such as to inspire spontaneous movement, creativity and emotional expression [22,23,44-46]. In some studies, music also involved a receptive listening experience with the aim of facilitating dialogue, where the participants engaged in a relational process with peers during the sessions [22,23,45,46].

In Hallberg [52] the women described dance as an enjoyable and desirable activity “...I’ll pretty much dance to every song during a dance evening...it was so much fun.” Although dance continued to be a valued activity in participants’ lives, their narratives closely interlaced the physical effort it represented, the persistence of pain, and limitations it caused. However, the sense of joy and perseverance prevailed: “*But it’s worth it, you*

have to live.” Madeiros [53] followed up after a 3-month Zumba intervention, and the women reported benefits on sleep quality, pain, self-esteem, and physical functioning.

Gaps in the Literature

We were unable to conduct comparative analyses of key concepts across studies due to lack of consistency in conceptual definitions of dance. Participants’ medications were not described in all studies, thus could not be summarized. In addition to lack of systematically measuring adverse events, no studies addressed concepts of communication (eg, isolation), challenges or barriers to participation or implementation, acceptability, feasibility or applicability for clinical practice. There was no information available on cost or equipment.

Figure 2. Dance and fibromyalgia publication's timeline.

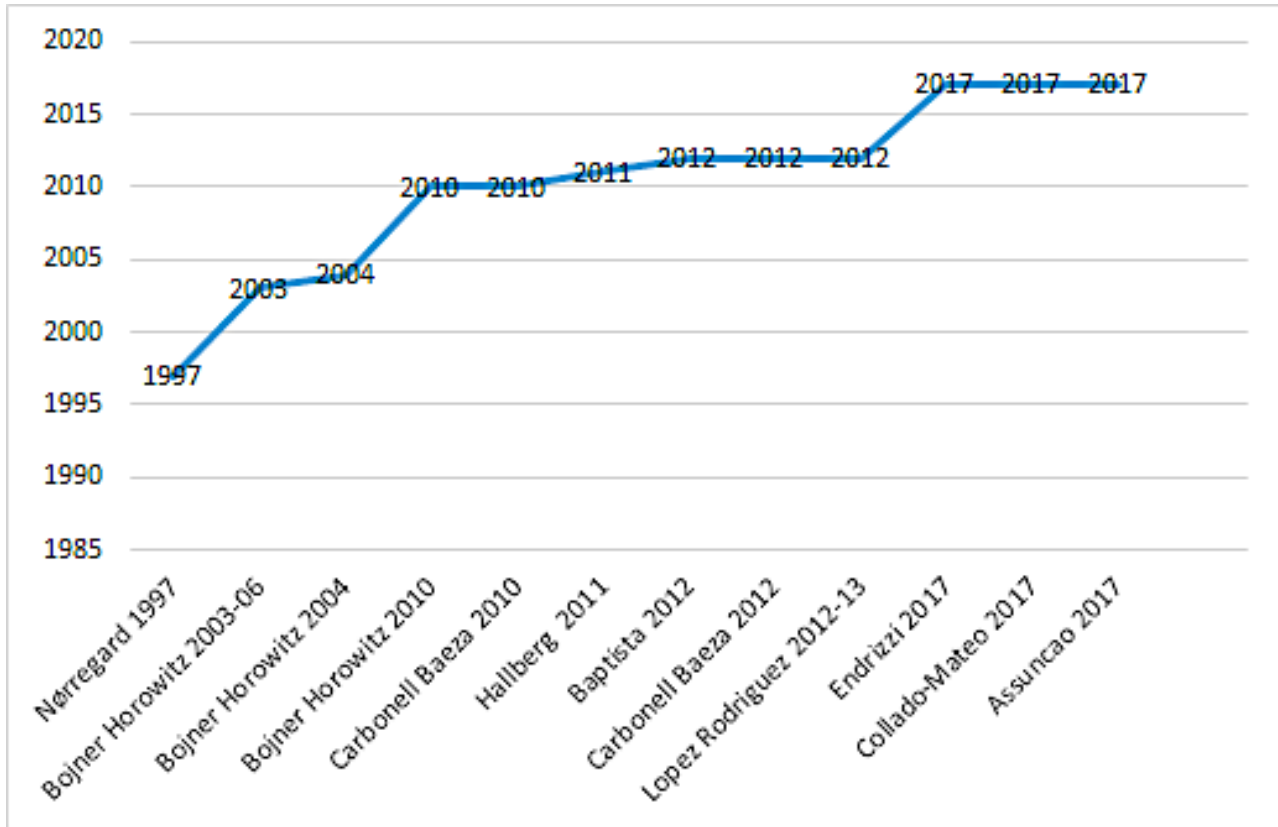


Figure 3. Methodological quality of randomized controlled trials.

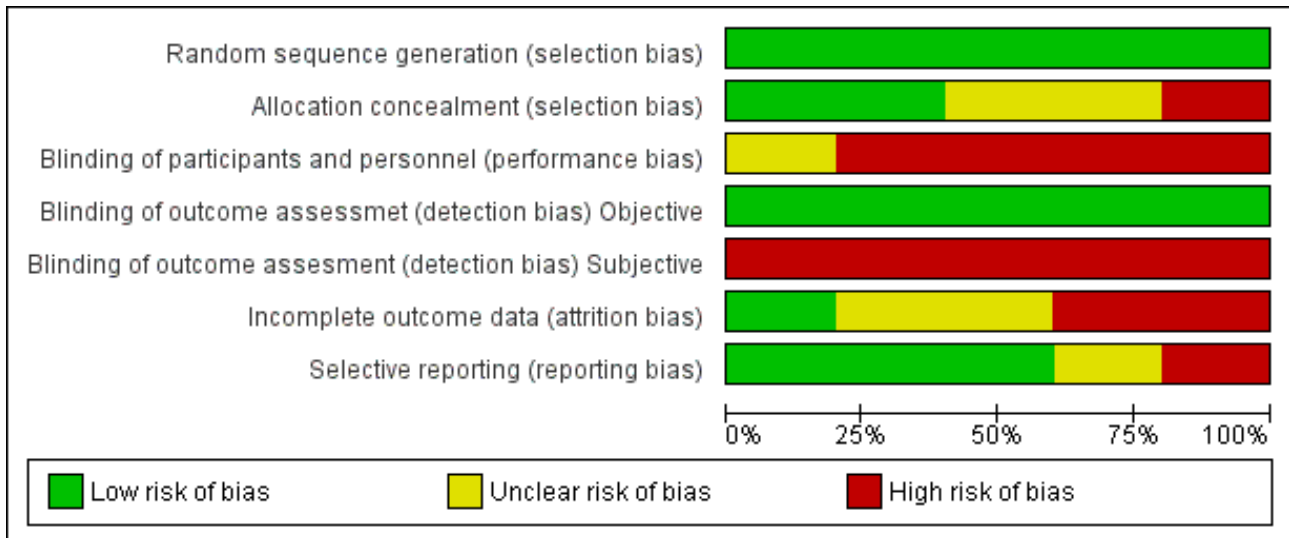


Figure 4. Methodological quality of randomized controlled trials.

	Random sequence generation (selection bias)	Allocation concealment (selection bias)	Blinding of participants and personnel (performance bias)	Blinding of outcome assessment (detection bias) Objective	Blinding of outcome assessment (detection bias) Subjective	Incomplete outcome data (attrition bias)	Selective reporting (reporting bias)
Baptista 2012	+	+	-	+	-	+	+
Bojner Horowitz 2003-06	+	?	-	+	-	?	?
Collado-Mateo 2017	+	+	-	+	-	?	+
Lopez Rodriguez 2012-13	+	-	-	+	-	-	+
Nørregard 1997	+	?	?	+	-	-	-

Table 2. Intervention characteristics.

Characteristics ^a	Value, n (%)
Times per week	
1x/week	5 (45)
2x/week	4 (36)
3x/week	2 (18)
Intensity	
Respect their body rhythm and limits	1 (9)
Ability to change intensity difficulty	1 (9)
40%-50% VO ₂ max ^b	1 (9)
Low	2 (18)
Not exceeding pain	1 (9)
No reported	5 (45)
Duration	
50 to 60 minutes	7 (64)
61 to 120 minutes	3 (27)
Not reported	1 (9)
Length of intervention	
8 to 11 weeks	3 (27)
12 to 16 weeks	7 (64)
>16 weeks	1 (9)
Follow up (ie, after end of intervention)	2 (18)
Delivery mode	
Individual	1 (95)
Small group or group	4 (36)
Individual, pair and group	2 (18)
Not reported	4 (36)

^aQualitative study and ongoing not included.

^bVO₂: maximal oxygen uptake.

Discussion

Principal Findings

There has been some interest in dance as a potential nonpharmacological intervention in fibromyalgia, yet the body of knowledge remains small. Most studies were published after 2003, included middle-aged women, and used a small number of dance modes (belly dance, DMT, aerobic dance, biodanza, Zumba). Currently, there is a broad variation across studies (ie, design, mode, delivery mode, intervention parameters); the creation and agreement of consistent terminology, starting with the definition of dance, would be beneficial.

Dance was used in the studies as a form of exercise training (eg, aquatic biodanza), or performed because of its artistic or creative nature (eg, DMT). Dance was one of a multi-component (or mixed) intervention; this is an important consideration for practitioners and individuals wishing to engage in dance. Interaction with others was important; dance was conducted in

groups or small groups to help socialization. This is not surprising as socialization holds potential to affect pain processing [32] thereby potentially improving treatment outcomes for individuals with fibromyalgia [37]. Music was used as a tool for creativity and expression, as well as socialization but its use was not well defined. Researchers need to provide better descriptions concerning parameters of the intervention, such as exercise frequency, intensity, time (duration), type (and mode), use of music, and instructor qualifications.

Dance mode, outcomes, and outcome measures were heterogeneous, which poses challenges for synthesizing evidence. Additionally, the risk of bias assessment of RCTs showed a high risk of selection bias related to subject allocation, performance and detection bias related to blinding and reporting biases. None of the included studies evaluated safety or adverse events systematically, which is a major weakness of these studies, and consistent with the fibromyalgia and exercise

literature more generally [57]. The lack of data on acceptability, feasibility, applicability, and cost-effectiveness represent drawbacks to informing clinical practice.

Future research may wish to consider the individual effects of socialization, music, and physical effects of dance itself to better understand the role of dance in enhancing treatment outcomes among individuals with fibromyalgia.

Some limitations to this scoping review exist. First, we have focused on providing the breadth rather than depth of information on this topic, so questions remain regarding the effectiveness of this intervention. Second, no electronic database contains all the information needed for a research project; the search is limited to what was available to researchers. Finally, we are aware others might define dance in a more or less inclusive way than we have done, consequently capturing somewhat different literature for review.

Acknowledging that these studies represent initial steps in the field, prudence is necessary when recommending dance to individuals with fibromyalgia as we do not yet have a proper understanding of its benefits and harms. This lack of evidence

will negatively impact knowledge translation efforts, such as safely integrating dance into clinical management approaches.

Conclusion

This scoping review is, to our knowledge, the first systematic and rigorous synthesis conducted of studies reporting on dance as a nonpharmacological intervention for adults with fibromyalgia. The study demonstrates there is a small body of evidence using interventions such as belly dance, DMT, aerobic dance, biodanza, and Zumba mostly conducted in middle-aged women. Safety issues were not assessed systematically or reported, representing a major gap in the current literature. Lack of common intervention approaches and outcome measures as well as standardization in reporting outcomes presents a barrier to pooling data. To date, adults with fibromyalgia interested in engaging in dance programs for control of symptoms have little evidence to aid in their decision-making. As this body of research grows, our understanding of dance in adults with fibromyalgia will improve and provide meaningful information about the potential role of dance in symptom management, physical and mental health of adults with fibromyalgia and for health practitioners working with these individuals.

Acknowledgments

We would like to thank Dr Candice Schachter and Janet Gunderson from the Fibromyalgia and Physical Activity Cochrane team.

Authors' Contributions

All authors contributed equally to the completion of this manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Glossary of terms.

[[PDF File \(Adobe PDF File\), 28KB - rehab_v5i1e10033_app1.pdf](#)]

Multimedia Appendix 2

PICO criteria.

[[PNG File, 88KB - rehab_v5i1e10033_app2.png](#)]

Multimedia Appendix 3

Search strategy.

[[PDF File \(Adobe PDF File\), 30KB - rehab_v5i1e10033_app3.pdf](#)]

Multimedia Appendix 4

Outcome and outcome measures (ie, scale or technique).

[[PDF File \(Adobe PDF File\), 31KB - rehab_v5i1e10033_app4.pdf](#)]

Multimedia Appendix 5

Adverse events.

[[PDF File \(Adobe PDF File\), 25KB - rehab_v5i1e10033_app5.pdf](#)]

Multimedia Appendix 6

Dance intervention classification and use of music.

[[PDF File \(Adobe PDF File\), 30KB - rehab_v5i1e10033_app6.pdf](#)]

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Abbreviations

DMT: dance movement therapy

PICO: population, intervention, comparator, and outcome

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

RCT: randomized control trial

VO₂ max: maximal rate at which an individual can process oxygen

Edited by G Eysenbach; submitted 06.02.18; peer-reviewed by S Stones, F Calvo; comments to author 31.03.18; revised version received 08.04.18; accepted 09.04.18; published 10.05.18.

Please cite as:

Bidonde J, Boden C, Kim S, Busch AJ, Goes SM, Knight E

Scoping Review of Dance for Adults With Fibromyalgia: What Do We Know About It?

JMIR Rehabil Assist Technol 2018;5(1):e10033

URL: <http://rehab.jmir.org/2018/1/e10033/>

doi: [10.2196/10033](https://doi.org/10.2196/10033)

PMID: [29748158](https://pubmed.ncbi.nlm.nih.gov/29748158/)

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Viewpoint

The Use of Digital and Remote Communication Technologies as a Tool for Multiple Sclerosis Management: Narrative Review

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Abstract

Despite recent advances in multiple sclerosis (MS) care, many patients only infrequently access health care services, or are unable to access them easily, for reasons such as mobility restrictions, travel costs, consultation and treatment time constraints, and a lack of locally available MS expert services. Advances in mobile communications have led to the introduction of electronic health (eHealth) technologies, which are helping to improve both access to and the quality of health care services. As the Internet is now readily accessible through smart mobile devices, most people can take advantage of eHealth apps. The development of digital applications and remote communication technologies for patients with MS has increased rapidly in recent years. These apps are intended to complement traditional in-clinic approaches and can bring significant benefits to both patients with MS and health care providers (HCPs). For patients, such eHealth apps have been shown to improve outcomes and increase access to care, disease information, and support. These apps also help patients to participate actively in self-management, for example, by tracking adherence to treatment, changes in bladder and bowel habits, and activity and mood. For HCPs, MS eHealth solutions can simplify the multidisciplinary approaches needed to tailor MS management strategies to individual patients; facilitate remote monitoring of patient symptoms, adverse events, and outcomes; enable the efficient use of limited resources and clinic time; and potentially allow more timely intervention than is possible with scheduled face-to-face visits. These benefits are important because MS is a long-term, multifaceted chronic condition that requires ongoing monitoring, assessment, and management. We identified in the literature 28 eHealth solutions for patients with MS that fall within the four categories of screening and assessment, disease monitoring and self-management, treatment and rehabilitation, and advice and education. We review each solution, focusing on any clinical evidence supporting their use from prospective trials (including ASSESS MS, Deprexis, MSdialog, and the Multiple Sclerosis Performance Test) and consider the opportunities, barriers to adoption, and potential pitfalls of eHealth technologies in routine health care.

(*JMIR Rehabil Assist Technol* 2018;5(1):e5) doi:[10.2196/rehab.7805](https://doi.org/10.2196/rehab.7805)

KEYWORDS

communication; eHealth; technology; multiple sclerosis; telehealth; telemedicine; telerehabilitation

Introduction

Multiple sclerosis (MS) is a chronic disease in which patients' physical and cognitive abilities often worsen progressively [1]. As well as having to come to terms with these clinical changes, patients frequently find that MS has an impact on social aspects of their lives and those of family members. It is very difficult for a single clinician to manage all areas of the disease; consequently, a multidisciplinary approach is advocated, involving a team of health care professionals (HCPs). To reduce the burden of MS, management strategies must be tailored to individual patients and include multidisciplinary assessment, services, rehabilitation, and appropriate treatment [2].

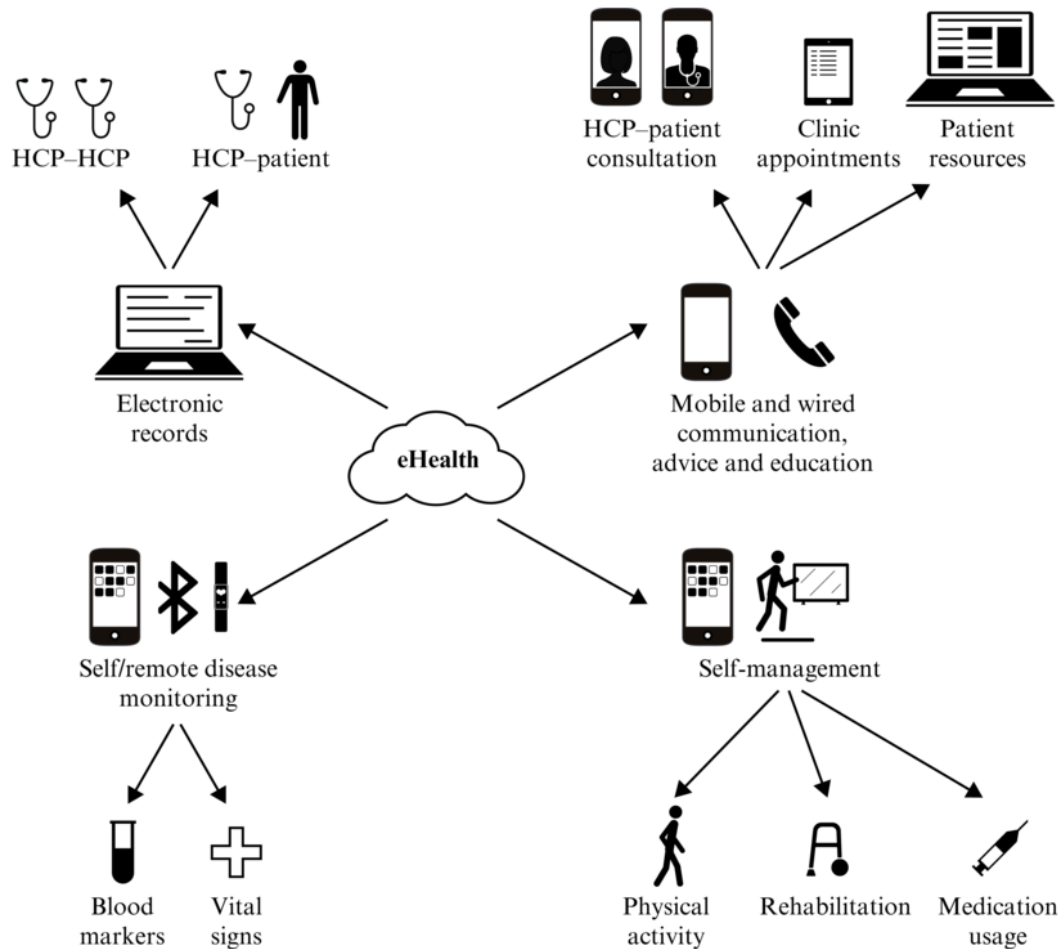
Important limitations of existing management strategies in chronic diseases such as MS are that clinical evaluation is cross-sectional at particular times, requiring patients to attend regular follow-up visits in MS clinics and comprehensive assessments to be undertaken. Ideally, this should happen at 6- or 12-month intervals, but even at this frequency, mild relapses and disease progression may go unreported. Although more frequent personal consultation could improve disease monitoring, this is probably precluded by time, cost, and geographical constraints. Furthermore, with median survival being as high as 78.6 years in women with MS [3], patients commonly require long-term, multidisciplinary care in both clinical and community settings [1,4]. Despite recent advances in MS care, the availability of expert medical and rehabilitation services may be limited or such services may not be regularly provided owing to a lack of health care reimbursement. Furthermore, many patients cannot access available services because of restricted mobility, fatigue, or travel costs [5-7]. The ability of patients to attend multiple sessions of personalized rehabilitation for specific indications can be constrained by these factors, and long in-patient stays, if necessary, are costly and not widely available. In brief, there are significant implications for patients, their caregivers, and physicians in terms of access to, and provision of, MS health care services [1,4].

Electronic health (eHealth) may help to address some of these issues. It has been defined as "an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies" [8]. As a subcategory of eHealth, telehealth is of particular note and is defined as "the use of information and communication technologies as a medium for the provision of rehabilitation services to sites or patients who are at a distance from the provider" [1]. eHealth technologies can improve access to health care resources and information by reducing barriers of distance,

time, and cost; they can also be deployed to educate and support patients and caregivers in ongoing self-management and to empower patients to become more actively involved in the management and treatment of their disease (Figure 1) [1,9]. Among these, it may be some time before technologies for remote self-monitoring of blood markers in MS are available, but they would be useful. For example, blood tests to monitor disease status in MS form an increasingly important part of disease management, with a requirement for fortnightly monitoring of liver enzyme levels in patients with MS taking teriflunomide. From a service-provider perspective, adoption of such technologies may lead to more efficient use of resources and clinic time, and provide opportunities for monitoring interventions, tracking adverse events, and optimizing therapy that would not be possible with traditional face-to-face approaches alone [1,9].

Many eHealth solutions have been shown to be effective in improving outcomes, in facilitating remote monitoring of symptoms, and in increasing patient engagement, treatment adherence, and access to services and information in chronic diseases such as type 1 diabetes [10] and asthma [11], and in neurological conditions including Parkinson disease [12], suggesting that they may also be effective in MS. Furthermore, by generating prospective, longitudinal, real-world data, eHealth solutions may yield valuable insights into MS disease progression, such as symptoms indicative of relapse. This could also facilitate characterization of different MS disease phenotypes that have been reclassified in recent years to take account of observable active disease [13]. Characterizing a patient's MS phenotype correctly is crucial, as it impacts directly on decision making regarding treatment.

Opportunities to deploy eHealth have increased significantly in recent years, largely owing to technological advances in mobile communications. For example, at the start of 2017, more than half of the world's population was using smartphones, nearly two-thirds of the world's population possessed mobile phones, and more than half of the world's Web traffic came from mobile phones [14], meaning that many people now have the opportunity to engage with eHealth solutions. A high level of Internet usage among patients with MS has been reported; a survey in 2011 of more than 8500 patients with MS in North America and Canada noted that about 90% of those who responded had access to the Internet or email, and about two-thirds used these at least once daily [15]. Although the situation is unclear among MS physicians specifically, surveys in 2010 and 2013 highlighted a dramatic increase in social media usage from 42% [16] to 75% [17] among practicing physicians in general. Ostensibly, both patients and physicians would seem receptive to the adoption of eHealth solutions.

Figure 1. Electronic health (eHealth) technologies and health care. HCP: health care professional.

Although the definition of eHealth can include traditional telephone use, our review will focus on more recent technologies [18] such as the Internet, mobile devices, and apps. The digital and remote technologies developed for individuals with MS that are identified and discussed here pertain to one of four categories: screening and assessment, disease monitoring and self-management, treatment and rehabilitation, and advice and education. There are some overlaps among these four groupings, but they serve to simplify the task of assessing the eHealth landscape and also align broadly with categories used in a recent comprehensive review examining these technologies in a range of clinical conditions [19]. We provide a narrative synthesis of previously published information obtained through a targeted literature search and informed by our personal experience and describe various eHealth solutions, summarizing the clinical evidence supporting their feasibility and use in patients with MS. This review presents a broad perspective on eHealth, a fast-developing field, providing a useful resource to stimulate improved multidisciplinary research projects and services. It will aid HCPs who are interested in integrating eHealth solutions within their clinical practice, offering patients a convenient summary of technologies that have been evaluated clinically, and perhaps helping those developing eHealth solutions in MS to broaden their knowledge of the field. Moreover, the review highlights the need for evaluation of eHealth solutions in MS both in phase 3 clinical trials and in large patient cohorts in real-world settings.

Screening and Assessment

Few studies have examined the use of digital technologies as MS screening or assessment tools, but they have demonstrated that these technologies provide an efficient alternative to traditional clinic-based methods and are sensitive to capturing important disease information (Table 1). The Multiple Sclerosis Performance Test (MSPT) is a tablet-based app developed to overcome the challenges associated with measuring MS-related disability accurately [20]. The app builds on the assessments in the MS Functional Composite instrument, tracking and providing precise quantitative data on balance, walking speed, visual function, manual dexterity, and cognitive information-processing speed [20]. These outcomes are calculated automatically, and gathering such quantitative performance data provides an opportunity to perform in-depth *post-hoc* analyses of performance patterns. For example, it is possible to gain insights about whether manual dexterity abnormalities are related to grasping, transporting, or releasing [21]. In a prospective clinical validation study that enrolled 51 patients with MS and 49 healthy individuals, data captured with the MSPT app compared favorably with those captured by technicians, and patients reported a high level of acceptance of the tool [20]. The MSPT can be distributed readily to nonexpert clinicians in rural settings and could be adapted for use in patients' homes, yielding valuable assessment data collected by the patients themselves.

Table 1. Digital and remote technologies in multiple sclerosis (MS): screening and assessment. BLCS: Bladder Control Scale; BWCS: Bowel Control Scale; CSI: Cognitive Stability Index; EDSS: Expanded Disability Status Scale; HCP: health care professional; MSPT: Multiple Sclerosis Performance Test; PASAT: Paced Auditory Serial Addition Test; TaDiMuS: Tablet-based Data capture in Multiple Sclerosis.

Tool	Study design	Number of participants	Patient characteristics	Outcomes or applications	Duration of recording	Conclusions
MSPT [20]	Prospective	MS patients: 51; Healthy controls: 49	Age in years, mean (SD): 46.2 (10.1); EDSS, mean (SD): 3.9 (1.8); Disease duration in years, mean (SD): 12.1 (9.1)	Five performance modules performed by each participant: Walking Speed Test, balance test, Manual Dexterity Test, Processing Speed Test, and Low-Contrast Letter Acuity versus technician testing	Tests repeated twice by each participant during 1 day	MSPT scores were highly reproducible, correlated strongly with technician-administered test scores, discriminated MS from healthy controls and severe from mild MS, and correlated with patient-reported outcomes. Measures of reliability, sensitivity, and clinical meaning for MSPT scores were favorable compared with technician-based testing.
ASSESS MS (Microsoft, Washington, USA; Novartis International AG, Basel, Switzerland) [22]	Prospective	MS patients: 51; Physicians: 12	Age in years, mean (range): 46.0 (23-73); EDSS, mean (range): 3.0 (1.0-7.0); Duration of symptoms in years, mean (range): 14.2 (0.5-47.0)	Classification of motor dysfunction in MS	Tests completed by a HCP within a week (most on a single day)	ASSESS MS is usable and acceptable to both patients and HCPs, generating data of a quality suitable for clinical analysis.
Internet-administered CSI (Headminder Inc, New York, USA)[23,24]	Prospective	MS patients: 40	Age in years, mean (SD): 45 (10.2); Time since diagnosis in years, mean (SD): 10 (7.4)	Measurement of cognitive function over the Internet	PASAT administered 6 times, the score from the last test recorded, then CSI administered. At 14 days, NPsych administered but blinded to PASAT or CSI data.	Compared with NPsych, CSI showed 83% sensitivity and 86% specificity in detecting cognitive impairment, and PASAT showed 28% sensitivity and 86% specificity.
TaDiMuS [25]	Pilot	MS patients: 157	Not reported	Bladder Control Scale BLCS; Bowel Control Scale BWCS	13 months	The mean time taken to complete the BLCS and BWCS was 56.6 s and 39.3 s, respectively. A total of 184 continence test sets (BLCS and BWCS) were completed; an electronic referral for formal continence review was automatically generated 128 times (68.8%) in 108 patients (68.8%), when scores ≥ 2 in the BLCS or BWCS were achieved.

Another tool, ASSESS MS, which captures depth videos (video images in which each pixel has a three-dimensional, 3D, position) of movement, is under evaluation for the assessment of motor dysfunction in MS within the clinical setting [22]. In a prospective, mixed-methods study that included six neurologists (mean MS experience: 4.3 years) and six nurses (mean MS experience: 2.7 years), ASSESS MS was used to record a predefined set of standard movements in 51 patients [22]. The tool was found to be usable by, and acceptable to, both patients and HCPs, and generated data of sufficient quality for clinical analysis. The tool may also improve accuracy when determining the Expanded Disability Status Scale (EDSS) score [26] by reducing subjectivity, for example, when rating tremor severity during the finger-nose test. Like the MSPT, ASSESS MS is currently at an early stage of development and is used only under the supervision of trained HCPs in a clinical setting, but the potential exists for its adoption in remote eHealth apps.

Although the physician-administered EDSS [26] is the current gold standard for monitoring MS disease severity [27], a patient-administered version could help to capture such data remotely in settings where patients cannot undergo regular physician assessment [27]. With this in mind, a pilot study was conducted [27] that compared an Internet-based version of the telephone-based EDSS [28] with the original physician-administered EDSS [26]. Overall patient satisfaction with the Web-based version was high, and results from it correlated well with those from the physician-administered version [27]. Although further studies are needed to validate the Internet-based tool, these findings suggest it will be invaluable in future long-term monitoring of patients with MS [27].

The heterogeneous nature of MS can make it challenging to measure patients' cognitive impairment, and it can be time-consuming and expensive to conduct a full battery of neurocognitive tests. Accordingly, an MS-center study enrolled 40 patients with clinically definite MS and subjective cognitive

complaints [23] to examine whether cognitive function could be measured remotely using the Internet-administered Cognitive Stability Index (CSI) [24]. The study found the CSI to be as specific as, and more sensitive than, other tools typically used to assess cognitive function in MS, including the neuropsychological battery of tests NPsych and the Paced Auditory Serial Addition Test [23].

Sphincter dysfunction is common in MS [29], but bladder and bowel incontinence can be underreported and poorly managed [25,30]. Furthermore, the use of existing continence-screening tools may be limited in practice by time constraints and physician workload [25]. To address these issues, a cross-platform tool (Tablet-based Data capture in Multiple Sclerosis, TaDiMuS) was developed for use by patients on a tablet computer [25]. In a pilot study, 157 patients completed the TaDiMuS versions of the Bladder Control Scale and the Bowel Control Scale from the MS Quality of Life Inventory [31] while waiting for their appointments (data were captured wirelessly from the waiting room). Scores of ≥ 2 on either questionnaire generated an automated electronic referral to the clinic's MS continence nurse [25]. The study confirmed the validity of TaDiMuS as a continence-screening tool, offering physicians an efficient, sensitive, and feasible method of screening patients for bladder and bowel dysfunction [25].

Disease Monitoring and Self-Management

Many tools have been developed to facilitate disease monitoring and self-management (Table 2). A major challenge facing physicians and patients with MS is how to organize, integrate, and interpret medical data to track disease progression, predict outcomes, and personalize treatment [32]. Accordingly, the University of California, San Francisco, CA, USA developed MS BioScreen, a tablet-based navigation system that integrates data from a patient's medical records with population-based data to inform physicians about their disease trajectory relative to reference populations and to guide the patient and physician in treatment decisions [32-34].

Table 2. Digital and remote technologies in multiple sclerosis (MS): disease monitoring and self-management. EDSS: Expanded Disability Status Scale; MS-HAT: Multiple sclerosis—specific version of Home Automated Telemanagement; MSDS3D: Multiple Sclerosis Documentation System: Three-Dimensional; MSRS-R: Multiple Sclerosis Rating Scale-Revised; N/A: not applicable; RMSS: relapsing-remitting multiple sclerosis; RC: routine care.

Tool	Study design	Number of participants	Patient characteristics	Outcomes or applications	Duration of recording	Conclusions
MS BioScreen (University of California San Francisco MS Centre, San Francisco, USA) [32-34]	N/A	N/A	N/A	Integrate patient information; analyze disease course; facilitate patient engagement	N/A	N/A
MSDS3D [35,36]	N/A	N/A	N/A	Electronic patient-management system that integrates MS registry data	N/A	N/A
MSmonitor (Curavista Health, Geertruidenberg, Netherlands) [37]	Web-based survey	MS patients: 55 ^a ; RMSS: 38; secondary progressive MS: 11; primary progressive MS: 4; clinically isolated syndrome: 1	Mean age (SD) in years: 46.3 (11.8)	Utilization and meaningfulness of the program's elements, perceived use of data by neurologists and nurses, and appreciation of care, self-management, and satisfaction	Data collection: January 2013 to April 2013; Survey time: 20 min	In 46% (25/55) of the respondents, the insight into their symptoms and disabilities increased. The overall satisfaction with the program was 3.5 out of 5, and 73% (40/55) of the respondents would recommend the program to other persons with MS.
<i>move II</i> (Movisens GmbH, Karlsruhe, Germany) [38]	Pilot	MS patients: 11	Mean (SD) age, in years: 41.0 (9.3). Mean (SD) disease duration, in years: 12.2 (10.7); EDSS 1.0-2.5: n=6; EDSS 3.0-5.0: n=5	Activity parameters	Measurements collected 4 times, each time lasting 10 days and separated by 3 months.	Changes in physical ambulatory activity were captured. <i>move II</i> was more responsive to slight disability changes than the clinical measures.
MSRS-R (PatientsLikeMe Inc Cambridge, MA, USA) [39]	Pilot	RRMS patients: 816	Mean (SD) age, in years: 45.9 (9.8); mean (SD) time since diagnosis, in years: 6.6 (6.6)	Measure of MS-related functional disability	2-hour cognitive interview; Web-based survey	The MSRS-R exhibited high internal consistency (Cronbach alpha=.86), correlated highly with existing instruments, (patient-determined disease steps, $\rho=.84$; Multiple Sclerosis Walking Scale-12, $\rho=.83$) patient-determined disease stage and relapse burden in the last 2 years. It assesses a number of disability-related domains, while minimizing patient burden.
SymTrac (Novartis International AG, Basel, Switzerland) [40]	N/A	N/A	N/A	Track general well-being and symptoms over time	N/A	N/A

Tool	Study design	Number of participants	Patient characteristics	Outcomes or applications	Duration of recording	Conclusions
My MS Manager (Multiple Sclerosis Association of America, Cherry Hill, NJ, USA; @Point of Care, Livingston, NJ, USA) [41]	N/A	N/A	N/A	Track disease activity; store medical information; generate charts and reports across various metrics such as treatments, moods, and symptoms	N/A	N/A
MSdialog (Merck Serono, Darmstadt, Germany) [42]	Pilot	MS patients: 42	Mean (SD) age in years: 43.9 (7.6); mean (SD) time since diagnosis, years: 7.0 (6.4); mean (SD) duration of drug treatment, years: 4.8 (4.5)	Health-tracking tool, data from which can be shared with health care providers	6 weeks	82% (32/39) of patients considered MSdialog better than previous methods for tracking their health, and 95% (37/39) would recommend its use.
MS Journal (Tensai Solutions LLC, CA, USA) [43]	N/A	N/A	N/A	Assist with injections	N/A	N/A
myBETAapp (Bayer AG, Leverkusen, Germany) [44]	N/A	N/A	N/A	Schedule, track, and record treatment	N/A	N/A
MS-HAT [45]	Randomized	MS patients: 30; RC: 13; MS-HAT: 17	Mean age (SD) in years—RC: 44.0 (11.8); MS-HAT: 51.0 (9.2). Mean (SD) time since MS onset, in years—RC: 11.9 (9.8); MS-HAT: 18.1 (13.4). Median EDSS (range)—RC: 3.0 (2.0-8.0); MS-HAT: 3.5 (2.0-8.0)	Medication adherence to interferon β -1a	6 months	There were strong correlations between self-reported and objective measures of medication adherence. The majority of patients found the system easy to use, wanted to continue using it after the study ended, and would recommend it to other patients.
MySupport program (Merck Serono, Darmstadt, Germany) [46]	Retrospective	MS patients; MySupport: 604; RC: 2461	Not reported	Persistence with interferon β -1a therapy	24 months	The odds of being on treatment were significantly greater at all time points for patients receiving MySupport versus those receiving routine support only ($P < .001$).

^aAlthough 55 patients were surveyed, the sum of patients by multiple sclerosis phenotype is only 54 [30].

The Multiple Sclerosis Documentation System: Three-Dimensional (MSDS3D) was developed following a survey on the inclusion of HCP perspectives on the adoption of eHealth services in neurological practice, which concluded that they were highly appreciated [35]. On the basis of MSDS, the most widely used electronic documentation system in Germany, MSDS3D helps HCPs and patients plan, document, and share clinical data via touchscreen terminals and devices,

apps, or a Web browser [35]. Multidimensional data collected by patients and HCPs, including that relating to specific disease-modifying therapies, can be integrated with that from MS registries to provide an innovative resource of long-term follow-up data [36]. In an environment with many disease-modifying therapies, the platform meets a need to monitor clinical outcomes and connect diagnostic and

therapeutic processes, thus improving patient care and representing an excellent resource for data mining [35,36].

A separate tool, MSmonitor, is an interactive, Internet-based program for the self-monitoring, self-management, and integrated multidisciplinary care of patients with MS [47]. The original content comprised (1) questionnaires to assess the impact of MS and related quality of life (QoL), fatigue, anxiety, and depression; (2) inventories to capture medication, adherence, and urological symptom data; (3) diaries to record activity, rest periods, micturition, and fluid intake; (4) an *e-consult* functionality to enable patients to contact their physician; and (5) an *e-logbook* [47]. Pilot data suggested that repeated use of MSmonitor led to an increase in health-related QoL and helped patients to self-manage fatigue [47]. In a subsequent survey of 55 patients with MS, MSmonitor has been shown to improve patients' insights into symptoms and disabilities and improve the quality of nursing care they received [37].

Ambulation is one aspect of physical disability on which the EDSS assessment focuses, particularly at advanced stages of disease. Abnormalities in spatiotemporal parameters that affect walking ability can present in the early stages of MS, and habitual walking performance is sensitive to disease progression and correlates highly with clinical tests of walking capacity and with EDSS score. As such, recording daily activity is considered important for tracking disability progression [48]. A pilot study testing a portable activity-monitoring sensor, designed to gather data on home-based, physical activity (PA) in 11 patients with MS, showed that a simple 3D accelerometer (*move II*) could track fluctuations in daily PA and also tracked disability changes better than EDSS scores [38]. If this finding can be reproduced in a larger group of patients, it may be possible to use the accelerometer to detect signs of worsening disability earlier than when using standard in-clinic measures [38]. Similarly, a study performed in eight patients with MS has demonstrated how data from wireless pressure sensors in patients' shoes can be combined with Web-based software and mobile technology to detect early signs of deterioration in gait, enabling physicians to intervene rapidly. Data collected were accessible to doctors, patients, and administrators via a Web app [49]. A further study also demonstrated the feasibility of using accelerometers and a multimedia platform to monitor walking function remotely in 25 patients with MS (EDSS score 1.0-6.0) over 2 years and the potential of this approach to capture changes that may indicate deterioration over time [50].

To improve the assessment of functional status in patients with MS, a new patient-reported rating scale, the Multiple Sclerosis Rating Scale-Revised (MSRS-R), was developed, refined, and validated using the Web-based data platform, PatientsLikeMe [39,51]. The MSRS-R was developed to capture disability-related information across a range of domains, rather than focusing on ambulation alone. The MSRS-R exhibits desirable psychometric properties and correlates with existing measures, with the advantage of being more concise than other measures and therefore less burdensome for the patient to

complete. Potentially, the MSRS-R, in conjunction with PatientsLikeMe, could provide a valuable source of real-world evidence, encompassing demographic, social networking, treatment, and symptom data [39].

Many apps have been developed to support MS symptom monitoring and disease tracking, but, to date, few have been the subject of published studies. Relapses may not always be tracked because patients forget to report them or because they are not recorded in a patient's notes. Underreporting of relapses may mean that patients are not receiving the most appropriate treatment, so an app has been developed to address this issue. The Novartis SymTrac app helps to identify when relapses occur by prompting patients to monitor their symptoms and well-being over time, logging information that can be sent automatically to physicians as needed [40,52].

The MS Association of America developed the app My MS Manager for storing medical information, tracking disease activity, generating private reminders, and connecting patients with physicians to share details of their progress [41]. The MSdialog app [53] is an Internet- and mobile-based app designed to capture remote data on clinical and patient-reported outcomes and on self-administration of interferon β -1a [42]. Data from the app are combined with information captured by RebiSmart, an adjustable electronic injection device [53,54]. The app allows patients to create their own health reports and share the information with their physicians. It also tracks trends in treatment adherence and health, and has a reminder function for medication administration and future appointments [53]. In a 6-week pilot study evaluating the app, patients (n=42) found it easy to use and to be superior to their previous health-tracking methods that were mostly handwritten [42].

Nonadherence to MS medications is common and is associated with a number of costs, but monitoring adherence can be challenging, time-consuming, and expensive [45,55]. In addition to the MSdialog app [53], the MSJournal app [43] and myBETAapp [44] have been developed to help patients and caregivers to track injections and injection-site history and to set reminder alerts for injections [43,44]. To test whether telehealth technologies could help to monitor or modify adherence, a study examined adherence to weekly interferon β -1a and daily vitamin D among patients randomized to routine care or to the use of an MS-specific version of the Internet-based Home Automated Telemanagement (HAT) system (MS-HAT) [45]. For 6 months, 30 patients with MS randomized to MS-HAT received text or email reminders to administer injections and a weekly probe asking when they had taken their vitamin D supplements [45]. Although, overall, no major improvements in medication adherence were reported with the MS-HAT system versus routine care, 4 patients (two using MS-HAT and two on routine care) discontinued therapy and did not alert their physicians to their decision: the MS-HAT system detected the discontinuations, allowing timely physician intervention.

Table 3. Digital and remote technologies in multiple sclerosis (MS): treatment and rehabilitation. ADL: activities of daily living; BDI: Beck Depression Inventory; EDSS: Expanded Disability Status Scale; GEMS: Guidelines for Exercise in Multiple Sclerosis; HAT: Home Automated Telemanagement; MACFIMS: Minimal Assessment of Cognitive Function in Multiple Sclerosis; MAPSS-MS: Memory, Attention and Problem-Solving Skills for Persons with Multiple Sclerosis; RMSS: relapsing-remitting multiple sclerosis; RC: routine care; tDCS: transcranial direct current stimulation.

Tool	Study design	Number of participants	Patient characteristics	Outcomes or applications	Duration of recording	Conclusions
HAT [56]	Pilot	MS patients: 12	Not reported	Symptom tracking, patient education, exercise regimen instruction and monitoring	12 weeks	Statistically significant improvement in a timed 25-foot walk, 6-min walk, and Berg Balance Scale compared with baseline. Patients were highly satisfied with the service.
MAPSS-MS program [57]	Randomized controlled single-blind	MS patients: 61; MAPSS-MS: 34; Control: 27	Mean (SD) age in years: 47.95 (8.76)	MACFIMS and self-report instruments (use of memory strategies, self-efficacy for control of MS, and neuropsychological competence in ADL) at baseline and after intervention at 2 and 5 months	8 weeks	Both groups improved significantly over time on most measures in the MACFIMS battery, as well as the measures of strategy use and neuropsychological competence in ADL.
Computerized specific training [58]	Randomized controlled double-blind	RRMS patients: 102; attention-specific training: 63; nonspecific training: 39	Mean (SD) age in years: 40.9 (11.5); mean (SD) disease duration in years: 13.0 (8.7); mean (SD) for EDSS: 2.7 (1.5)	Neuropsychological assessment, depression, fatigue, everyday activities, and attentive performance	3 months	A benefit with attention-specific training was observed on the Paced Auditory Serial Addition Test ($P < .002$). However, patient self-reported outcomes did not reveal differences between the training groups.
Home eTraining [59]	Randomized controlled	MS patients: 18; e-training: 9; Hippotherapy: 9	Mean (range) age in years: 45.5 (32-57); mean (range) for EDSS: 3.8 (2-6); mean (range) disease duration in years: 19.0 (1-35)	Static and dynamic balance	12 weeks	Both interventions demonstrated similar and significant improvement in static and dynamic balance capacity.
COGNI-TRAcK (Italian Multiple Sclerosis Foundation, Genoa, Italy) [60]	Pilot	Cognitively impaired MS patients: 16	Mean (SD) age in years: 49.1 (9.1); mean (SD) for EDSS: 3.8 (1.9); mean (SD) disease duration (months): 161.7 (109.6)	Usability, motivation to use, and compliance to treatment	8 weeks	Adherence was 84% (33.4/40). A total of 100% (16/16) of patients felt independent to use the app at home, 75% (12/16) found the exercises interesting, and 81% (13/16) found the exercises useful and were motivated to use the app again.

Tool	Study design	Number of participants	Patient characteristics	Outcomes or applications	Duration of recording	Conclusions
Web Based Physio [61]	Randomized controlled pilot study	MS patients: 30; Intervention: 15; Control: 25	Mean (SD) age in years: 51.7 (11.2); mean (SD) time since diagnosis (years): 12.7 (9.1); mean (SD) EDSS: 5.9 (0.5)	Mobility, quality of life, and anxiety or depression	12 weeks	No significant between-group difference in primary endpoint (timed 25-foot walk, $P=.17$) or other secondary endpoints except Multiple Sclerosis Impact Scale ($P=.048$). Participants found the website easy to use, convenient, and motivating, and were happy to use it in the future.
MS Invigor8 (University of Southampton, Southampton, UK) [62]	Randomized controlled phase 2 trial	MS patients: 40; MS Invigor8: 23; RC: 17	Mean (SD) age in years—MS Invigor8: 40.1 (17.8); RC: 41.8 (11.4); RRMS (%)—MS Invigor8: 43.5% (10/23); RC: 71% (12/17)	Efficacy in reducing fatigue, feasibility, and cost-effectiveness	10 weeks	There were significantly greater improvements in anxiety, depression, and quality-adjusted life-years in patients receiving MS Invigor8.
GEMS [63]	Randomized, controlled pilot study (ongoing)	MS patients: target recruitment: 30	N/A	Efficacy and safety of a home-based, exercise program	4 months	N/A
Deprexis (Galia AG, Hamburg, Germany) [64]	Randomized, controlled phase 2 trial	MS patients: 90; Deprexis: 45; Waiting list: 45	Mean (SD) age (years)—Deprexis: 45.4 (12.6); Waitlist: 45.2 (10.6); Disability, % patients with walking ability <500 m—Deprexis: 51 (23/45); Waitlist: 49 (22/45). Mean (SD) disease duration in years—Deprexis: 8.2 (7.3); Waitlist: 8.4 (7.6)	BDI	9 weeks	BDI scores decreased in the Deprexis group and increased in the control group (mean difference -4.02 points, 95% CI -7.26 to -0.79 ; $P=.02$).
Remotely controlled tDCS [65,66]	Pilot	MS patients: 20	Mean (SD) age in years: 51 (9.3); Median (range) EDSS: 4.0 (1.0-8.0)	Feasibility of remote supervision	2 weeks	Across a total of 192 supervised treatment sessions, no session required discontinuation, and no adverse events were reported.

Physicians were pleased to be able to monitor adherence more efficiently than via chart reviews or telephone calls. Furthermore, most patients found the system easy to use, wanted to continue using it after the study, and indicated that they would recommend it to others [45]. Similarly, in the industry-sponsored MySupport program, which provides telephone, text, and website access to patients prescribed interferon β -1a, a retrospective study of anonymized data from 604 patients in the Republic of Ireland found an increased probability of patients using MySupport remaining on treatment compared with a control group of 2461 patients receiving routine care [46].

Treatment and Rehabilitation

Various treatment and rehabilitation solutions are shown in Table 3. The Internet-based HAT system was designed for use in patients' homes to monitor symptoms and educate them about their condition [56]. It was also developed to provide step-by-step instructions on how to follow a tailored exercise regimen, to monitor exercise compliance, and to adapt the exercise regimen based on performance [56]. A 12-week pilot study that enrolled 12 patients with MS provided a preliminary demonstration of the feasibility of the HAT system and its potential for use on other devices such as tablets and mobile phones. Its ease of use and convenience were considered particularly beneficial for patients who may be reluctant or unable to visit a physician frequently [56].

The use of other home-based technologies has been explored in a variety of MS rehabilitation settings, including Internet- or computer-assisted training to enhance cognitive performance [57,67], attention [58], and balance, posture, and strength [59]. The Memory, Attention, and Problem Solving Skills for Persons with MS (MAPSS-MS) program is a computer-assisted cognitive rehabilitation intervention for enhancing cognitive function in patients with MS [57]. In the 8-week, single-blind, randomized controlled MAPSS-MS study involving 61 patients with MS, significant improvements in cognition were observed with the MAPSS-MS program, and it was found to be feasible to use and well accepted by patients [57]. COGNI-TRAcK, a self-administered cognitive training app, has also been shown to provide intensive and personalized cognitive rehabilitation [60,68]. In 16 patients with MS and cognitive impairment who underwent an 8-week intervention at home, COGNI-TRAcK was found to be highly usable, motivating, and well accepted by users [60]. COGNI-TRAcK was also evaluated in 28 patients with MS and cognitive impairment to determine the effects of adaptive versus nonadaptive cognitive training. Adaptive training involved increasing or decreasing the difficulty level of an exercise based on whether a participant completed preceding exercises correctly. COGNI-TRAcK was shown to be suitable for administering personalized training to patients with cognitive impairment. It also demonstrated that an adaptive work load is crucial for determining the effectiveness of cognitive treatment, with only patients in the adaptive group showing improvements in cognitive function on study and at 6-month follow-up [68].

A double-blind, randomized controlled study has evaluated a home-based computerized program for retraining attention dysfunction under the supervision of a caregiver in 102 patients with relapsing-remitting MS [58]. Compared with nonspecific training, the attention-dysfunction-specific training resulted in some improvements exclusively in tasks of sustained attention, although patient-reported outcomes did not reveal differences between the groups [58]. Balance was also shown to be improved using the Internet-based program Home eTraining. In a randomized controlled study that enrolled 18 patients with MS, eTraining demonstrated significant improvements in static and dynamic balance that were similar to those resulting from hippotherapy [59].

Home-based technologies have also been used for Web-based physiotherapy exercises [61,69], physical telerehabilitation [70], and physical-activity-targeted behavioral interventions [71,72]. Web Based Physio, developed by the University of Glasgow, Glasgow, United Kingdom, provides Web-based physiotherapy exercise programs personalized for individual patients with long-term conditions including MS, with the aim of allowing patients to self-manage their condition [69]. The effectiveness of this individualized, Internet-based physiotherapy program was evaluated in a 12-week randomized controlled pilot study in community-dwelling adults moderately affected by MS (EDSS score 5.0-6.5). Although there was no significant difference in the primary outcome measure (timed 25-foot walk), patients found the website easy to use, convenient, and motivating, and indicated a willingness to use it in the future.

A fully powered, definitive randomized controlled trial is planned to determine the tool's effectiveness [61].

Another 12-week study assessed feasibility of use, patient acceptance, and magnitude of clinical benefit of home-based physical telerehabilitation in 12 individuals with MS (75%, 9/12, had self-reported moderate MS) who received a tailored rehabilitative exercise program [70]. Home-based physical telerehabilitation was shown to significantly improve functional outcomes including walking and balance. Internet-delivered behavioral interventions have also demonstrated an increase in activity among patients with MS. A 3-month randomized controlled study evaluating an Internet-delivered and theory-based behavioral intervention that was supplemented with video coaching in 45 patients with MS showed a large increase in PA after 12 weeks that was sustained over 3 months [72].

Computer- or gaming-based systems, such as the Nintendo Wii Fit console or Kinect motion sensor, may offer the potential for telerehabilitation applications in patients with MS because patients enjoy these exercises and find them motivating [73]. Although some of these applications have demonstrated significant beneficial effects, the results of others have been mixed. For example, the Nintendo Wii platform appears to stimulate the postural control system only in the frontal plane and not the sagittal plane [74]. Thus, although available games are beneficial in some settings, they will be more effective if tailored to the type and severity of impairments present in individual patients with MS and adapted to offer Internet-assisted monitoring [74,75]. In general, the success of Nintendo Wii or *exergaming* technologies in randomized controlled clinical studies has also been mixed [76-78], but in a 24-week diffusion tensor imaging study, modifications in the microstructure of superior cerebellar peduncles were observed following 12 weeks of Nintendo Wii balance-board training [79]. These changes correlated with clinical improvements in participants' balance, suggesting that high-intensity, task-oriented exercises could induce favorable, myelin-related microstructural changes in the brains of patients with MS [79].

To address the potential issue of patients performing their rehabilitation exercises incorrectly, a comprehensive system is in development that combines weekly face-to-face clinic sessions with remotely supervised exercise training at home, using a Web-based platform and tracking tool that analyzes and corrects patients' positions in real time [80]. This tool is currently being validated, and preliminary results indicate that the system can be used effectively by patients and HCPs [80].

In light of the success of telephone-administered interventions for improving various MS-associated symptoms and QoL [81-85], several studies have examined (or will examine) whether interactive telehealth interventions can improve MS-associated anxiety, cognitive function, mood, fatigue, impact, pain, QoL, and sleep quality [62-64,86-90]. These include a Web-based self-help program (Deprexis) that combines cognitive behavioral therapy (CBT) with mobile platform and dialog technology and has proven efficacy in treating depression [64,91]; an Internet-based CBT program (MS Invigor8) administered with or without email support to help reduce

fatigue symptoms [62,90]; MS-specific multimedia software that delivers a meditation course designed to decrease anxiety, depression, and fatigue, as well as improve quality of sleep and QoL [88]; the project Guidelines for Exercise in Multiple Sclerosis, an interactive, guidelines-based exercise program aimed at improving MS symptoms and QoL [63]; and physical exercise e-training programs that demonstrate positive and significant effects on muscle strength, lung function, and sports activity, but not on QoL or fatigue [92,93]. Perhaps the most robust of these studies was a 9-week randomized trial conducted in patients with MS who had self-reported depression symptoms (N=90) [64]. Patients received the intervention (Deprexis [91]) or remained on a waiting list (control) for 9 weeks, and over the course of the study, use of Deprexis significantly reduced Beck Depression Inventory scores, whereas scores increased in the control group. These results highlight the utility of Web-based intervention programs, especially for patients who

cannot attend or do not like to participate in treatment sessions regularly [64].

Home-based, but clinician-supervised, technologies have also been examined, such as the remotely supervised *self- or proxy-administration protocol* for home delivery of transcranial direct current stimulation (tDCS) [65]. Across 192 supervised treatment sessions, remotely supervised protocol adherence was greater than that observed in clinic-based delivery studies. Furthermore, there were no reported discontinuations or adverse effects. Thus, remotely supervised tDCS could be used to expand patient access to this potential treatment option [65].

Advice and Education

Several apps have been developed to provide advice and education to individuals living with MS, including the MS Buddy app [94] and the MS self app, which, in addition to providing MS-related information, can synchronize with Fitbit devices (Table 4) [95].

Table 4. Digital and remote technologies in multiple sclerosis (MS): advice, support, and education. MCCO: Mellen Center Care Online; N/A: not applicable.

Tool	Study design	Number of participants	Patient characteristics	Outcomes or applications	Duration of recording	Conclusions
MS Buddy (Healthline Networks Inc., San Francisco, USA) [94]	N/A	N/A	N/A	An app for discovering support and getting advice from an MS peer	N/A	N/A
MS self (Acorda Therapeutics Inc., New York, USA) [95]	N/A	N/A	N/A	An app designed to help patients manage their MS	N/A	N/A
My MS Manager (Multiple Sclerosis Association of America, Cherry Hill, NJ, USA; @Point of Care, Livingston, NJ, USA) [41]	N/A	N/A	N/A	Provides advice and support	N/A	N/A
Deprexis (Gaia AG, Hamburg, Germany) [64]	Randomized, controlled phase 2 trial	MS patients: 90; Deprexis: 45; Waiting list: 45	Mean (SD) age, in years—Deprexis: 45.4 (12.6); Waitlist: 45.2 (10.6). Disability, % patients with walking ability <500 m—Deprexis: 51; Waitlist: 49. Mean (SD) disease duration, in years—Deprexis: 8.2 (7.3); Waitlist: 8.4 (7.6)	Web-based psychoeducation; Beck Depression Inventory	9 weeks	N/A
MCCO system (Cleveland Clinic, Cleveland, OH, USA) [97]	Randomized controlled	MS patients: 206; MCCO-original: 104; MCCO-enhanced: 102	Mean age (SD), years—MCCO-original: 48.1 (9.7); MCCO-enhanced: 48.1 (9.1) Mean Incapacity Status Scale (SD)—MCCO-original: 12.3 (9.2); MCCO-enhanced: 12.7 (8.2)	Compare MCCO-original versus MCCO-enhanced	12 months	No differences in patient- or physician-reported outcomes were reported.

The Mellen Center Care Online (MCCO) secure Internet-based portal was developed in 1998 to empower patients to participate more actively in their own health care [96,97]. It is designed to help address patients' concerns, enhance communication between patients and physicians, provide links to patient information about MS symptoms, and allow patients to monitor changes in their disease status and prepare for upcoming health care visits [96,97]. The system functionality was later expanded to include a self-monitoring and self-management component that allowed patients to assess their MS symptoms and receive graphical feedback and evaluate symptom changes to make decisions about how to respond to them [97]. Apps that have been developed for disease monitoring or rehabilitation also provide patient advice and support, including the My MS Manager app [41] and Deprexis [91]. In addition, patients with life-changing illnesses (including MS) who use Web-based, quantitative, personal research platforms such as PatientsLikeMe report important benefits such as being able to learn more about their symptoms and understand potential side effects of their treatment [51].

Discussion

Summary

There has been a rapid increase in the development, testing, and use of digital and remote communication technologies in MS in recent years, with numerous studies demonstrating the value of these tools. The MS eHealth solutions identified here (Figure 2) mostly support disease monitoring, self-management, treatment, and rehabilitation. A few of these also offer patient advice and education, although apps have also been developed specifically for this. Fewer technologies address screening and remote assessment, and it may be that this area has the greatest scope for the development of new tools in the future.

Principal Findings

Of the 28 eHealth solutions discussed here, 14 are Web-based (Computerized Specific Training, CSI, Deprexis, HAT, Home eTraining, MAPSS-MS, MCCO, MSDS3D, MS-HAT, MSInvigor8, MSMonitor, MSRS-R, MySupport, and Web Based Physio), and 11 are apps (COGNI-TRAcK, MS Bioscreen, MS Buddy, MSdialog, MS Journal, MSPT, MS self, MyBETAapp, My MS Manager, SymTrac, and TaDiMuS). The remaining three use home-based technologies found in games consoles (ASSESS MS and *move II*) or specialist equipment (Remote tDCS). Apps are more represented than other platforms among solutions that relate to disease monitoring and self-management, and Web-based solutions account for more of the treatment and rehabilitation solutions than do apps. This trend probably reflects the frequency of use (and hence portability) and data burden (and therefore bandwidth) associated with different solutions.

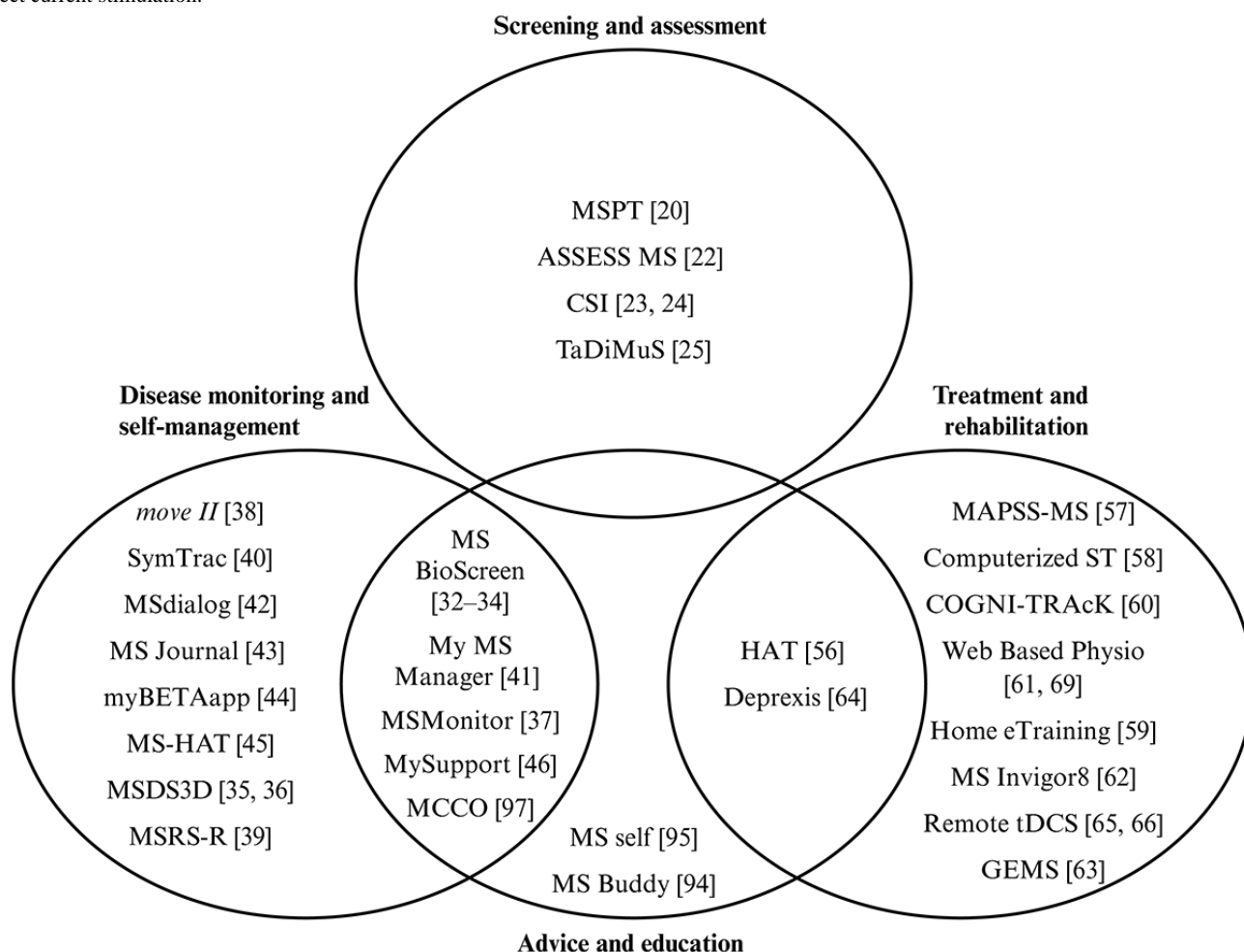
Although the development of digital and remote communication technologies is welcome, their true value can be realized only if patients and physicians jointly engage with them. Despite the

solid evidence base demonstrating the success of telephone-based interventions, many patients with MS do not receive this relatively basic therapy. Thus, it may be helpful to understand what barriers impede delivery of telephone-based rehabilitation before attempts are made to roll out more technologically advanced telehealth solutions on a large scale. It is likely that factors such as mobile Internet access, available bandwidth in remote geographical regions, and cost are all barriers to global uptake of eHealth solutions and that other factors such as availability of specialist clinicians and adaptation of established solutions to suit local situations (language and cultural and educational issues) will need to be overcome. Irrespective of the setting, it is likely that educational programs will be needed as part of training within health care systems to help clinicians understand the value that various communication technologies could bring to routine patient assessment and to ensure that any technologies that are adopted are applied with standardized methods and reporting.

Encouragingly, studies in patients with MS that have examined the use and acceptance of communication technologies suggest that adoption is unlikely to be a major issue; proportionally more patients with MS than in the general population use the Internet in the United States [98], and the majority of German patients at MS specialist centers regularly use modern communication technologies and are happy to use them to communicate with their physicians and other HCPs, including MS nurses [99]. Notably, most patients participating in the North American Research Committee on Multiple Sclerosis Registry (2011) reported that the Internet was their first source for health information [15], and studies examining the browsing habits of patients with MS show that the most-viewed topics related to *understanding the disease* and *treatments* [100]. Finally, patients express high levels of satisfaction with home telehealth monitoring [101] and have high levels of acceptance of systems such as MS-HAT [102], finding them easy to use [45].

There are aspects of these technologies with which patients are uncomfortable. Some patients were intimidated by the Nintendo Wii Fit owing to concerns about falling, and some disliked exergaming feedback because it reminded them of their impairments [103]. Furthermore, some were unsure how to use a video game [73], so appropriate training is needed. Particular challenges for those with MS using Web-based technologies include difficulties in reading website text, problems with flashing or moving objects, and operation of a mouse or keyboard because of dexterity issues [96]. Patients can also be unaware of accessibility features that facilitate navigation of websites [96]. Finally, patients may dislike interventions that are overly intrusive, and they may have concerns about security issues associated with remote transmission of personal data. This particular issue may be resolved with emerging security technologies such as Integrated Circuit Metric [104], but these will almost certainly need to be safeguarded with appropriate legislation.

Figure 2. Overview of electronic health (eHealth) technologies applied in multiple sclerosis. CSI: Cognitive Stability Index; GEMS: Guidelines for Exercise in Multiple Sclerosis; HAT: Home Automated Telemanagement; MCCO: Mellen Center Care Online; MS: multiple sclerosis; MS-HAT: Multiple Sclerosis—specific version of Home Automated Telemanagement; MSDS3D: Multiple Sclerosis Documentation System: Three-Dimensional; MSPT: Multiple Sclerosis Performance Test; MSRS-R, Multiple Sclerosis Rating Scale-Revised; TaDiMuS: Tablet-based Data capture in Multiple Sclerosis; MAPSS-MS: Memory, Attention and Problem-Solving Skills for Persons with Multiple Sclerosis; ST: specific training; and tDCS: transcranial direct current stimulation.



Digital technologies should complement but not replace face-to-face consultations and should thus be welcomed by physicians, especially if they reduce the burden on health care services. It is possible that the high volume of data that certain tools may generate could discourage their adoption clinically, and it is to be determined whether data gathered remotely provide a better picture of disease status than standard follow-up visits and whether these technologies are associated with improvements in long-term patient outcomes. Consensus about which technologies are most useful and cost-effective is lacking, and physicians may be reluctant to invest the time needed to become familiar with such tools, irrespective of any potential efficiency they offer.

In the future, digital and remote technologies may expand to other uses; for example, Web-based platforms such as PatientsLikeMe have been used to develop disease-specific instruments (ie, the MSRS-R) [39], and the Internet-based Dutch Multiple Sclerosis Study used the Internet to recruit patients, monitor symptoms, and capture long-term disease progression data in real-world settings [105]. Similarly, interactive technologies such as the Web-based patient-management system MSDS3D may become increasingly common [106]. There are

ongoing initiatives to develop transparent systems for disease monitoring and self-management in MS, such as Remote Assessment of Disease and Relapse in Central Nervous Disorders. This international research project is applying wearable devices and mobile phone technology to develop ways of measuring major depressive disorders, epilepsy, and MS [107]. There is also the MAPPING-MS initiative, a mobile health intervention that will deliver self-management strategies in patients with MS [108]. It seems likely that elements of the many different apps, Web-based tools, and remote monitoring systems that have already been adopted or are in development will become part of larger integrated systems that facilitate eHealth care conveniently for both patients and HCPs.

Conclusions

In conclusion, many digital and remote communication technology applications have been developed for patients with MS, and evidence is accumulating for the benefits some of these can bring compared with, and complementary to, traditional in-clinic approaches. Most tools focus on disease monitoring, self-management, treatment, and rehabilitation, so greater emphasis could be placed on developing tools dedicated to screening and assessment. However, irrespective of the eHealth

solution under consideration, data from large, controlled, multicenter trials are lacking (only MSInvigor8 and Deprexis were phase 2 trials), so it is difficult to draw objective conclusions about clinical benefits associated with each technology. Evaluation of eHealth solutions in phase 3 trials may be precluded by cost, in which case prospective surveys

in real-world settings [39] or large, retrospective database analyses [46] may be the most pragmatic means of evaluation. Ultimately, the long-term benefits afforded to patients and clinicians by any of these technologies will need to be established before their widespread adoption is likely.

Acknowledgments

The authors acknowledge Oxford PharmaGenesis for providing editorial and medical writing support, which was funded by Novartis Pharma AG.

Conflicts of Interest

MM has received lecture fees, travel grants, and fees for consulting from Bayer HealthCare AG, Beiersdorf AG, Biogen Idec GmbH, Merck KGaA, Novartis Pharma GmbH, Pfizer Pharma GmbH, Sanofi-Aventis (Genzyme), and Teva. GB has nothing to disclose. PF has received lecture fees from Excemed and Biogen Idec and consulting fees from Biogen Idec and Novartis. UM-L has received lecture fees and travel grants from Almirall, Bayer, Biogen Idec, Genzyme, Merck Serono, Novartis, Boehringer Ingelheim, Sanofi, and Teva. KV has received lecture fees, travel grants, and fees for consulting from Bayer Schering, Biogen Idec, Genzyme, Merck Serono, Novartis, and Teva. SGM has received honoraria for lecturing and travel expenses for attending meetings and has received financial research support from Bayer, Bayer Schering, Biogen Idec, Genzyme, Merck Serono, MSD, Novartis, Novo Nordisk, Sanofi-Aventis, Teva, and UCB.

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Abbreviations

ADL: activities of daily living
BDI: Beck Depression Inventory
BLCS: Bladder Control Scale
BWCS: Bowel Control Scale
CBT: cognitive behavioral therapy
CSI: Cognitive Stability Index
EDSS: Expanded Disability Status Scale
eHealth: electronic health
GEMS: Guidelines for Exercise in Multiple Sclerosis
HAT: Home Automated Telemanagement
HCP: health care professional
MACFIMS: Minimal Assessment of Cognitive Function in Multiple Sclerosis
MAPSS-MS: Memory, Attention and Problem-Solving Skills for Persons with Multiple Sclerosis
MCCO: Mellen Center Care Online
MS: multiple sclerosis
MSDS3D: Multiple Sclerosis Documentation System: Three-Dimensional
MS-HAT: Multiple Sclerosis—specific version of Home Automated Telemanagement
MSPT: Multiple Sclerosis Performance Test
MSRS-R: Multiple Sclerosis Rating Scale-Revised
PA: physical activity
PASAT: Paced Auditory Serial Addition Test
QoL: quality of life
RC: routine care
RRMS: relapsing-remitting multiple sclerosis
TaDiMuS: Tablet-based Data capture in Multiple Sclerosis
tDCS: transcranial direct current stimulation
3D: three-dimensional

Edited by G Eysenbach; submitted 05.04.17; peer-reviewed by R Haase, J Apolinário-Hagen; comments to author 22.07.17; revised version received 08.01.18; accepted 26.01.18; published 24.04.18.

Please cite as:

Marziniak M, Brichetto G, Feys P, Meyding-Lamadé U, Vernon K, Meuth SG
The Use of Digital and Remote Communication Technologies as a Tool for Multiple Sclerosis Management: Narrative Review
JMIR Rehabil Assist Technol 2018;5(1):e5
URL: <http://rehab.jmir.org/2018/1/e5/>
doi: [10.2196/rehab.7805](#)
PMID: [29691208](#)

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Original Paper

Understanding the Digital Gap Among US Adults With Disability: Cross-Sectional Analysis of the Health Information National Trends Survey 2013

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Abstract

Background: Disabilities affect more than 1 in 5 US adults, and those with disabilities face multiple barriers in accessing health care. A digital gap, defined as the disparity caused by differences in the ability to use advanced technologies, is assumed to be prevalent among individuals with disabilities.

Objective: This study examined the associations between disability and use of information technology (IT) in obtaining health information and between trust factors and IT use. We hypothesized that compared to US adults without disabilities, those with disabilities are less likely to refer to the internet for health information, more likely to refer to a health care provider to obtain health information, and less likely to use IT to exchange medical information with a provider. Additionally, we hypothesized that trust factors, such as trust toward health information source and willingness to exchange health information, are associated with IT use.

Methods: The primary database was the 2013 Health Information National Trends Survey 4 Cycle 3 (N=3185). Disability status, the primary study covariate, was based on 6 questions that encompassed a wide spectrum of conditions, including impairments in mobility, cognition, independent living, vision, hearing, and self-care. Study covariates included sociodemographic factors, respondents' trust toward the internet and provider as information sources, and willingness to exchange medical information via IT with providers. Study outcomes were the use of the internet as the primary health information source, use of health care providers as the primary health information source, and use of IT to exchange medical information with providers. We conducted multivariate logistic regressions to examine the association between disability and study outcomes controlling for study covariates. Multiple imputations with fully conditional specification were used to impute missing values.

Results: We found presence of any disability was associated with decreased odds (adjusted odds ratio [AOR] 0.65, 95% CI 0.43-0.98) of obtaining health information from the internet, in particular for those with vision disability (AOR 0.27, 95% CI 0.11-0.65) and those with mobility disability (AOR 0.51, 95% CI 0.30-0.88). Compared to those without disabilities, those with disabilities were significantly more likely to consult a health care provider for health information in both actual (OR 2.21, 95% CI 1.54-3.18) and hypothetical situations (OR 1.80, 95% CI 1.24-2.60). Trust toward health information from the internet (AOR 3.62, 95% CI 2.07-6.33), and willingness to exchange via IT medical information with a provider (AOR 1.88, 95% CI 1.57-2.24) were significant predictors for seeking and exchanging such information, respectively.

Conclusions: A potential digital gap may exist among US adults with disabilities in terms of their recent use of the internet for health information. Trust toward health information sources and willingness play an important role in people's engagement in use of the internet for health information. Future studies should focus on addressing trust factors associated with IT use and developing tools to improve access to care for those with disabilities.

(*JMIR Rehabil Assist Technol* 2018;5(1):e3) doi:[10.2196/rehab.8783](https://doi.org/10.2196/rehab.8783)

KEYWORDS

disability; health information; Internet; health care provider; trust; psychosocial factors

Introduction

Disability is a common condition in the United States [1]. According to recent data from the Behavioral Risk Factor Surveillance System (BRFSS 2013), more than 1 in 5 adults (22.2%) reported having disability [1]. Risk of disability increases with age, and the number of individuals with disabilities will likely rise as the elderly population continues to grow. Those with disabilities have been shown in previous studies to have a higher demand for health information but often experience a lack of such information compared to those without disabilities [2].

The internet has the potential to bridge disparities in obtaining health information. Americans widely use the internet to obtain health information [3,4]. Internet use, in terms of obtaining health information and exchanging medical information, has shown to improve health outcomes and lower health care costs [5-11]. Rapid advancements in information technology (IT) and increasing ownership of mobile devices make electronic health information more easily accessible. For those with physical and sensory impairments, the internet and IT have created potential opportunities to offer health information that can be accessed by those with disabilities [3,12-18].

Despite these advancements, those with disabilities experience a digital gap, defined as a disparity caused by differences in the ability to use advanced technologies [19]. The gap is partially explained by the higher proportion of people with disabilities having characteristics associated with lower use of the internet to obtain health information compared to people without disabilities; they tend to be older in age, unemployed, less educated, and have low income [20-28]. Additionally, studies show an association between psychosocial factors associated with the digital gap [4,29]. However, there is a lack of research examining an association between trust factors, specifically trust toward a health information source and willingness to exchange medical information, associated with the digital gap among people with disabilities at a national level.

For this study, we used recent data from the National Cancer Institute's Health Information National Trends Survey (HINTS) to explore the association between (1) disability and use of the internet as the primary information source and (2) disability and IT to exchange medical information with a health care provider. Next, we examined the association by specific disability conditions and then studied trust factors associated with the internet and IT use. We hypothesized that US adults with disabilities are less likely to use the internet for health information, more likely to use a health care provider for health

information, and less likely to use IT to exchange medical information with a provider compared to those without disabilities. We also hypothesize that trust factors such as trust toward a health information source and willingness to exchange health information with a health care provider are associated with the utilization.

Methods

Study Sample

We used data from HINTS 4, Cycle 3 (2013) [30]. HINTS is a nationally representative mail survey that contains questions about health information seeking behaviors and health information sources. The sample design for this survey consisted of 2 stages: a stratified sample of household addresses was first selected from a residential file, and then 1 adult in the household was identified to complete the survey. The survey was mailed in 2 versions (English and Spanish), with the majority of the responses collected from the English version (94.7%) [30]. The unweighted sample size for HINTS 4 Cycle 3 was 3185. Due to the skip pattern in the survey instrument, the study sample for the first 2 hypotheses only included those who had ever sought health-related information (N=2508). For the third hypothesis, all respondents were included in the analyses (N=3185).

Main Outcome

Main outcomes of this study were defined by 3 questions: "The most recent time you looked for information about health or medical topics, where did you go first?" (HINTS A2); "Imagine that you had a strong need to get information about health or medical topics. Where would you go first?" (HINTS A8); and "In the past 12 months, have you used any of the following to exchange medical information with a health care professional?" (HINTS B6).

Specifically, hypotheses 1 and 2 examined sources of health information reported by respondents. In the survey, a list of common health information sources was provided, including health care provider, internet, family, etc. These sources were exclusive and respondents were asked to identify only one. For the purpose of this study, we focused on internet and health care provider. In addition, the survey also differentiated actual use, defined as the primary health information source that they had used recently (HINTS A2), and hypothetical use, defined as the source that they would use to obtain health information when there is a strong need for such information (HINTS A8). In this study, we examined both actual use and hypothetical use of internet and health care provider as health information sources.

Hypothesis 3 looked at exchanging health information via IT. Respondents of the survey were asked to identify the routes they had used to exchange medical information with their health care providers (HINTS B6). We defined IT use as exchanging medical information with health care professionals via any of the following: email, text message, app on a smartphone or mobile device, video conference, or social media.

Disability Measure

The survey included questions recommended by the US Department of Health and Human Services to measure disability in 6 domains: hearing (deaf or serious difficulty in hearing), vision (blind or serious difficulty in seeing even with glasses), cognition (serious difficulty concentrating, remembering, or making decisions because of a physical, mental, or emotional condition), mobility (serious difficulty walking or climbing stairs), self-care (difficulty dressing or bathing), and independent living (difficulty doing errands alone because of a physical, mental, or emotional condition) [31]. This classification aligns with the comprehensive measures for defining disabilities in the World Health Organization's International Classification of Function, Disability, and Health [32] and emphasizes the impact of the disabilities on functional limitations. Having one or any combination of these conditions was classified as "any disability."

Trust Factors

We evaluated participants' trust toward various health information sources for hypotheses 1 and 2 and willingness to exchange medical information with providers for hypothesis 3. We dichotomized participants' trust toward getting health information from the internet, health care providers, family, or friends to "a lot" versus "some/little/not at all," which respectively captured higher and lower levels of trust [33]. For the willingness to electronically exchange medical information, we assigned a score of 1 ("not at all") to 4 ("a lot") for each category of medical information and calculated the average willingness score for each respondent.

Covariates

We also controlled for several factors known for their association with use of health information sources: gender, age, marital status, race/ethnicity, education, insurance status, annual income level, designated regular provider, mobile device ownership, self-rated health status, respondents' perceptions of the importance of the patient accessing medical information electronically, and existence of an electronic medical record system [34]. The response to the question, "Overall, how confident are you that you could get advice or information about health or medical topics if you needed it?" (HINTS A6), was used as a proxy for health literacy with respect to the ability to obtain health information [35].

Statistical Analysis

We used multiple imputation with fully conditional specification to impute all variables with missing values in our statistical model. The imputation model for race/ethnicity included strong predictors of this variable: survey language (English or Spanish), Hispanic household stratum, birthplace (United States or foreign born), income level, and English proficiency. For other

variables, imputation models included all variables in this study. Our implementation of the fully conditional specification approach incorporated sample weights and design effects in the imputation to account for the complex sample design [36]. We generated 10 imputed datasets for subsequent analysis. The results of all of our analytic models were computed using standard methods for combining model estimates and standard errors across the multiple imputed data sets.

We assessed sample characteristics of the entire study sample and by disability status. Unweighted frequencies and weighted percentages were presented. We examined the difference between any disability and no disability for each sample characteristic using chi-square tests with Rao-Scott correction for categorical variables and *t* tests for continuous variables and reported the corresponding *P* values.

We conducted logistic regressions to examine the association between each sample characteristic with the outcomes. We evaluated 2-way interactions between disability status and sample characteristics. Because none of these 2-way interactions were statistically significant, we only included main effects in the final model. To examine our hypotheses, we performed multivariable logistic regression adjusting for relevant covariates, and as noted above, compiled the results across imputed datasets. We reported the range of *c*-statistics from the 10 models with imputed values for each outcome to evaluate the goodness of fit. Furthermore, to examine the potential heterogeneity within the disability group created by its composite measure, we conducted multivariable logistic regression for each of the 6 disability subgroups controlling for the same covariates. The reference group for each disability type comprised those without any type of disability. Data were weighted using jackknife variance estimation with 50 replicate weights to produce a sample representative of 235 million US adults [30].

Statistical analyses were conducted in SAS 9.4 (SAS Institute Inc). The Boston University Institutional Review Board approved this study.

Results

Sample Characteristics

Of the total sample, 19.6% (796/3185) reported any type of disability (Table 1). Approximately two-thirds (473/796, 66.7%) of those with disability rated their general health as excellent, very good, or good, which was significantly lower than those without disability (2086/2274, 90.9%). Among those with disabilities, difficulty with cognition was the most prevalent (310/796, 49.1%), followed by mobility (459/796, 48.6%) and hearing (242/796, 29.9%) (Multimedia Appendix 1). Compared to the no-disability group, those with disabilities had a significantly higher proportion (with disability, 351/796, 34.3%; without disability, 523/2274, 12.6%) of individuals aged 65 years or older ($P<.001$). Higher proportions of people with disabilities were single ($P<.001$) and had low household income ($P<.001$), low health literacy ($P=.02$), and low levels of education ($P<.001$) compared to those without disabilities. Overall, more than half of the sample (1794/3185, 55.5%) had

high confidence in obtaining health information, a proxy for higher health literacy.

Next, we examined characteristics associated with electronic health information communication between those with and without disability (Table 2). Overall, more than one-third (986/3185, 36.4%) of the study participants reported not having a regular health care provider; the majority (2721/3185, 87.7%) of respondents reported their providers maintained health records in a computerized system. Results suggest the use of an electronic medical record system by the health care providers to exchange medical information was independent of disability status (with disability, 697/796, 89.0%; without disability, 2024/2274, 87.2%; $P=.47$). The majority of the study sample (2754/3185, 91.7%) owned 1 or multiple electronic mobile devices (with disability, 622/796, 82.5% without disability, 2132/2274, 94.1%; $P<.001$). A smaller percentage of those with disabilities rated the high importance of electronically accessing their own medical information (with disability, 454/796, 58.2%; without disability, 1493/2274, 66.5%, $P<.001$).

Seeking Health Information

In the study sample, 69.4% (1334/2508) reported using the internet in their most recent search for health information; a smaller percentage (969/2508, 46.6%) of respondents reported referring to the internet as their first choice when there was a strong need for health information. In bivariate analysis, those with disabilities, compared to those without disabilities, were significantly less likely to use the internet as the source for health information in both actual (odds ratio [OR] 0.32, 95% CI 0.24-0.45) and hypothetical situations (OR 0.42, 95% CI 0.29-0.60). Only 13.6% (362/2508) of all respondents reported high trust toward the health information from the internet, and there was no difference in trust between those with and without disabilities ($P=.54$).

Adjusting for other covariates, those with disabilities remained significantly less likely to use the internet in their most recent search for health information (adjusted OR [AOR] 0.65, 95% CI 0.43-0.98) but not in their proposed hypothetical use (AOR 0.66, 95% CI 0.41-1.06). Those with a higher level of trust toward the internet were 3.62 times and 2.53 times more likely to use it in actual and hypothetical searches for health information, respectively, compared to respondents with lower trust (Table 3).

Subgroup analyses were performed to identify specific disability conditions associated with lower internet use in the most recent search for health information (Table 4). Compared to those without any disability and controlling for other covariates, those with impairment in vision (AOR 0.27, 95% CI 0.11-0.65) and

mobility (AOR 0.51, 95% CI 0.30-0.88) were less likely to have used the internet in their last search for health information.

Seeking Health Information From a Health Care Provider

The majority of the respondents (1733/2508, 70.1%) indicated a high level of trust for a health care provider as their primary information source. When respondents have a strong need for health information, 45.1% (1173/2508) responded that they would turn to a doctor or health care provider, which was nearly 3-fold the proportion of those who reported actually using a health care provider as the information source (408/2508, 14.8%). Compared to those without disabilities, those with disabilities were significantly more likely to consult a health care provider for health information, in both actual (OR 2.21, 95% CI 1.54-3.18) and hypothetical situations (OR 1.80, 95% CI 1.24-2.60). This significant association shown in the bivariate analysis between disability status and seeking health information from a provider was no longer statistically significant when controlling for other covariates (Table 3).

High trust for providers was a significant factor in seeking health information from a provider when the patient had strong needs; those who had high trust toward a provider (AOR 2.26, 95% CI 1.71-2.99) were more likely to seek health information from a provider. On the other hand, those with higher trust for health information online were significantly less likely to use a provider as either the actual (AOR 0.38, 95% CI 0.19-0.78) or hypothetical source (AOR 0.47, 95% CI 0.32-0.69) of health information compared to respondents with a lower level of trust, when adjusting for other covariates.

Exchanging Health Information via Information Technology With a Health Care Provider

Those without disabilities indicated they were statistically significantly more willing to exchange health information via IT (mean willingness score 2.62, SD 0.03) compared to those with disabilities (mean willingness score 2.39, SD 0.07; $P<.01$) (Table 2). Willingness to share health information (AOR 1.88, 95% CI 1.57-2.24) was significantly associated with exchanging medical information with a health care provider via IT. Contrary to our hypothesis, there was no association between medical information exchange via IT and the disability condition (OR 0.76, 95% CI 0.53-1.09; AOR 1.37, 95% CI 0.92-2.04). This finding persisted in analyses with all 6 disability conditions. For those with disability in vision, they were shown to have marginally significant higher likelihood (AOR 1.55, 95% CI 0.99-2.43) of exchanging medical information via IT with health care providers (Table 4).

Table 1. Sociodemographic characteristics of the study sample.

Characteristic	Total (n=3185), % ^a	Any disability (n=796), % ^a	No disability (n=2274), % ^a	P value ^b
General health				
Excellent, very good, or good	86.1	66.7	90.9	<.001
Fair or poor	13.9	33.3	9.1	—
Gender				
Male	48.4	46.3	49.2	.43
Female	51.6	53.7	50.9	—
Age group, years				
Younger than 65	82.8	65.7	87.4	<.001
65 or older	17.2	34.3	12.6	—
Marital status				
Married or living as married	58.8	47.0	61.8	<.001
Single ^c	41.2	53.0	38.2	—
Race/ethnicity				
Non-Hispanic white	66.9	63.7	68.1	<.001
Hispanic	15.4	15.7	14.7	—
Non-Hispanic black or African American	10.5	16.4	9.3	—
Non-Hispanic Asian	5.1	2.7	5.6	—
Other	2.1	1.5	2.3	—
Education				
Less or complete high school	34.1	50.0	29.4	<.001
Some college	32.7	33.0	32.8	—
College graduate	33.2	17.0	37.7	—
Health literacy				
High	55.5	49.8	57.3	0.02
Low	44.5	50.2	42.7	—
Insurance				
Have insurance	83.0	83.2	82.6	—
No insurance	17.0	16.8	17.4	0.85
Income^d				
Less than \$20,000	20.9	40.9	15.9	<.001
\$20,000 to \$34,999	14.3	16.4	13.8	—
\$35,000 to \$49,999	14.6	14.5	14.6	—
\$50,000 to \$74,999	17.7	12.2	19.1	—
\$75,000 or more	32.6	16.0	36.7	—

^aWeighted percentage. Missing value was excluded.

^bRao-Scott chi-square test. Missing value was excluded.

^cSingle included divorced, widowed, separated, single, or never been married.

^dAll monetary values presented in USD.

Table 2. Characteristics associated with electronic health information communication.

Characteristic	Total ^a (n=3185)	Any disability ^a (n=796)	No disability ^a (n=2274)	P value ^b
Regular provider, %				
Yes	63.6	71.2	61.7	.003
No	36.4	28.8	38.3	—
Electronic medical record use by health care provider, %				
Yes	87.7	89.0	87.2	.47
No	12.3	11.0	12.8	—
Mobile device, %				
Have one or more than 1 electronic mobile device (eg, mobile phone)	91.7	82.5	94.1	<.001
No mobile device	8.3	17.5	5.9	—
Importance of patient accessing medical information electronically, %				
Very important	64.9	58.2	66.5	.009
Somewhat/not at all important	35.1	41.8	33.5	—
Willingness to exchange medical information with provider, mean (SD)	2.57 (0.03)	2.39 (0.07)	2.62 (0.03)	<.001

^aWeighted percentage. Missing value was excluded.

^bRao-Scott chi-square test for categorical variables and *t* test for continuous variables. Missing value was excluded.

Table 3. Predictors of seeking information from health care provider and internet as health information source.

Predictors	Internet						Provider					
	As actual source ^{a,b}			As hypothetical source ^{b,c}			As actual source ^{a,b}			As hypothetical source ^{b,c}		
	AOR ^d	95% CI	P	AOR ^d	95% CI	P	AOR ^d	95% CI	P	AOR ^d	95% CI	P
Disability (ref: no disability)	0.65	0.43-0.98	.048	0.66	0.41-1.06	—	1.24	0.76-2.04	—	1.25	0.77-2.03	—
Aged 65 years or older (ref: younger than 65 years)	0.30	0.21-0.45	<.001	0.45	0.30-0.68	<.001	2.07	1.36-3.14	<.001	1.88	1.28-2.75	<.001
High trust (ref: low trust) with information from												
Internet	3.62	2.07-6.33	<.001	2.53	1.63-3.92	<.001	0.38	0.19-0.78	<.001	0.47	0.32-0.69	<.001
Provider	1.23	0.82-1.84	—	0.54	0.40-0.71	.001	1.50	0.93-2.40	—	2.26	1.71-2.99	<.001
Family and friends	0.38	0.20-0.70	.003	0.74	0.40-1.36	—	1.41	0.62-3.21	—	0.88	0.49-1.57	—
High health literacy (ref: low health literacy)	0.71	0.48-1.06	—	1.31	0.94-1.83	—	1.47	0.87-2.49	—	0.84	0.59-1.18	—

^aStudy outcome actual source (provider and internet) for health information was measured by HINTS A2.

^bc-statistic was used to evaluate the goodness of fit of the models. We reported the range of c-statistics for each set of the models using 10 imputed datasets: (1) internet as the actual source: 0.788-0.804; (2) internet as the hypothetical source: 0.729-0.743; (3) provider as the actual source: 0.721-0.751; (4) provider as the hypothetical source: 0.685-0.696.

^cStudy outcome hypothetical source (provider and internet) for health information was measured by HINTS A8.

^dAOR (adjusted odds ratios): logistic regression model adjusted for gender, age group, marital status, education, perception on the importance of patient accessing personal health record, income, health insurance, having a regular provider, owning any mobile device, general health status, and electronic medical record system.

Table 4. Association between disability types and use of health information.

Type of disability	Seeking information from internet as actual source			Seeking information from provider as actual source			Exchanging health information with provider		
	AOR ^a	95% CI	P value	AOR ^a	95% CI	P value	AOR ^a	95% CI	P value
Hearing	0.58	0.32-1.06	—	1.75	0.78-3.90	—	1.09	0.76-1.56	—
Vision	0.27	0.11-0.65	.003	1.62	0.51-5.10	—	1.55	0.99-2.43	—
Cognition	0.69	0.37-1.27	—	1.21	0.58-2.52	—	1.15	0.89-1.48	—
Mobility	0.51	0.30-0.88	.02	1.60	0.89-2.85	—	1.16	0.87-1.53	—
Self-care	0.46	0.17-1.27	—	2.50	0.80-7.86	—	1.27	0.77-2.10	—
Independent living	0.55	0.25-1.25	—	1.67	0.67-4.14	—	1.47	0.94-2.29	—

^aAOR (adjusted odds ratios): logistic regression model for each disability subgroup, with reference group as participants without any disability, adjusted for gender, age group, marital status, education, health literacy, trust toward information sources (provider, family and friends, internet, media, government health agencies, charitable or religious organizations), perception on the importance of patient accessing personal health record, income, health insurance, having a regular provider, owning any mobile device, general health status, and electronic medical record system.

Discussion

Principal Findings

This study analyzed nationally representative survey data on the association between disability and the use of the internet for health information and the use of IT to exchange information with a medical provider. Findings suggested a potential digital gap existed among adults with disabilities in using the internet to obtain health information, in particular for those with vision and mobility problems, but not in using IT to exchange medical information with a provider.

We also found associations between trust factors and health information obtaining behaviors. Those with a higher level of trust toward the internet for health information were significantly more likely to refer to the internet for health information compared to their counterparts in both their recent search and hypothetical scenarios. In addition, our study suggests that those who were more willing to exchange medical information via IT with provider were significantly more likely to do so compared to their counterparts. There was a significant difference in willingness to exchange medical information between those with and without disability, but the clinical significance of this difference is unclear. However, these results were consistent with previous research, indicating that psychosocial factors such as trust toward certain sources of health information and willingness to share medical information with a provider were significant predictors for actual use [37]. The trust factors represent potential areas for intervention to bridge the digital gap. Trust is a complex attitude that may encompass prior experiences with their providers and health care system. Improving the validity of websites through accredited and certified professional organizations along with enhancements to the comprehensibility of content might contribute to building trust toward health information online for those with disabilities [37].

In this study, we identified that disability conditions, specifically those affecting vision and mobility, were associated with decreased internet use to obtain health information. Implementing user interface incorporating features to enlarge font sizes and handy navigating tools may improve readability,

build trust, and eventually improve the use of internet for health care services among adults with disabilities [37-39]. This also applies to the willingness to exchange medical information with a health care provider via IT. Having a reliable and user-friendly platform to exchange such information may help increase patients' willingness to engage in exchanging health information with a provider. Future studies should evaluate the specific needs of those with disabilities and incorporate such needs in the design of websites in order to allow those with disabilities to obtain and exchange the relevant health information as conveniently as possible.

Another noticeable finding was that there were more individuals who reported they had used the internet to obtain health information in recent search than in hypothetical scenarios. We conducted subsequent analysis to examine the association between disability status and this observed discrepancy through logistic regression adjusting for the same covariates described earlier in this paper. Disability status was not significantly associated with this discrepancy, nor were the other covariates. The survey question for hypothetical scenario emphasized the strong need for health information, whereas such need was not specified in the actual scenario, which may contribute to the difference in measuring the 2 distinct outcomes. But more importantly, this observed discrepancy may reflect known barriers for patients to access a health care provider outside of the scope of this study [40,41]. Thus, people turned to the more readily available internet.

Limitations

There are several limitations with this study. Because this is a retrospective cross-sectional study, a causal relationship cannot be established between disability status and study outcomes. Due to the nature of the secondary data, not all variables of interest were available for the analyses. For example, factors such as social support that could substantially impact the individual's activity and societal participation were not available. Also, although the survey was designed to capture nationally representative data, certain selection bias and nonresponse bias cannot be ruled out. The overall survey response rate was relatively poor (35.2%), and the majority of the survey respondents completed the survey in English (94.7%)

[30]. In addition, misclassifications of information sources due to the recall bias could potentially exist. Last, disability status was self-reported, which could affect the validity of the measure. There is limited information about whether respondents, especially those with disability, had used proxy respondents to help complete the survey. The weighted percentages of all 6 domains of disability were comparatively lower than the national estimates [1], suggesting a potential underrepresentation of the disability community.

Conclusion

We found a potential digital gap among US adults with disabilities in terms of their recent use of the internet for health information but not in their IT use to exchange medical

information with a provider. Also, we found trust toward health information source and willingness to exchange medical information with a health care provider were associated with the health information seeking behavior. This study contributes to the understanding of the disparities in accessing health information today among US adults with disability using a nationally representative survey. Future work should evaluate the potential for enhancing exchanges between those with disabilities and their providers through referrals to well-established and high-quality websites. Additionally, studies should focus on developing specific tools to improve access and develop trust with these sources to bridge the digital gap among those with disabilities.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Distribution of disabilities.

[PDF File (Adobe PDF File), 30KB - [rehab_v5i1e3_app1.pdf](#)]

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Abbreviations

AOR: adjusted odds ratio

HINTS: Health Information National Trends Survey

IT: information technology

OR: odds ratio

Edited by G Eysenbach; submitted 18.08.17; peer-reviewed by E Hahn, E Agree; comments to author 14.10.17; revised version received 02.01.18; accepted 06.01.18; published 16.03.18.

Please cite as:

Kim EJ, Yuan Y, Liebschutz J, Cabral H, Kazis L

Understanding the Digital Gap Among US Adults With Disability: Cross-Sectional Analysis of the Health Information National Trends Survey 2013

JMIR Rehabil Assist Technol 2018;5(1):e3

URL: <http://rehab.jmir.org/2018/1/e3/>

doi: [10.2196/rehab.8783](https://doi.org/10.2196/rehab.8783)

PMID: [29549074](https://pubmed.ncbi.nlm.nih.gov/29549074/)

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Original Paper

Exercise Therapy Interventions in Patients With Hip Osteoarthritis: Comparison of the Effects of DVD and Website-Based Interventions

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Abstract

Background: Prevalence of developmental hip dysplasia is high in Japan. Exercise therapy has been proven effective to treat certain aspects of hip osteoarthritis. Moreover, therapy provided via digital video discs (DVDs) and websites allows patients to exercise in the comfort of their own homes. However, no studies have evaluated the effectiveness of visual instructions in patients with hip disorders.

Objective: This study aimed to compare the effectiveness of exercise therapy administered via DVD and that administered via a website.

Methods: We developed a six-step progressive exercise therapy program for patients with hip osteoarthritis, which included three kinds each of open kinetic chain and closed kinetic chain exercises. Once the program was developed, exercise DVDs were produced. In addition to the six-step exercise program, our website was enabled to count the number of exercises performed by each patient and was accessible via the Internet at any time. Patients with hip osteoarthritis for whom surgery was not advised were enrolled by one university hospital in the Kansai area in Japan. Clinical symptoms and hip function were quantified using the Japanese Orthopedic Association Hip Disease Evaluation Questionnaire (JHEQ) and the Oxford Hip Score (OHS). Quality of life was measured using the SF-8 Health Survey, and self-efficacy for continued exercise was measured using the General Self-Efficacy Scale (GSES). Questionnaires were completed preintervention and after 6 months.

Results: At 6-month follow-up, 10 DVD users (1 male, 9 female; mean age 51.3, SD 16.1 years) and 18 website users (2 male, 16 female; mean age 52.4, SD 10.4 years) were reachable. The change in each parameter could not be confirmed a significant improvement. However, most items tended to reflect overall improvement during the 6 months of intervention ($P=.05-.94$; paired t test). Regarding effect size, we considered a small effect to be greater than 0.2. Little effect was observed for JHEQ pain, SF-8 physical component summary (PCS), and SF-8 mental component summary in the DVD group, as well as OHS, SF-8 (PCS), and GSES in the website group.

Conclusions: When comparing the effectiveness of exercise therapy between our DVD and website, we found that although both groups tended to improve in physical function, only the website group showed tendency of enhanced self-efficacy.

KEYWORDS

hip osteoarthritis; exercise; DVD; website; self-efficacy

Introduction

Many people needing care in daily life have low activity levels due to decreased musculoskeletal function [1]. Hip and knee osteoarthritis are the major causes of decreased physical function in this population. Prevalence of developmental dysplasia of the hip is high in Japan, and morbidity associated with hip osteoarthritis has been reported to be 1.0% to 4.3% [2]. It is estimated that these figures will continue to rise as the aging population grows.

Conservative methods to treat hip osteoarthritis include pharmaceutical treatment, exercise therapy, thermotherapy, and surgeries such as osteotomy and arthroplasty, depending on a patient's general condition and progress in the alleviation of symptoms [3]. Among the conservative treatments, exercise therapy has the advantage of fewer adverse effects on internal organs, it can be practiced anywhere, and at little cost [4]. Moreover, exercise therapy in a patient's home is effective for gait ability and activities of daily living owing to improvement in joint stability, muscle strength, and range of motion [5]. Previous studies have demonstrated that hip osteoarthritis patients can experience improvements in their pain and physical function through exercise therapy [6-8], and that this therapy is more effective when it is conducted in a patient's home rather than at a hospital [9]. Therefore, it is important to provide an effective home-exercise program that can be easily understood, that can be performed at home by patients, and that is adaptable to their individual symptoms.

In recent years, visual instruction using digital video discs (DVDs) has been used to promote continued exercise in patients with knee osteoarthritis [10] and disuse syndrome [11]. Exercise therapy via DVDs and websites allows patients to exercise while watching video exercise demonstrations in the convenience of their own homes. However, DVD exercise programs can only be utilized with the delivery of a copied DVD to the patients. On the other hand, websites allow patients wider access to up-to-date exercise programs via the Internet and provide additional information via interactive communication, despite concerns regarding affinity to the Internet in older patients. Moreover, to our knowledge there are no studies that have evaluated the effectiveness of exercise videos in patients with hip disorder.

We developed a video exercise program and provided it through both a DVD and a website. Therefore, the purpose of this study was to compare the effectiveness of these modes of exercise therapy.

Methods

Developing the Exercise Program and Intervention Tool

As an intervention tool, we developed a six-step progressive exercise therapy program for patients with hip osteoarthritis. The program is a modification of an exercise program conceived by Conn et al [12] and Imada et al [13]. On developing the exercise program, the contents were tested by a team of three orthopedic surgeons specializing in lower extremity joints, two physical therapists providing rehabilitation exercise training for hip osteoarthritis patients, and one orthopedic research nurse. The program was finalized by confirming whether patients who were undergoing treatment for hip osteoarthritis were able to do the exercises.

The six steps in the program consisted of three levels of both open kinetic chain (OKC) and closed kinetic chain (CKC) exercises. An OKC exercise refers to an exercise done while the limbs are free, and a CKC exercise is performed while limbs are on the floor. Both OKC and CKC exercises are considered to be most effective when done in combination [14]. The OKC exercises included hip contraction, hip abduction, hip external rotation, and side-lying hip abduction. The CKC exercises, performed with the patient standing, included hip contraction with hands placed on a table, adductor contraction using a ball, and knee flexion. The exercise menu was designed so that patients could reach final step (step 6) in a minimum of 3 months by advancing to new steps for both OKC and CKC exercises every 2 weeks, with 30 to 40 minutes of exercise a day (Figure 1).

Once the program was developed, a professional company produced the exercise DVD, which included easily comprehensible pictures and videos accompanied by relaxing music. The DVD instructed the user about the number of times each exercise should be performed to promote exercise continuity. Some exercises for adductor muscles required a ball, which was provided to the patients along with the DVD. We also constructed a website including the same exercise program as that on the DVD. In addition, this platform had the facility to count the repetitions of exercises performed by the patients, and was accessible to the patients via the Internet at any time. Moreover, the program allowed patients to record their pain levels by using the Numerical Rating Scale (NRS): ranging from zero for no pain to 10 for severe pain. We also developed a platform for counting exercise repetitions and for recording any comments. In addition, website group patients were provided with an exercise ball along with information about the website.

For both the DVD and website programs, we asked the patients to begin their regimens at an appropriate level. We recommended that participants only advance one step on either set every 2 weeks (Figure 1). If the exercise menu was not

completed due to pain, we recommended that the patients discontinue the exercise for a couple of days and resume exercising after pain relief, with extension of the step for more than 2 weeks. After reaching the final step (step 6), we suggested that the patients continue the exercise at the step 6 level.

Participants and Measurements

Patients with hip osteoarthritis were recruited into the study when surgery was not advised because of their levels of pain, activity impediments, and results of X-rays, or patients did not wish to receive surgery in the orthopedic outpatient facility of one university hospital in the Kansai area in Japan. From June 2011 to April 2012, we asked 24 patients; 17 patients who could use a DVD player were enrolled into the DVD study. From July 2014 to April 2015, we asked 40 patients, and 29 patients who had accessibility to the Internet were enrolled into the website study. The intervention times of the two groups were different because we confirmed the effect of the DVD first and then developed the website system in expectation of widespread use of exercise videos among patients.

Clinical symptoms and hip function were quantified using the Japanese Orthopedic Association Hip Disease Evaluation Questionnaire (JHEQ) [15] and the Oxford Hip Score (OHS) [16]. General quality of life (QOL) was measured by the SF-8 Health Survey [17] and self-directed continued exercise was measured using the General Self-Efficacy Scale (GSES) [18]. The exercise count for Web intervention users was recorded on the website.

Questionnaires were completed in an outpatient orthopedic setting before the intervention and after 6 months on the program. The questionnaires were provided in paper form for both groups of participants. We mailed the questionnaire to the

homes of those patients who did not consult a doctor at the appropriate time.

Measurement

The JHEQ, a useful, statistically reliable, and valid tool to evaluate patients with hip arthritis in Japan, is comprised of three categories—pain, movement, and mental. Each category consists of seven items, for a total of 21 items, which are used as evaluation criteria for hip joint function. Scores can range from zero to 28 points, with higher scores reflecting fewer symptoms and better functioning [15].

The OHS, a health-related QOL scale for hip arthritis patients, consists of 12 items, with higher scores reflecting better functioning and less pain. The scores can range from zero to 48 [16,19,20]. The reliability and validity of the OHS have been confirmed by a prospective study [21].

The SF-8 Health Survey is a generic, eight-item assessment that generates a health profile consisting of a physical component summary (PCS) and a mental component summary (MCS). The average value is 50 points, with higher scores indicating better functioning [22].

The GSES is a 16-item questionnaire measuring self-efficacy. The total score ranges from zero to 16 points, with higher scores indicating higher self-efficacy. Self-efficacy describes the belief that a person is capable of conducting their own actions independently. A number of literature reviews have examined the relationship between patient education and self-efficacy, suggesting that patient education increases self-efficacy and improves patients’ management skills [18,23,24]. At the end of this questionnaire, we provided recording space for patients to comment on their intervention.

Figure 1. Model exercise program.

	Step1	Step2	Step3	Step4	Step5	Step6
Term	First 2 weeks	3-4 weeks	5-6 weeks	7-8 weeks	9-10 weeks	11-12 weeks
Exercise menu	stretch	stretch	stretch	stretch	stretch	stretch
	OKC1	OKC1	OKC2	OKC2	OKC3	OKC3
		CKC1	CKC1	CKC2	CKC2	CKC3

OKC: Open-Kinetic-Chain, CKC: Closed-Kinetic-Chain

Targeted Muscle

OKC1: Gluteus maximus muscle, Gluteus medius, Adductors
 OKC2: Gluteus maximus muscle, Gluteus medius, Adductors
 OKC3: Gluteus maximus muscle, Gluteus medius, Adductors, iliopsoas
 CKC1: Gluteus maximus muscle, Gluteus medius, Adductors
 CKC2: Gluteus maximus muscle, Gluteus medius, Adductors
 CKC3: Gluteus maximus muscle, Gluteus medius, Adductors, Quadriceps

Figure1. Model exercise program

Intervention

The exercise menu was designed so that patients could reach the final step in a minimum of 3 months; however, patients were advised to discontinue the exercise for a couple of days when they felt remarkable pain, and continue the exercise program past 3 months.

We recommended that the exercises be carried out daily by providing the patients with a model exercise schedule. However, we also considered the pain and fatigue of the patient. We asked participants to schedule their exercise according to their physical condition and to take a break when they experienced pain. After reaching final step 6, the patients were asked to continue exercising at the step 6 level.

We also confirmed the difference between QOL and self-efficacy scores between preintervention and after 6 months for both the DVD and website groups considering effective period. Similarly, another study reported the effect of exercise intervention after 6 months [25].

Ethical Considerations

Patients were informed that participation was voluntary, that they would not be treated unfavorably if they declined, that consent could be retracted at any time during the study, and that the research data would be coded to ensure confidentiality and privacy. We assigned an ID and password to each patient to protect their information on the website. The study was approved by the ethics committee of Kobe University Graduate School

of Health Sciences. All participants provided written informed consent.

Statistical Analysis

We compared the difference in mean data for both the DVD and website groups between preintervention and postintervention (paired *t* test). We also compared the difference in effect between the two groups. The effect size was calculated by dividing the difference in mean data by standard deviation.

Results

A total of 17 eligible patients were enrolled in the DVD group, and 29 were enrolled in the website group. At the 6-month follow-up, seven patients in the DVD group (one male and six female; mean age 44.9, SD 13.9 years) did not respond to the mailed questionnaires. In the website group, two patients dropped out due to intolerable pain during exercise, and nine patients did not respond to the mailed questionnaires. Of the 11 patients who dropped out, one was male and 10 were female (mean age 38.2, SD 14.1 years). Therefore, 10 patients from the DVD group and 18 patients from the website group were included in our final analysis. Table 1 presents the characteristics of the 10 patients from the DVD group (1 male, 9 female; mean age 51.3, SD 16.1 years) and the 18 patients from the website group (2 male, 16 female; mean age 52.4, SD 10.4 years). Nonrespondents in the website group were younger than the respondents ($P=.02$).

Table 1. Characteristics of respondents and nonrespondents.

Characteristics	Respondents (n=28)	Nonrespondents (n=18)	<i>P</i> value ^a
DVD group, n	10	7	N/A ^b
Age (years)			
Mean (SD)	51.3 (16.1)	44.9 (13.9)	.73
Range	29-77	26-66	N/A
Sex, n (%)			
Male	1 (10.0)	1 (14.3)	N/A
Female	9 (90.0)	6 (85.7)	N/A
BMI (kg/m ²), mean (SD)	22.4 (3.1)	22.1 (3.5)	.96
Website group, n	18	11	N/A
Age (years)			
Mean (SD)	52.4 (10.4)	38.2 (14.1)	.02
Range	25-69	20-57	N/A
Sex, n (%)			
Male	2 (11.1)	1 (9.1)	N/A
Female	16 (88.9)	10 (90.9)	N/A
BMI (kg/m ²), mean (SD)	22.0 (3.0)	24.0 (10.0)	.70

^aMann-Whitney *U* test.

^bN/A: not applicable.

Table 2. Scores of Japanese Orthopedic Association Hip Disease Evaluation Questionnaire (JHEQ), Oxford Hip Score (OHS), SF-8 Health Survey, and General Self-Efficacy Scale (GSES) for preintervention (pre) and after 6 months (post) in the digital video disc (DVD) and website groups.

Intervention	DVD (n=10)					Website (n=18)				
	Pre ^a , mean (SD)	Post ^b , mean (SD)	Diff ^c	ES ^d	<i>t</i> ₉	Pre, mean (SD)	Post, mean (SD)	Diff	ES	<i>t</i> ₁₇
JHEQ										
Pain	13.5 (5.8)	15.6 (7.1)	2.1	-0.4	0.35	11.4 (6.7)	12.3 (7.0)	0.9	-0.1	0.52
Movement	12.9 (9.5)	13.4 (8.9)	0.5	-0.1	0.69	11.7 (8.3)	11.6 (9.0)	-0.1	0.0	0.94
Mental	17.6 (7.8)	18.6 (7.5)	1.0	-0.1	0.58	12.3 (8.0)	13.3 (7.6)	1.0	-0.1	0.46
OHS	38.1 (5.8)	37.5 (6.6)	-0.6	0.1	0.74	33.9 (8.7)	36.7 (7.5)	2.8	-0.3	0.05
SF-8										
PCS	44.1 (6.2)	45.6 (7.1)	1.5	-0.2	0.70	43.2 (7.7)	44.8 (6.0)	1.6	-0.2	0.32
MCS	52.3 (7.0)	54.1 (2.2)	1.8	-0.3	0.45	49.7 (5.0)	49.9 (7.2)	0.2	0.0	0.89
GSES	9.2 (4.7)	9.4 (4.8)	0.2	0.0	0.62	7.8 (4.1)	8.7 (4.6)	0.9	-0.2	0.09

^aPre: preintervention.

^bPost: 6 months after intervention.

^cDiff: difference.

^dES: effect size.

There were four bilateral osteoarthritis patients in the DVD group (40%) and three in the website group (17%). The change in each parameter during the 6 months (preintervention to postintervention) were as follows: JHEQ pain in the DVD group was 2.1 and in the website group was 0.9, JHEQ-movement was 0.5 in the DVD group and -0.1 in the website group, JHEQ mental was 1.0 in both the DVD and website groups, OHS was -0.6 in the DVD group and 2.8 in the website group, SF-8 (PCS) was 1.5 in the DVD group and 1.6 in the website group, SF-8 (MCS) was 1.8 in the DVD group and 0.2 in the website group, and GSES was 0.2 in the DVD group and 0.9 in the website group (Table 2). Although a significant improvement could be not confirmed, most items tended to reflect overall improvement during the 6 months of intervention ($P=.05-.94$; paired *t* test).

Regarding effect size, we considered a small effect to be greater than 0.2 [26]. Little effect was observed for JHEQ pain, SF-8 (PCS), and SF-8 (MCS) in the DVD group, as well as OHS, SF-8 (PCS), and GSES in the website group.

In the website group, seven patients counted the number of exercises. The range of counts was 6 to 47 (mean 24.6, SD 19.8) 6 months after intervention. In one day, the mean number of exercises was 4.6 (SD 3.6). Five patients recorded their pain by NRS on the website but continued to exercise. We received comments from nine patients in the website group by questionnaire; of these, two patients mentioned difficulty in continuing (eg, they had hoped to continue exercising at first, but were unable to do so because they were tired by their work).

Discussion

Principal Results

In both the DVD and the website groups, a majority of clinical and physical scores tended to improve; however, the difference in the effectiveness of the physical therapy between the two modes was not significant. However, effect size was greater

than 0.2, indicating a small effect [26]. These findings suggest that the effectiveness of exercise therapy via both DVD and website is similar. Results of JHEQ pain and movement scores shows a tendency of relief of hip joint pain and expansion of movements related to hip joint function through the exercises provided. Tendency of improvement in SF-8 PCS scores on the general QOL scale suggests that not only can better hip joint function be achieved, but also function of movements can be improved, through exercises such as those outlined in this program. These improvements are reflected in JHEQ mental and SF-8 (MCS) scores in this study.

After 6 months, the effect size was greater than 0.2 as reflected by JHEQ pain, SF-8 (PCS), and SF-8 (MCS) scores in the DVD group, and OHS, SF-8 (PCS), and GSES scores in the website group. Tendency of improved physical function is reflected in the SF-8 (PCS) scores seen in both groups. This may be the result of both groups performing the same exercises. Improvement in preintervention to postintervention JHEQ pain scores in the DVD group was 2.1, which was higher than that of the website group (0.9). However, the effect size of OHS was higher in the website group than that in the DVD group. In the website group, the ratio of unilateral patients was high, which suggests the possibility of improvement in function toward that of normal. In the website group, a tendency of improved GSES scores was seen. To enhance self-efficacy, it is preferable to guide the patients to help them obtain a sense of achievement, which is important for behavior modification [18].

In the website group, seven participants recorded that their number of exercise repetitions (range 6-47 times; mean 24.6, SD 19.8). The mean number of exercises was 4.6 (SD 3.6) per one day. The number of exercises required for each step was different, according to patients. However, the trending improvement of their physical function suggests some patients continued exercise although they did not count. We have to confirm that they developed an exercise habit.

In a previous study investigating the effect of exercise intervention, the group receiving normal care and additional exercise therapy showed improvements after 3 months; however, after 12 months there was no significant difference [27]. Likewise, the study of a Web-based intervention showed significant improvements after 3 months, but these were not significant when compared to those of the control group after 12 months [28]. Moreover, it has been reported that adherence to continuing positive behavior is related to patients recognizing the benefits of exercise, and that the problem is the lack of a patients' perception of exercise's long-term effects [29].

Our findings suggest that some patients might quit exercise after 6 months because of the difficulty in continuing. However, patients who were recorded on the website commented that they could not continue although they had hoped to at first. At the beginning of the intervention, patients held a high level of interest, but their motivation decreased gradually. A previous study reported that it was difficult for patients to keep up an effective rate of continuing exercise without continued intervention [30]. It is suggested that more intervention to enhance their motivation was needed during 6 months.

In our study, the patients in the DVD group could only exercise by watching the video, whereas those in the website group had to count their exercise repetitions. This suggests that they felt a sense of achievement toward accomplishing their goals, which in turn, improved their self-efficacy scores. Thus, a website-based intervention might improve the motivation to exercise.

In this study, we provided two interventions—DVD and website—and both of these were effective. The mean ages of the DVD and website groups were not significantly different. This suggests that patients who have use of an intervention medium get effective exercise. Some elderly patients might not use the Internet and it is not convenient for them. Therefore, it is good for patients to be able to choose the medium that is the most convenient for them.

Although this study showed no difference in effectiveness between the DVD and website groups, the website platform

may be more useful because instructors have the ability to modify both the interface and exercise program via the Internet at any time. Recently, there have been an increasing number of studies investigating tools that make use of websites. Moreover, the effects of Web interventions have been reported as resulting in greater learning and changes in behavior than have other modes of intervention [31]. However, patients using a website require individual information, support, and feedback; therefore, it is important to develop a website to allow better interaction between patients and to provide individualized feedback regarding patients' progress and outcomes [32].

Limitations

One limitation of this study was the low retention rate. The nonrespondent patients were younger than the respondent patients were. The younger patients tended to play many roles in society, such as working and parenting; therefore, they may have had difficulty continuing this study and responding to us. Another study limitation was that the sample size was small and the differences in the results were not statistically significant. The most probable cause of this divergence was stochastic variation. Finally, there was insufficient diversity in the patients because they were all enrolled from the same facility. Most patients were in their fifties, so the study sample was predominantly a middle-age group. Therefore, in the future, we will design a system and conduct a study for use with elderly hip osteoarthritis patients.

Conclusions

We investigated the effects of exercise therapy interventions via DVD and a website. After 6 months, the effect size was greater than 0.2 as reflected by JHEQ pain, SF-8 (PCS), and SF-8 (MCS) scores in the DVD group, and OHS, SF-8 (PCS), and GSES scores in the website group. Although both groups we studied tended to report improved physical function, only the website group reported a tendency of enhanced self-efficacy—an important factor in behavior modification. Therefore, it is vitally important that we continue studying the use of website-based interventions for patients suffering from hip osteoarthritis.

Acknowledgments

The authors would like to thank the participants in this study. This work was supported by JSPS KAKENHI Grant Number JP 21592892, JP24593295.

Conflicts of Interest

None declared.

Authors' Contributions

YU was the main researcher, designed the study, and analyzed the results. KT and RY together developed the exercise program of this study. JK and SH collaborated with YU in the execution of this research. Finally, TN supervised the research design and provided suggestions about what to analyze for this research.

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Abbreviations

CKC: closed kinetic chain

DVD: digital video disc

GSES: General Self-Efficacy Scale

JHEQ: Japanese Orthopedic Association Hip Disease Evaluation Questionnaire

MCS: mental component summary

NRS: Numerical Rating Scale

OHS: Oxford Hip Score

OKC: open kinetic chain

QOL: quality of life

PCS: physical component summary

Edited by G Eysenbach; submitted 23.06.17; peer-reviewed by J Pearson, S Manzanero; comments to author 07.10.17; revised version received 01.02.18; accepted 14.03.18; published 07.05.18.

Please cite as:

Uesugi Y, Koyanagi J, Takagi K, Yamaguchi R, Hayashi S, Nishii T

Exercise Therapy Interventions in Patients With Hip Osteoarthritis: Comparison of the Effects of DVD and Website-Based Interventions
JMIR Rehabil Assist Technol 2018;5(1):e10

URL: <http://rehab.jmir.org/2018/1/e10/>

doi: [10.2196/rehab.8251](https://doi.org/10.2196/rehab.8251)

PMID: [29735473](https://pubmed.ncbi.nlm.nih.gov/29735473/)

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Original Paper

Participatory Design of an Online Self-Management Tool for Users With Spinal Cord Injury: Qualitative Study

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Abstract

Background: Rehospitalization rates resulting from secondary conditions in persons with spinal cord injuries (SCI) are high. Self-management programs for many chronic conditions have been associated with decreases in hospital readmissions. However, in the SCI community, evidence suggests that satisfaction with traditional self-management programs is low. Users with SCI have indicated preference for programs that are online (rather than in-person), that target SCI-specific concerns, and are led by peers with SCI. There is currently no program with all of these features, which addresses self-management of secondary conditions after SCI.

Objective: The aim of this study was to provide details of a participatory design (PD) process for an internet-mediated self-management program for users with SCI (called SCI & U) and illustrate how it has been used to define design constraints and solutions.

Methods: Users were involved in development as codesigners, codevelopers, and key informants. Codesigners and codevelopers were recruited from consumer advocacy groups and worked with a core development team. Key informants were recruited from geographically distributed advocacy groups to form a product advisory council that met regularly with the core team. During meetings, codesigners and informants walked through stages of work that typify PD processes such as exploration, discovery, and prototyping. This paper details the process by analyzing 10 meetings that took place between August 2015 and May 2016. Meetings were recorded, transcribed, and subjected to an inductive thematic analysis; resulting themes were organized according to their relationship to PD stages.

Results: A total of 16 individuals participated in meeting discussions, including 7 researchers and 9 persons with SCI from 4 Canadian provinces. Themes of trust, expertise, and community emerged in every group discussion. The exploration stage revealed interest in online self-management resources coupled with concerns about information credibility. In general, participants indicated that they felt more confident with information received from trusted, in-person sources (eg, peers or health care professionals) than information found online. The discovery stage saw participants propose and discuss concepts to filter credible information and highlight community expertise, namely (1) a community-curated resource database, (2) online information navigators, and (3) group chats with peers. Several tools and techniques were collectively prototyped in an effort to foster trust and community; these are illustrated in the Results section.

Conclusions: A PD process engaging users as codesigners, codevelopers, and informants can be used to identify design concerns and prototype online solutions to promote self-management after SCI. Future work will assess the usability of the collectively designed tools among a broad population of Canadians with SCI and the tools' impact on self-efficacy and health.

(*JMIR Rehabil Assist Technol* 2018;5(1):e6) doi:[10.2196/rehab.8158](https://doi.org/10.2196/rehab.8158)

KEYWORDS

health education; internet; spinal cord injuries; self-management

Introduction

Self-Management of Spinal Cord Injury

Managing a spinal cord injury (SCI) is a lifelong process. Within the first year of injury, more than half of the people discharged with SCI may require rehospitalization due to a secondary condition (eg, a pressure sore); even 20 years post injury, rehospitalization rates remain over 30% [1]. Rehospitalization rates in Canada have remained high for more than 10 years [2], whereas, at the same time, length of stay in inpatient rehabilitation has decreased dramatically [3]. Therefore, there is a growing need to emphasize health management support for persons with SCI in the community. Self-management is one support option; this has been described by Barlow et al as an “individual’s ability to manage the symptoms, treatment, physical, and psychosocial consequences and lifestyle changes inherent in living with a chronic condition” [4]. Effective self-management, Barlow and colleagues explain, requires the ability to “monitor one’s condition and to affect the cognitive, behavioral, and emotional responses necessary to maintain a satisfactory quality of life” [4]. In the SCI community, poor self-management has been identified as a factor in the development of an inactive lifestyle and secondary conditions [5,6].

Self-management programs encourage self-management through activities such as symptom monitoring, medication management, problem solving, and health-related decision making [7]. Established community-based programs, such as Stanford’s chronic disease self-management program (CDSMP) [8] and the UK’s expert patient program [9], rely on trained peers to guide activities for groups comprising people with different chronic conditions [8,9]. Both programs have been associated with positive health outcomes such as improvements in health-related self-efficacy [7-9], lower hospitalization rates [7], and reduced health care expenditures [10,11]. However, evidence suggests that they do not effectively address the needs of persons with SCI. For example, a qualitative study on the experiences of CDSMP participants with neurological conditions (eg, stroke, multiple sclerosis, and SCI) saw participants with SCI reporting the least program satisfaction [12]. Participants with SCI and group leaders both suggested that SCI-focused groups (eg, groups with modules adapted for SCI-specific concerns) would be preferable to the SCI community [10]. These findings were underscored by a Canadian survey where the participants with SCI expressed a desire for condition-specific self-management programming, mentoring by peers with SCI, and virtual or online participation [13].

Virtual Self-Management Support

In response to the need for targeted and remote programs, telephone-based programs have emerged [14-17]. Participants in these programs have reported high ratings for their experience [14,15], left with improved levels of activation, social participation, and awareness [16], and have found information presented to be credible [17]. However, participants in the

Canadian survey indicated a distinct preference for online-program delivery over phone delivery [13]. In addition, participants of telephone-based programs have reported difficulty in assembling program information [15]; an online program may mitigate this problem by centralizing information.

Consistent with these data is the evidence showing that the SCI community increasingly turns to the internet for self-management information. In a 2008 survey of almost 3000 US residents with SCI, approximately 65% reported using the internet and most claimed to be online daily [18]. Similar results were produced by a 2014 survey of 500 veterans with SCI [19]. For those with internet access, educational videos addressing management of SCI secondary conditions (eg, managing or preventing pressure ulcers or pain) have increased health-management knowledge and encouraged behavior changes (eg, the adoption of hypnosis) [20,21]. E-learning modules on topics such as pressure ulcer or bladder management have been linked to increased management knowledge [22-24] and internet usage has generally been associated with emotional health [25,26]. However, despite the benefits of internet for the SCI community, there is still no known tailored and internet-based self-management program.

Design of an Online Program

In 2012, to help fill the need for high-quality online self-management support, a team of researchers including a lead author (JS) created several short e-courses for people with SCI [22,23]. This paper documents efforts to extend this online service to include peer-led self-management support. The name of the extension, SCI & U, is a gesture to the project’s relationship to SCI-U and a reference to the peer connections that form the basis of successful self-management programs, such as My Care My Call [15,16] and SCI Action Canada [14,17]. SCI & U was initiated by stakeholders funded by the Rick Hansen Institute to explore self-management; these included rehabilitation researchers, users with SCI, and clinicians [27].

To increase the likelihood of users accepting the resulting self-management tools, a participatory design (PD) approach was utilized, which includes people with SCI as codesigners and informants. This paper describes the process in detail and illustrates how it has been used to define design constraints and create solutions that have been prototyped [28].

Methods

The Participatory Design Process

Knowledge about how to manage the health-related consequences of SCI may be possessed by persons with SCI implicitly rather than explicitly, that is, it may be tacit. For example, persons with SCI have expressed difficulty articulating sensations during wheelchair selection [29]; however, this input is critically relevant to accessing appropriate care. PD is an iterative design and research process that acknowledges the importance of tacit end user knowledge and attempts to access

it by involving users. A central PD concept is that participatory action expresses tacit knowledge and encourages sensitivity. Although the mechanisms for user involvement vary from project to project, the primary goal of PD is to improve users' quality of life [30]. Typical PD processes see users involved in design continually and in a sustained fashion [31] either as informants (eg, via focus groups and key informant interviews) or as codesign partners (eg, partnered with design and development teams) [32,33].

When related to lifestyle promotion applications, PD processes have been found to empower and educate users as well as encourage application adoption and effectiveness [33]. Such benefits may have special relevance to persons with SCI, as people with SCI (and groups of disabled users, more generally) are often not consulted during the design of the health interventions that target them [34]. This is despite the recognized utility of community consults by national consumer advocacy organizations [35].

Figure 1 shows that a 4-member codesign and codevelopment team met daily to create product designs and prototypes; designs were refined at monthly meetings of a product advisory council. This council contained 5 core users with SCI (the "CAG").

To maximize potential benefits of PD during the development of SCI & U, potential end users have been embedded as both program informants and codesigners. The organizational structures used to facilitate this involvement are illustrated in Figure 1 and described as follows:

Codesign and Codevelopment Structures

The core design and development team consisted of 4 individuals and was co-led by 2 researchers (JS and SA). One (JS) was a person with SCI, who was closely involved with the

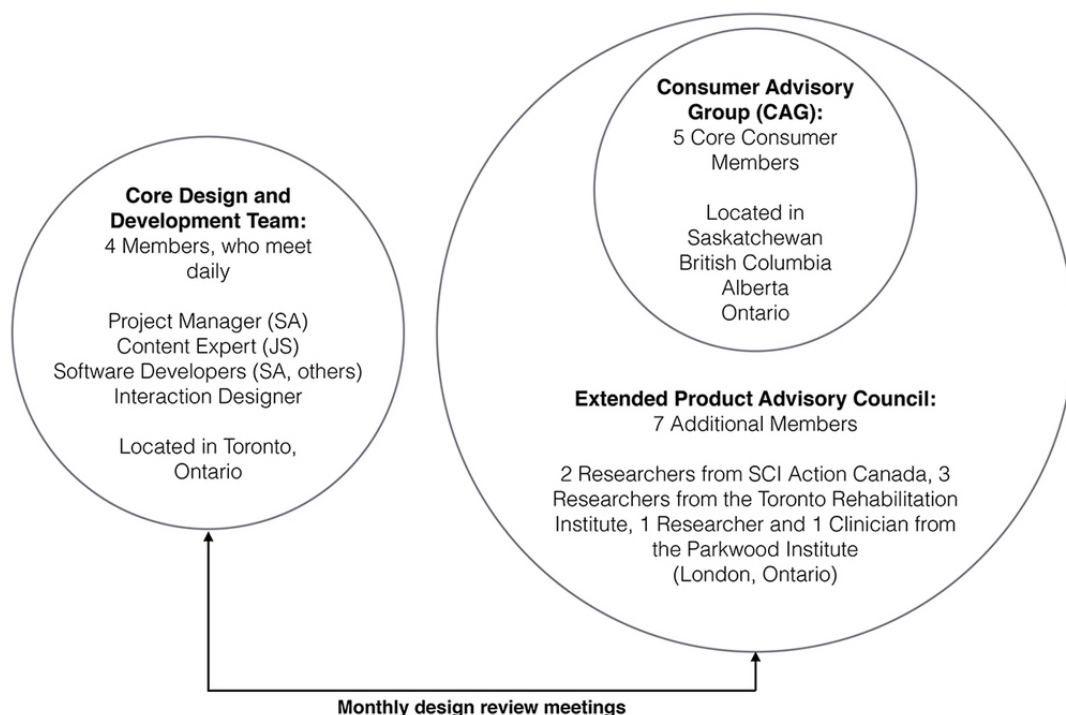
development of online health information resources for the SCI community [22,23] and the other (SA) was a human-computer interaction researcher. Additional design and development members were recruited through SCI-Ontario, an Ontario-based consumer advocacy group. These additional members, who were people with SCI, included the project's lead programmer and an interaction designer. The core design and development team interacted regularly and met weekly.

Informant Structures

The codesign team was informed by monthly interactions with a product advisory council. Original members of this council were 5 geographically distributed people with SCI (called the Consumer Advisory Group or CAG) who were recruited through Canadian SCI advocacy organizations (eg, SCI-Ontario, SCI-British Columbia, and the Rick Hansen Institute). Recruitment was designed to promote diversity; original members were from several Canadian provinces (Saskatchewan, British Columbia, Ontario, Alberta), from both rural and urban areas, and reflected lived experiences with different levels of injury. The size of CAG was designed to capture differing perspectives while allowing everyone's meaningful participation in discussions (groups ranging in size from 8-12 are typically recommended in qualitative research [36]). Membership also rotated annually. Other stakeholders from clinical and research communities were also invited to participate in periodic discussions; these individuals included physical activity experts from SCI action Canada and a dietitian from Parkwood Hospital in London, Ontario.

Activities undertaken during group meetings have, to date, loosely followed the stages of PD described by Spinuzzi [31], which are as follows:

Figure 1. The core design and development team met daily; designs were refined at monthly meetings with a Product Advisory Council containing 5 core users with SCI (the CAG). SCI: spinal cord injury.



Exploration

During initial meetings, participants described experiences with self-management and use of internet to facilitate health and well-being. To encourage discussion, members of CAG were asked to independently review 5 to 10 online resources designed to support independent self-management. Online resources were discovered based on literature reviews and internet searches. Resources with interactive features (eg, resources that provided feedback on symptoms or treatments) were prioritized and have been correlated with positive health outcomes in reviews of health-information technologies [37]. Examples of selected resources include e-learning modules (eg, [23]), discussion forums (eg, [38]), and sites with community reviews (eg, [39]).

Discovery

After discussion of online self-management strategies and tools, the group fleshed out features for a first iteration of novel online programming. Key concerns and barriers constraining the development were also identified during these discussions.

Prototyping

Finally, the group worked to prototype proposed features in such a way so as to mitigate concerns and barriers identified by the group. Concepts were translated into drawings and interactive wireframes by the core design team and were iterated upon, based on the group feedback. To date, several concepts have been built into a functioning prototype, which is currently accessible online (at <http://www.sci-and-u.ca>).

Data Analysis

In the sections that follow, we analyze the content of the first 10 meetings between the CAG members of the product advisory team and the core development team. Meetings took place between August 2015 and May 2016; each meeting lasted about 90 min and was mediated via Skype and digitally recorded in the MP4 format using Call Recorder (eCamm Network, Sommerville, Massachusetts, USA). Resulting MP4 data was professionally transcribed and the accuracy of transcripts was verified by the lead author (SA).

Transcripts were analyzed using an inductive thematic analysis using Nvivo 10 software (QSR International, Doncaster, Australia). The paradigm that guided this analysis was pragmatic and focused on discussion around specific phenomena, that is, the use of internet to support self-management activities. It has been argued that a focus on specific phenomena is well suited to health-services research as it caters to both qualitative and quantitative analyses [40].

Codes representing key themes were identified in transcripts by the 2 authors (SA and SH) as per the instructions of Braun and Clark [41] and organized around PD stages outlined by

Spinuzzi (eg, exploration, discovery, and prototyping) [31]. Meetings with additional authors (JS and SM) were held to discuss and resolve discrepancies in coding and to decide the umbrella “labels” for resulting themes. It is to be noted that one of these authors was a summer student in health systems (SH) and the other (SM), a knowledge-translation researcher with experience in qualitative analysis. Changes to the coding scheme were made iteratively and by consensus between 3 authors (SA, SM, and JS). Once the consensus was achieved, the lead author organized codes so as to highlight core concepts.

This process received Research Ethics Board approval from the University of Toronto (REB # 26429), and all individuals who participated in meetings consented to participate.

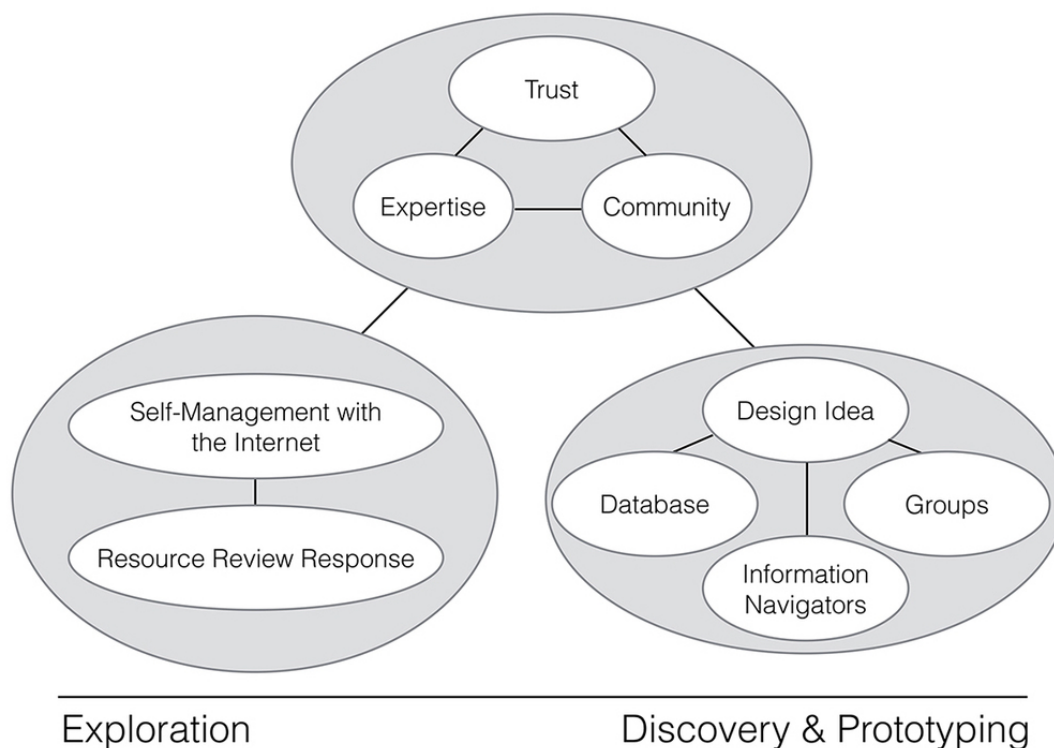
Results

A total of 16 people participated in the 10 meetings between the product advisory council and the development team. These included 8 individuals with SCI (3 on the core design and development team, 4 in the original CAG, and 1 on the extended product advisory council) and 1 person with cerebral palsy (who was an original member of the CAG). Additional members of the product advisory council included 2 members of the SCI Action Canada research team and rehabilitation researchers from the University Health Network/University of Toronto and the Parkwood Institute in London, Ontario. Twelve meeting participants were from Southern Ontario (Toronto, London, Kingston, or Waterloo); remaining participants came from Saskatchewan, British Columbia, and Alberta. Among the 8 participants with SCI, 5 were from Ontario, 3 were women, 3 had injuries above the T1 level, and all had been living independently with SCI in the community for more than 5 years. Although the CAG and core design and development team were present at most meetings, other attendees were present only at 1 or 2 meetings when topics of relevance to their expertise were discussed.

A thematic map illustrating high-level themes can be found in [Figure 2](#). Themes of trust, expertise, and community were represented in every group conversation, whereas other themes were focused around particular PD process stages. For example, themes labeled “Self-Management” and “Internet and Resource Review Response” were largely confined to transcripts of Exploration Stage meetings. In contrast, themes associated with idea generation were more commonly found in later transcripts, during Discovery and Prototyping stages.

In the results that followed, we teased apart high-level themes and illustrated them with representative quotes. Quotes are identified by number rather than name to protect the participants’ anonymity.

Figure 2. A thematic map illustrating key concepts and their relationship to the PD stages of Exploration, Discovery and Prototyping.



Stage One: Exploration

During initial meetings, participants described a wide range of techniques and services they had used to support and maintain their health when living in the community. These included the services of community-based organizations (eg, ParaSport New Brunswick), health care practitioners (personal trainers or physical therapists), and peer-support networks.

Self-Management and Internet

Internet, however, was described as playing an important role in self-management for participants with SCI, as it had helped them to do the following:

Discover Services or Interventions

Internet forums helped 1 participant decide whether or not to get a colostomy; as he was making this decision, he explained that:

looking at forums...helped me get my head wrapped around a few things and come out thinking more clearly. [ID #1]

Others acknowledged online-discussion groups and forums to be sources of community as well as information. According to 1 CAG member:

...interacting with other people with the same kind of problems is probably a useful thing...if for no other reason than to know you're not alone. [ID #2]

Some participants described using internet to locate specific community services. For example, one member of CAG described taking charge of and modifying her personal environment with the help of a contractor she located on the internet; she had communicated with this person using images from her phone.

It was very useful because there were lots of things that I couldn't explain verbally...but once he saw a picture it's like...oh, okay, I get it. [ID #3]

Prepare for Meetings With Health Care Professionals

Participants described performing internet searches to prepare for meetings with health care practitioners. As one participant explained:

I look to get enough information [from the Web] so that I sound educated when I go speak to a professional, whether it be my personal trainer or my physician or my OT for seating and wheelchairs. I want to be informed before I go and advocate for what it is I think I need. [ID #5]

Internet searches were also described as being useful to determine whether HCP visits were, in fact, required. This was explained by one participant in this way:

I like...to piece together all the puzzle pieces and to go, 'yeah, okay, that is the thing I want to do' or 'no I don't need to go to the doctor' or 'yes, I do need to call Emergency.' [ID #3]

Revisit Skills Learned in Rehab

Many participants described the period of time surrounding discharge from rehabilitation as particularly overwhelming; although self-management information was provided during inpatient rehabilitation, not all patients were ready to absorb it all. As one participant stated:

...when we're in rehab, we get more information than we would admit to getting but we just don't process it. And so, shortly after injury, when you're back at home...then the things you didn't pay enough attention to in rehab become salient as a problem. [ID #6]

It is at this point that participants remembered searching for information on the Web. As one participant explained:

...that's when you may be looking for how-to [videos] related to self-management concerns. [ID #3]

Access Research Information

People more distant from inpatient rehabilitation, however, were described as having different information needs and as more likely to use the internet to research particular interventions or services in depth. One participant said:

It depends on where you're at in your post-injury life. I'm more keen to look at research-based content than...step-by-steps. [ID #1]

Another participant defined self-management shortly after injury as being about “managing an unknown entity” while now, several years later:

...it is [about] tertiary conditions and how my disability interacts with those. [ID #2]

This same participant described using the internet to locate research reports and inform self-management decisions. One had influenced him to stop taking fiber pills:

...when I read that report, I thought...well I'll just see what happens. I was kind of surprised at the results...and I shared that with my family doctor. [ID #2]

Ease the Burden of Travel

While several participants explained that they had taken advantage of peer-support services after their injury, one participant indicated he had used Skype to deliver peer support to a colleague:

I establish a Skype contact with her...it was interesting to establish the contact and then figure out what needs she has and what I can do to help. It's very useful for both of us. [ID #1]

Others similarly described use of videoconferencing tools to access social support or employment. One participant explained he had once attended group meetings in person, requiring him to drive more than thirty minutes and endure pain as a result. Videoconferencing improved his situation. He stated:

I'm in a lot of pain. I'm just about to head out the door and I think, someone suggested you can use Skype. I think it is an effective way to meet, for sure. [ID #2]

Resource Review Responses

Independent review of online resources for self-management also generated conversation around several themes, including:

Lack of Familiarity

Although participants reported using the internet to support and maintain their health, many were unfamiliar with online resources presented for review. For example, when reviewing forums for users with SCI to exchange health information, one participant commented that he had:

...never used such a forum...didn't know they even existed. [ID #1]

Other participants indicated that, although they may have used forums to decide on things to buy, they had never considered using forums for self-management decisions. At the same time, participants responded positively to online resources they were asked to review. One participant, who was not only a person with SCI but also a clinician, indicated she would be sharing details about discussion sites for accessibility products with “patients ... looking at home modifications for discharge” [ID #8] based on the group discussion. Forums containing personal stories of treatment or recovery were also found to be useful and appealing; 1 participant felt they allayed “fears and ... trepidation” related to care decisions [ID #2]. Sites containing community ratings or discussions of care provided by local clinicians were similarly unfamiliar, yet described as “really interesting” [ID #5] or “quite unique” [ID #8] by participants in the group.

Appreciation of Diversity

In addition, most participants indicated they were impressed by the range of self-management resources available online and felt this diversity had utility. One participant explained that she “liked a lot of links” [ID #3] to follow when doing online research related to care, while another acknowledged:

...everybody is different and different people are going to find different things useful. It's a tricky thing to know who is going to want what or trying to second guess what people would be interested in. [ID #2]

Questions of Trust

Despite the appeal of the online resources, participants with SCI expressed strong concerns related to the credibility of online information. The group clearly preferred self-management information obtained in-person from trusted sources. As one participant explained:

I'm more likely to take the advice of a trusted friend, doctor or service coordinator...rather than going to the internet. [ID #2]

Even users of internet forums described online information as less credible than in-person information:

It's a lot of crap in those forums. [ID #2]

I'm always a little skeptical of Joe Public. [ID #4]

Moreover, participants characterized users of online self-management tools as potentially vulnerable to bad information or advice.

People might be overwhelmed if they're looking for this information. [ID #7]

If you're in a lot of pain, you'll look at whatever. [ID #2]

Protecting vulnerable or compromised users from misinformation was understood to be important:

Some people really need this information and we need to do our best to implement safety measures for them. [ID #7]

At the same time, limiting exposure to information, or acting as an information “censor” was described by one participant [ID #1] as contrary to users’ need for information diversity.

What defined credibility of online information varied from participant to participant. Some expressed feeling confident when information was clearly associated with reputable health care institutions, that is, when “coming from health care professionals or something” [ID #2]. Others perceived information from health care professionals and research institutions to be incomplete or biased; research information was described by one participant as “based on such narrow criteria...when there’s so much more” [ID #4]. In addition, participants prioritized information associated with peers as it was based on “personal experience,” and therefore more likely to address “what works with us” [ID #9]. In general, participants expressed a need to be clear as to the meaning and labeling of expert or credible self-management information; as was stated:

We need to come up with some very specific ideas [as to] how we’re defining those terms. [ID #7]

Questions of Accessibility

The discussion of existing online self-management resources raised accessibility concerns related to the use of technology and health care services. Persons with SCI experience significant care limitations; it was felt that internet resources might not be sensitive to these. Sites designed for communities to share information about clinicians, for example, were questioned because users of clinical services for SCI often “don’t have choice” [ID #3]. As one participant noted, if he were to discover that a clinician profiled on a website had a “bad rating, well, then there isn’t a hell of a lot I can do about that” [ID #2]. Another participant who was both a clinician and a person with SCI expressed concern that finding doctors or services to be “rated poorly” might decrease users’ “confidence” in care [ID #8], thereby taking away from self-management efforts.

Diversity of physical accessibility issues were also revealed by the resource review. For example, while one participant responded positively to short videos of self-management strategies claiming that these catered to her “YouTube mentality” [ID #3], another found the same videos challenging to operate. As this second participant explained:

I’d like to read [information] so that I can re-read it, rather than trying to get my...hand on the [video control] to scrub it back 5 seconds. [ID #2]

Interest in and ability to access information on mobile devices was similarly varied. Although some participants responded positively to the idea of mobile-friendly services, one participant with a high-level injury indicated he could “not really use a (mobile) phone” or tablet and had found tools to promote accessibility of these devices, such as voice activation, to be “anything but relaxing” to configure [ID #2]. Participants with comparable injuries, however, reported different experiences with the same devices. One explained he used “commercial products” such as the Tecla Shield (Komodo OpenLab, Toronto, Ontario) [42], which facilitates access to touchscreen devices via assistive buttons and other controls [ID #6]. This had allowed

him to comfortably use a mobile phone despite having high-level injury, and his mobile phone was his primary device.

In summary, discussions during the exploration phase demonstrated value in exposing users with SCI to a wide variety of interactive self-management resources. At the same time, conversations highlighted the need to organize and promote information credibility and to accommodate individuals with very different accessibility needs.

Stage Two: Discovery

To mitigate credibility concerns, the discovery phase focused on mechanisms to help filter, or lend credibility to, online self-management information. The mechanisms proposed were as follows.

A Community-Curated Resource Database

In response to the diversity and quantity of online self-management resources, participants proposed the creation of a collaborative database for self-management information that might operate something like a Wiki. As was explained:

Not all [Wikis] have immediately useful information but they are a very good start for me to add data. [ID#1]

Others responded positively to this idea, suggesting such a tool might help filter through information and be better than:

just going on Google [for information about] a new chair or an accessible vehicle or whatever. [ID #5]

Several ideas for information vetting (eg, using moderators) were floated to allow high quality information to be more visible or accessible.

Online Information Navigators

Discussions made it clear that information from in-person resources was perceived as more trustworthy than information from online collectives. In response, participants proposed the idea of internet-accessible information navigators. As one of the CAG members explained:

...rather than let 1000 people express their opinion...it’d better to go to an expert; [online] experts...might filter out useless [database] contributions. [ID #1]

Others similarly agreed that “a direct resource that you can communicate with” would be preferable to a database with comments or reviews written by “a bunch of guys who know as much or less than you” [ID #7]. A use-case scenario was detailed in which a user might interact with an online peer using a webcam. The online peer, she explained, might suggest resources based on this information, that is:

...say...you could use this, you could use that, here are a couple of links for the equipment for grips or whatever. [ID #5]

Others received this idea positively, agreeing that:

...it’s good to have somebody to help you [learn] what...to look for. [ID #1]

Online Groups

For some participants, the act of meeting regularly with peers and researchers during the exploration phase increased awareness of self-management strategies and techniques. For example, one participant explained that he had experimented with different management strategies for bowel care based on resources he encountered during the exploration phase and found that videoconferencing sessions with CAG helped him “build a relationship” around the experience [ID #2]. Another participant, who lived in a relatively remote part of Canada, similarly described the value she found in sharing information about self-management as a result of the PD sessions. As she explained:

I like these meetings. I know people with SCI but the community is relatively small. The ability to connect with...people that “get it” because they’re in the same situation...that’s what I’m most excited about. [ID #5]

Stage Three: Prototyping

On the basis of this input, the group began fleshing out design concepts for a resource database. During prototyping, the core design and development team worked to accommodate diverse interests and perspectives; this meant, for example, that information in both video and text format was highlighted and a responsive framework (ie, one that could conform to phone, tablet, and desktop displays) assumed. Prototyping involved creating drawings and interactive wireframes. Wireframes were subsequently translated into a functioning prototype located online (as of June 1, 2017) [28]. An open-source platform called Ruby on Rails (version 3.2) was selected for development of functional prototypes so as to enable end users to contribute.

To illustrate the benefit of the PD process, we describe prototyping tools and techniques to identify credible content. The tools, and the discussion surrounding them, are described in Figures 3 and 4.

Figure 3. Information Wiki or resource database entry, with star ratings from experts and others.

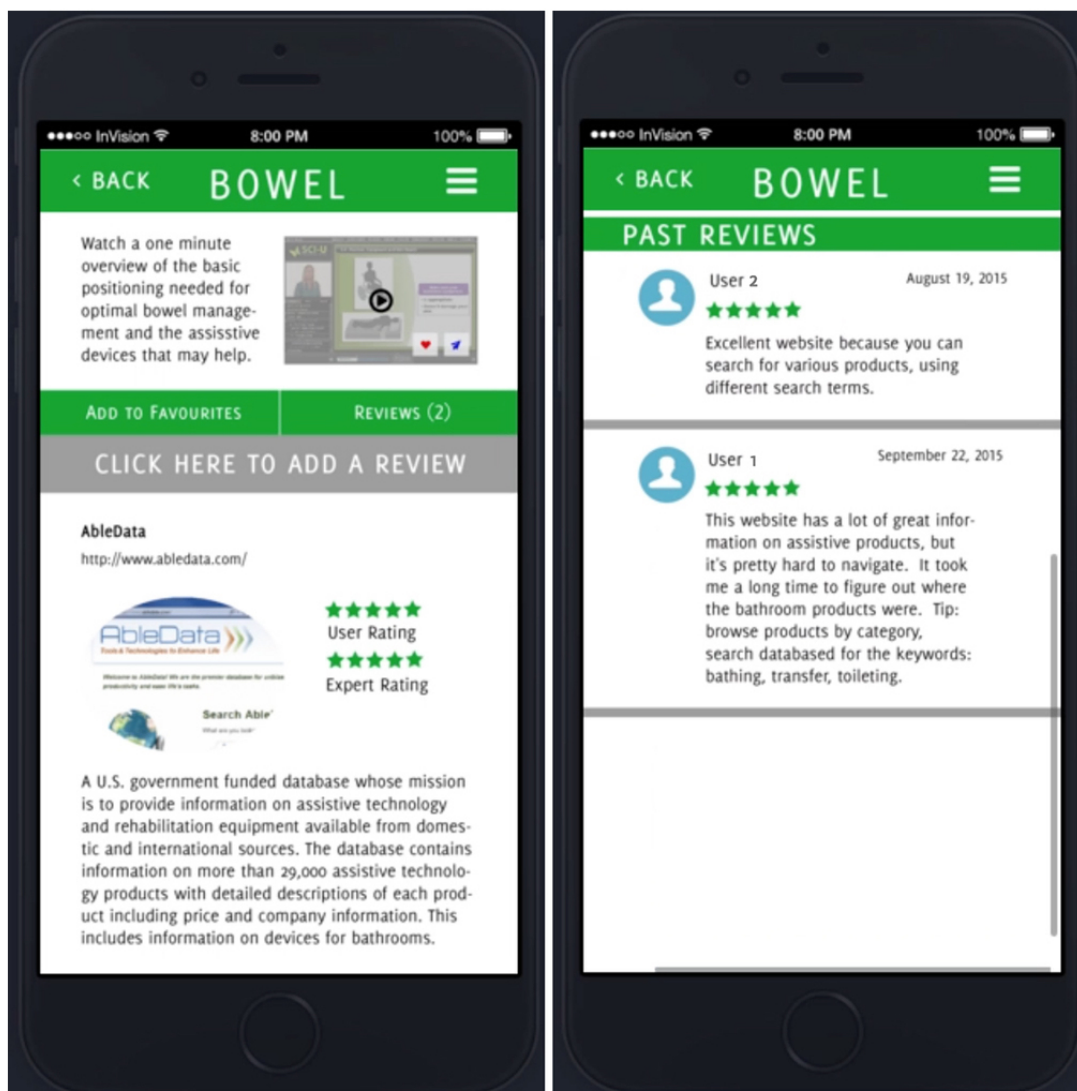
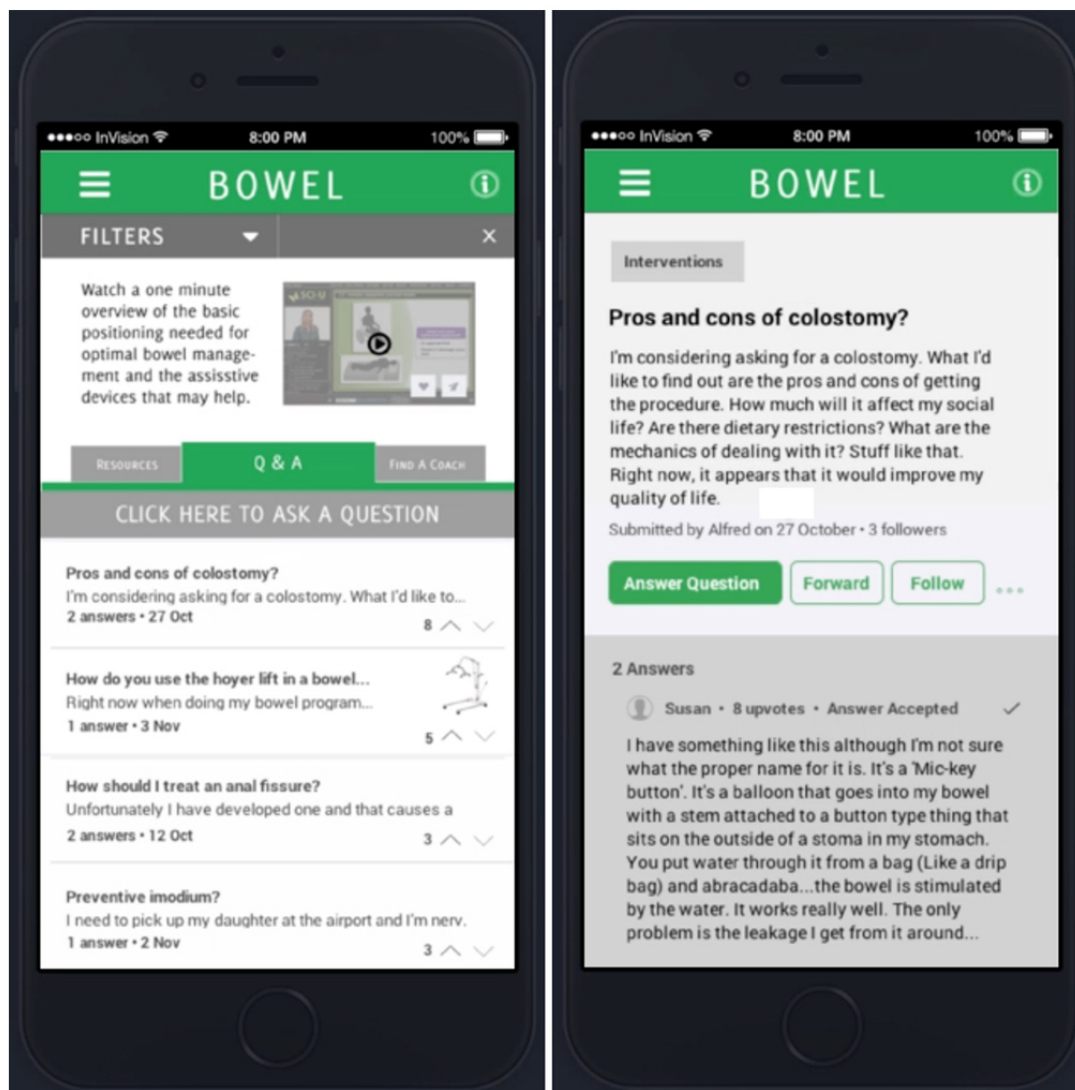


Figure 4. Example of up-voting online information.



Stars and Up-Voting

The core team proposed enabling community ratings (ie, stars) to label credible information in the database. An illustration of a star-based rating system as it was presented to CAG is shown in [Figure 3](#).

Participants responded positively to this idea but were concerned that ratings might lose value when aggregated over a large community of users. As one group member explained:

...absolutely there's value in ratings from the user population, but the challenge with anything online and open...is that some [ratings] will be valuable and some will not. [ID #4]

In response, the core team proposed ratings from an expert panel that were distinguished from those of the broader SCI community. Participants also created a formula for the ideal membership of this panel. Consensus was that it should be diverse and include "health care practitioners, researchers, and people who are living (with SCI) every day" [ID #3]. As one participant explained, the ideal expert panel would be one containing:

...someone who is keen but green, someone who has been around the block a few times, someone who is a frontline service provider, and someone who has got their roots in academia. [ID #4]

In addition, the core team suggested enabling up-voting and down-voting of reviews to identify information with value. Up-voting of comments is a technique used by several review-based sites. On Amazon, for example, users are asked whether reviews of products are helpful, and reviews are ranked (or up-voted) based on their overall helpfulness to the user community. The concept, as it relates to designs for SCI & U, is illustrated in [Figure 4](#).

Up-voting for SCI & U was met with similarly positive feedback; participants called up-votes "a good tool to push expertise to the top" [ID #1]. A perceived additional advantage was the idea that up-votes might be associated with, or help identify, users with a track record of high-quality reviews or responses. As one participant explained, up-voting creates "a chance for people to be able to see" who is producing high-quality information and "for [online] 'experts' to gain recognition for their expertise" [ID #6].

Expertise Points and Activity Feeds

Up-voting led the group to consider ways one might associate expertise with content and individual users. More specifically, participants discussed the idea of rewarding contributors with “points” reflecting the value of their contributions. It was further suggested that users might gain points in specific health management areas, for example, they might gain expertise in bowel or skin management based on their contributions of information to these sections. This concept is illustrated in Figure 5.

However, the suggestion of user points was seen as controversial. One participant felt the idea risked “introducing competition” [ID #4]. Others concurred, saying that points would garner users nothing other than “bragging rights,” that is, the ability to say “I’m better because I know more” [ID #1]. Moreover, the formula for awarding points was recognized to be complicated; simply being an active contributor was not seen as sufficient to merit a badge of expertise.

People that are really active on the site may just be looking for something to do... [activity] doesn't necessarily equate to expertise. [ID #3]

At the same time, some participants perceived that recognizing frequent contributors, or users who had produced demonstrably useful information, could have meaning when associated with user profiles of potential information navigators. Participants suggested that, for individuals who were publicly identified as information navigators, points might act as a “way ... to build a resume” [ID #6].

Ultimately, the group chose to incorporate activity feeds on user profiles rather than points, as shown in Figure 5. Activity feeds were seen as a relatively nonjudgmental way to illustrate user contributions without forcing comparisons between community members. One participant explained that activity feeds:

...[let you] look at the kind of comments [users] have made, and the areas they've made them in, and determine whether or not you're going to take their two cents. [ID #4]

Figure 5. User points at left; user activity feed at right.



Discussion

Principal Findings

Results serve to illustrate how the CAG and core development team employed a PD approach to create functioning online self-management tools, including a resource library (Wiki), a library of accessible online peer information navigators, and infrastructure to host online community discussions or events.

Discussions that took place during the development of SCI & U reflect research results demonstrating most North Americans with SCI both use the internet and turn to it for health information [18,19]. At the same time, accuracy of online health information was a concern for participants; this is consistent with research showing online health information to be variable in quality [43,44]. However, the online health information landscape is quickly changing; more recent studies of forum discussions of care for HIV, for example, have found information posted by online users to be of “good quality” when evaluated by medical professionals [45]. Trustworthy sources of information about SCI are, moreover, increasingly available online (eg, [20-22,46]).

Discussions in this study also echo findings regarding preferred modes of health information delivery in the SCI community. A 2010 review of physical activity information for SCI demonstrated a clear preference for face-to-face information delivery and for family, peers with SCI, and health professionals as information sources [47]. A preference for health information directly obtained from health professionals over information on the internet was also apparent in results from a 2016 survey of US veterans [19]. Similarly, participants in this research made it clear they trust direct communications with individuals over communications with online groups. Information received from trusted peers was especially emphasized as valuable and relevant. This prioritization of peers as information sources is echoed in results from 2011 focus groups on the topic of exercise and SCI; as one participant in this prior study explained, the experience of peers “speaks volumes to someone with an injury” [47].

However, in both this study and the studies conducted before this [47], participants with SCI were relatively distant from the time of their injury (ie, injuries had happened more than 5 years prior). Time since injury is known to influence preferred modes of health information delivery; while recently injured individuals may prefer interactive, face-to-face modes of health information delivery, passive or mediated modes of information delivery (eg, via the internet) may be more appropriate at later stages of recovery [47]. In addition, in both this study and others [48], locating information while transitioning from the hospital to home was described as particularly challenging; there is an apparent need to provide tailored online information for the SCI community at this time.

In addition to shedding light on the access and use of online health information, the SCI & U process proved to engage potential end users while building capacity and promoting information awareness. Several participants indicated that they found valuable information as a result of the PD process and

one participant reported modifying behavior based on information shared during meetings. Such process-related benefits are common to PD, as its focus rests primarily on the development of participants and organizations; tools are seen as subsidiary [30,31]. Moreover, PD processes are strongly aligned with the increasing emphasis on “person-centered” health care [49]. Groups that have adopted participatory methods in the design of self-management interventions for the SCI community are small in number [14-17,50], and the process described here extends these methods to the development of supporting technologies.

Limitations

There are several limitations to results. Most notably, those involved in the participatory process were small in number; experiences or perceptions of the group therefore cannot be guaranteed to generalize to the experiences and perceptions of a broader community of users with SCI or SCI stakeholders. Nonetheless, efforts were made to ensure the CAG’s diversity with respect to geography, sex, and injury levels, and results obtained reflected findings associated with surveys of larger populations of individuals with SCI. This potential limitation of our study is, moreover, a commonly cited limitation of participatory processes, that is, extensive involvement of users may result in designs tailored to the needs of a small group [51].

In addition, participant selection was biased as all participants have regular access to high-speed internet. However, research indicates a significant proportion of the SCI community in North America (between 30% and 40%) do not have this kind of regular access, and almost 20% have never referred to the internet for health information [18]. Moreover, regular access to the internet has been found to be associated with high education level, socioeconomic status, and self-reported health status [19]. Participants with SCI in this study, then, may be individuals who are less in need of self-management support than those in the community and who are not currently online. A parallel telephone support process may prove to be better suited for more vulnerable users with limited access to online information.

Conclusion and Future Research

In summary, a participatory process including potential users as codesigners, codevelopers, and informants has been shown to benefit the design of an online self-management resource for Canadians with SCI called SCI & U. Benefits demonstrated here include:

1. Elicitation and consideration of diverse accessibility considerations (eg, use of online video vs text, use of mobile devices vs PCs).
2. Prioritization of features and identification of core design concerns, including those related to online information credibility (eg, the need to define and highlight “quality” information).
3. Cocreation of acceptable strategies and techniques to mitigate identified concerns (eg, community ratings and reviews, access to online information navigators).

Currently, the team is working to evaluate the basic usability of the existing prototype based on input from a broader

collection of end users and using the Mobile App Rating Scale [52]. This will help determine if the described process has successfully created products that serve both design participants and others in the Canadian SCI community. Once this is complete, evaluation efforts will shift to focus the tools' impact on users' self-efficacy (ie, confidence in the ability to independently manage their health) and health care utilization.

Extension of the prototype is also taking place in order to support richer interactions with "information navigators" that are analogous to the interactions with the trained peer-health coaches of SCI Action Canada's Get In Motion service [14,17] or My Care My Call [15,16]. A pilot trial to explore the impact of online interactions with trained peers is ongoing.

Acknowledgments

The authors would like to thank the members of the Consumer Advisory Group and Shawn Farrugia, Eric Wan, Marla Rogers, Lindsay Sleeth, and SperoGinis. The authors also acknowledge the Ontario Neurotrauma Foundation and the Rick Hansen Institute for their support of this work. SJ holds the Toronto Rehabilitation Institute Chair at the University of Toronto.

Conflicts of Interest

None declared.

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Abbreviations

CAG: Consumer Advisory Group

CDSMP: Chronic Disease Self-Management Program

PD: participatory design

SCI: spinal cord injury

Edited by G Eysenbach; submitted 06.06.17; peer-reviewed by J Amann, A Machado-Lima, G Luo, A Loyola Sanchez; comments to author 20.07.17; revised version received 15.11.17; accepted 06.01.18; published 21.03.18.

Please cite as:

Allin S, Shepherd J, Tomasone J, Munce S, Linassi G, Hossain SN, Jaglal S

Participatory Design of an Online Self-Management Tool for Users With Spinal Cord Injury: Qualitative Study

JMIR Rehabil Assist Technol 2018;5(1):e6

URL: <http://rehab.jmir.org/2018/1/e6/>

doi: [10.2196/rehab.8158](https://doi.org/10.2196/rehab.8158)

PMID: [29563075](https://pubmed.ncbi.nlm.nih.gov/29563075/)

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Original Paper

Preferences for Web-Based Information Material for Low Back Pain: Qualitative Interview Study on People Consulting a General Practitioner

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Abstract

Background: Information on self-management, including addressing people's fears and concerns, are core aspects of managing patients with low back pain (LBP). Web apps with patient information may be used to extend patient-physician consultations and encourage self-management outside of the consultation room. It is, however, important to identify the end users' needs and preferences in order to maximize acceptance.

Objective: The aim of this study was to identify preferences for the content, design, and functionality of a Web app with evidence-based information and advice for people with LBP in Denmark.

Methods: This is a phenomenological qualitative study. Adults who had consulted their general practitioner because of LBP within the past 14 days were included. Each participated in a semistructured interview, which was audiotaped and transcribed for text condensation. Interviews were conducted at the participant's home by 2 interviewers. Participants also completed a questionnaire that requested information on age, gender, internet usage, interest in searching new knowledge, LBP-related function, and pain.

Results: Fifteen 45-min interviews were conducted. Participants had a median age of 40 years (range 22-68 years) and reported a median disability of 7 points (range 0-18) using the 23-item Roland Morris Disability Questionnaire. Participants reported that Web-based information should be easy to find and read, easily overviewed, and not be overloaded with information. Subjects found existing Web-based information confusing, often difficult to comprehend, and not relevant for them, and they questioned the motives driving most hosting companies or organizations. The Patient Handbook, a Danish government-funded website that provides information to Danes about health, was mentioned as a trustworthy and preferred site when searching for information and advice regarding LBP.

Conclusions: This study identified important issues to consider when developing and supplementing existing general practice treatment with Web-based information and advice for patients with LBP. Development of a Web app should consider patient input, and developers should carefully address the following domains: readability, customization, design, credibility, and usability.

(*JMIR Rehabil Assist Technol* 2018;5(1):e7) doi:[10.2196/rehab.8841](https://doi.org/10.2196/rehab.8841)

KEYWORDS

patient education as topic; medical informatics app; patient participation; general practice; low back pain

Introduction

Background

With a point prevalence of 9.4% globally, low back pain (LBP) is the health condition that causes the most years lived with disability [1]. All innervated structures in the spine are potential sources of nociception; however, the etiology underlying LBP is often unknown but may include biological, psychological, and social factors [2-4]. Although most episodes of LBP are relatively short, 45% of patients may experience recurrent or persistent pain that causes some to withdraw from work and leisure activities [5,6]. Consequently, people with LBP often consult their general practitioner (GP) for advice. Patient information about staying active, supporting self-management, and removing fears and concerns about LBP are core aspects of evidence-based management [7]. Web apps containing relevant patient information may be used to extend the patient consultation and encourage self-management outside the GPs' consultation rooms. To ensure the patients' acceptance and thus, the use of such Web apps, it is important to identify their needs and preferences for the technology.

A recent systematic review highlighted that patient education had positive long-term effects for patients with LBP [8]. Maintaining physical activity and avoiding bed rest can reduce pain and maintain and restore function in acute LBP, whereas behavioral advice can prevent LBP from becoming chronic [9,10]. However, because patients with LBP represent a heterogeneous group, some will, even when receiving evidence-based treatment and advice, have persistent pain [11]; for these patients, information on how to cope with pain is particularly important.

Web Apps

Information technology-mediated personalized Web apps can improve accessibility and exchangeability of information [12,13]. A personalized approach may address the individual biologic, physiologic, and social factors that are particularly important for the individual patient by addressing the different needs among patients and supporting self-care, which may have long-term effects [14,15]. As such, a Web app tailored to the patient's profile can differentiate between several types of content (text, pictures, films, and print options) and Web designs.

To inform the developers of Web apps regarding the patients' preferences, it is essential to involve the end users during the development process. Elucidating barriers and enablers are likely deciding factors for future acceptance and use. Otherwise, patients may find content and design irrelevant and consequently be dissatisfied [16].

Objective

The aim of this study was to identify preferences for the content and design of a Web app with information and advice for people with LBP consulting a GP.

Methods

Design

This was a phenomenological qualitative study based on a constructivist research paradigm. The interview guide was based on methods for designing semistructured interviews [17]. The interview guide was pilot-tested 3 times, resulting in small adjustments (Multimedia Appendix 1).

Additionally, visible, tangible artifacts, as post-it notes and photos, were presented to participants, since these could help to foster a creative environment and support dialog during interviewing [18]. This was performed by giving artifacts to the participants and asking them to be creative during interviewing. The activities were to give insights into the patients' needs and let them express the knowledge that might be tacit [18]. The visible tangible artifacts were used for 3 activities. In the first activity, post-it notes and a ball pen were handed out to the participants. The purpose of this activity was to gain insight into what knowledge participants found most important in relation to their LBP and use of a Web app. Patients were asked to write one aspect on each post-it note. Following this, patients were handed 6 stickers and asked to prioritize the importance of the post-it notes.

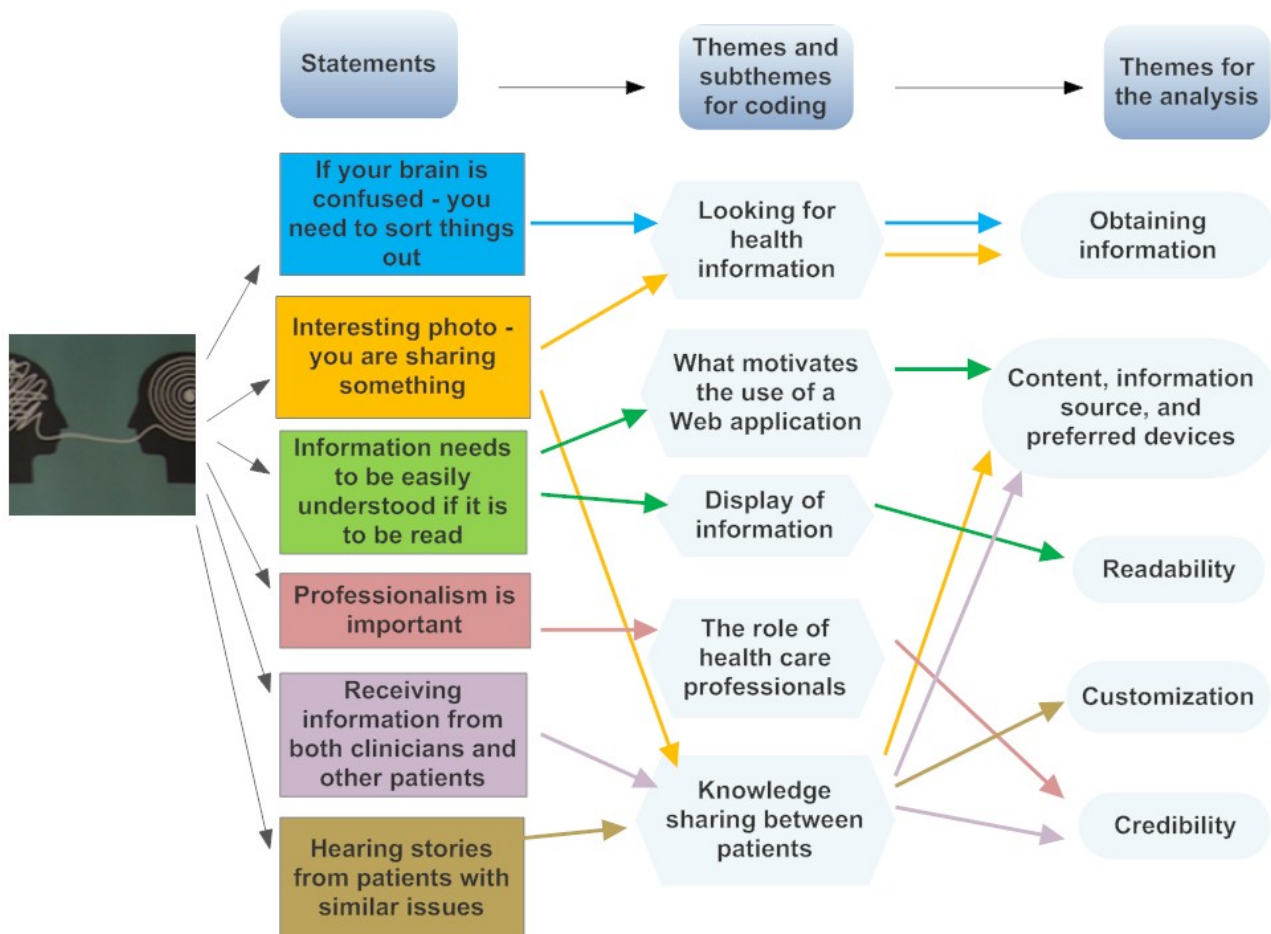
The second activity also included post-it notes. The participants' inputs were discussed to create an overview of objects and techniques used to cope with pain. In some interviews, participants noted down on post-it notes by themselves, whereas in other cases, the interviewers assisted them. In the third activity, laminated cards with photos and graphics (Figure 1) were used as "interview stimuli" [19]. Participants were asked to use these photos as inspiration when describing which aspects they found most important when using Web apps to acquire information related to LBP. Consequently, the artifacts can facilitate participants to select the reference points in the conversation and thus to take lead in inquiry [18]. The photos were placed on the table (Figure 1). Participants were asked to select 3 photos, which they found useful, to support their presentation of important aspects. Besides being an explanation object, the photos contributed to a conversation about positive and negative aspects when using a Web app to obtain information. Furthermore, the variety of photos was selected by the interviewers (LDV and DMH) to support participants in being creative.

The participants were interviewed in their homes by 2 interviewers. The interviews were audiotaped and transcribed without fill-words, but pointing to pictures or objects, and any recorded sounds that influenced the conversation were noted. Interview data were analyzed inspired by a thematic approach in 6 phases [20].

Figure 1. Photos and graphics. Illustration of different photos applied to foster a creative environment and support dialogue. This picture was taken during interviewing at a participants' home.



Figure 2. Coding of statements in relation to the photos. The process starting from commenting on a photo, to coding the comment in NVivo, and finally including the comment in the themes for the analysis. The processes are illustrated by unique colors for each statement.



In phase one, data from audio recordings were transcribed by LDV and DMH. Followed by reading the transcriptions and writing down 2 sets of initial ideas for coding, LDV and DMH wrote their combined ideas for coding, and AR noted his suggestions for coding. In phase two, the 2 initial ideas for coding were discussed and consensus for coding themes was agreed upon ([Multimedia Appendix 2](#)). In phase three, annotations were gathered under the coding themes, including inputs from the chosen photos during interviews (by AR, LDV, and DMH), allowing annotations to occur under multiple coding themes ([Figure 2](#)). In phase four, the themes were reviewed by AR and LDV (or AR and DMH) checking whether the themes worked in relation to the coded extract and with special attention to not missing important information during coding. In phase five, the themes were refined, with special attention to the aim of this study, to the themes being presented in the analysis ([Multimedia Appendix 2](#)). In phase six, the final adjustments were made to the analysis by all authors with special focus on translations of quotations from Danish to English.

The study population was balanced between the 3 Stratified Targeted Treatment (STarT) Back groups, with the purpose of including patients with heterogeneous bio-psycho-social profiles and variation in response to commonly used treatment strategies [21]. Following the interviews, participants were given a combined questionnaire that included baseline information regarding age, gender, risk of poor prognosis, use of the STarT Back Tool (SBT), [22], pain duration, pain intensity (Numerical Pain Rating [23]), responses to the Roland Morris Disability Questionnaire [24], and health-related internet search behavior. Reporting followed the standards for reporting qualitative research [25]. A study protocol for this study has previously been published [26].

Research Group Characteristics

The 2 interviewers (DMH and LDV) did not have any private or clinical knowledge of the respondents other than knowing that the individuals being interviewed met the inclusion criteria. The researchers involved in this project encompass a broad range of professional backgrounds, including a bachelor of radiography and master of techno-anthropology student (DMH), a bachelor of techno-anthropology and master of techno-anthropology student (LDV), a GP practitioner (MBJ), a chiropractor (JH), and 2 physiotherapists (AR and MSR). The authors had expected that participants would have found it difficult to find Web-based information suited to them. The authors had also expected that Web-based information would be reported to be provided in a boring manner and described as time-consuming to read long passages of text before reaching the essential information. Our research is aimed to support the development of guideline-concordant Web-based information. Consequently, a description of requested content compromising this aim has partly been omitted from reporting.

Context

This study included people aged older than 18 years who were consulting their GP because of LBP of longer than 14 days' duration. People without access to the internet were excluded, as were pregnant women, people who did not speak Danish as

their native language, or those who had signs of a serious underlying disease.

Sampling Strategy

A physiotherapist, a GP, or a medical staff member acted as a recruiter and invited potential participants, including people currently consulting general practice, people who had previously consulted general practice regarding LBP (cold list recruitment), or people who had recently been referred from general practice to a physiotherapist. The recruiters recorded the contact information and gave it to AR, who contacted eligible participants to make appointments for interviews. AR provided verbal information by phone, and the participants received written information before being interviewed. AR was responsible for including a heterogeneous group of patients with 5 patients from each STarT Back group to ensure variation in bio-psycho-social profiles. Before interviewing, it had been decided to include more than 15 participants to inform us regarding our secondary purpose, "differences in preferences between SBT groups," if needed. However, following the 15 interviews, no distinctive patterns between the SBT groups were identified. Thus, increasing the sample size did not seem likely to add knowledge about clear differences and was consequently not performed.

Approval and Ethics

This study was approved by the Danish Data Protection Agency (registration number 2015-57-0001) and conducted according to the principles of the Declaration of Helsinki. The study was not registered with the local ethics committee, as this was not required for interview studies. Participants gave written informed consent.

Approach

The interviews occurred in people's homes because that is where the participants cope with their pain and everyday life, and where the information and technology they use most often is present. The 2 interviewers (DMH and LDV) provided written information and collected written informed consent from the patients. After the interviews, people were asked to complete a questionnaire in the presence of the interviewers, who did not assist in filling in the information [26].

Data Analysis

Participant characteristics determined from the questionnaires [26] were presented as numbers (%) for categorical variables, and mean values (range) for continuous variables. The interviews were analyzed according to a phenomenological approach and using an interpretative analysis to identify preferences for the content and design of a Web app. Furthermore, the study population was divided into 3 groups according to the STarT Back risk groups, and differences between the groups were explored. The coding of the interviews was performed using the NVivo software package (QSR International Pty Ltd, Victoria, Australia).

Results

Participant Characteristics

Between October 4, 2016 and January 11, 2017, 15 interviews were conducted. The study population consisted patients with heterogeneity in their baseline characteristics (Table 1).

The interviews lasted approximately 45 min. The initial reading of the transcriptions yielded 16 potential coding themes that during the recoding for the final themes, and subsequently coding for the analysis, were reduced to 7 themes for the analysis (Multimedia Appendix 2).

Obtaining Information

This theme consisted of earlier experiences and expressed preferences for obtaining information regarding LBP.

Some participants trusted the GPs to supply the necessary information, which was their explanation for not searching for information themselves:

When visiting the GP, you trust him to provide you with relevant information. [Interview 2]

Another participant expressed:

The insight [into LBP] is just as important to me and not only to the GP's...When you understand, it's possible to take action yourself. [Interview 3]

Participants agreed that finding a health information technology (HIT) that encouraged self-management would provide inspiration about what they can do themselves. In general, participants showed skepticism regarding using existing HIT apps; as one participant explained:

You can easily end up looking like a hypochondriac. I think it would seem like that to me. [Interview 1]

Existing HITs were mainly associated with information explaining symptoms and diagnostics, which participants found hard to navigate through. Participants did not consider their professional judgments sufficient to relate to the Web-based information. They felt it only made them more confused and frustrated. However, participants were aware of existing HIT apps. The most frequently mentioned were the information site "Net-doktor.dk" (privately owned and financed by advertisements) and "the Patient's Handbook" at the "Sundhed-dk" (the National Danish eHealth portal financed by the Danish government, which provides access to information for the public and for health care professionals). Some participants associated "Netdoktor.dk" with "serious" conditions such as heart diseases rather than with LBP. Some participants were advised by their GP to look up "Patient's Handbook" but found the webpage hard to use:

It was difficult for me to find the specific exercises. I had to be persistent – I think others might have given up. [Interview 14]

The Patient's Handbook was, however, the most frequently visited site. HIT apps related to health care professions, such as chiropractors and physiotherapists, were mentioned as relevant, although not often visited. Facebook had introduced some participants to information on both exercises and health care professionals. However, information on Facebook was described as having a low degree of credibility; patients used Facebook as inspiration when the information might result in less pain:

Not everything on the internet is rubbish; even though it seemed unreliable, I thought I might as well try it. [Interview 8]

Table 1. Baseline characteristics.

Baseline characteristics ^a of patients with low back pain	Value
Number of participants, N	15
Age in years, median (range)	40 (22-68)
Gender, n (%)	
Male	11 (73)
STarT ^b Back Tool risk-group	5 in each group
Pain duration > 12 weeks, n (%)	9 (60)
Pain score ^c , median (range)	4 (1-8)
Functional Disability score ^d , median (range)	7 (0-18)
Health information seeking behavior on the internet, monthly or more; n (%)	5 (33)

^aN=15, questionnaires were filled-in during interviewing. However, for 3 participants, the SBT was reported over the phone to balance participants between the 3 SBT risk-groups (low, medium, or high).

^bSTarT: Stratified Targeted Treatment.

^cNumerical Pain Rating (0-10, 0=no pain).

^dRoland Morris Disability Questionnaire (23 items, Patrick version).

Content, Information Source, and Preferred Devices

This theme consisted of earlier experiences with seeking health information on the internet on different devices.

Participants would rather ask GPs than use the internet for information with regard to a diagnosis:

I would rather talk to a professional when it concerns a clarification [of the cause] who I can sit in front of and ask questions if necessary. [Interview 1]

However, regarding whether participants used an HIT app to find information, it would make a difference if GPs recommended it. Furthermore, if GPs recommended an HIT app, participants felt it would save them time searching online. One participant used the term “jungle” about the internet, meaning it is time-consuming to find what is requested because the World Wide Web contains tons of information that may be irrelevant:

Maybe it would increase the interest in the particular webpage, since there are hundreds [of webpages] to choose from. Knowing which one to use, you do not have to go through all to figure out which one is the best. [Interview 4]

Participants used a range of devices such as personal computers, smartphones, and tablets when searching online. They argued that their smartphone was always within reach, whereas a computer or tablet was useful when reading larger pieces of text.

Readability

This theme comprised earlier experiences with reading and understanding Web-based information, including preference to support this in Web apps.

Participants found language style important on HIT apps. One participant expressed:

When a health care professional explains, I don't understand all of it. Not to be rude – but not all healthcare professionals are able to present information which can be understood, and then it ends up being gibberish [to me], and I will exit the homepage. [Interview 1]

A participant described that language should be:

...understandable, like the language non-professionals use: Even though I work in healthcare and am familiar with some Latin, I'm challenged when encountering a lot of [difficult words]. [Interview 5]

Participants suggested a textbox explaining the Latin words, as this could ease the reading, and having professional text writers do the writing. Participants also stated the importance of considering colors on the webpage because certain color combinations reduce readability.

Customization

This theme consisted of earlier experiences with the ability of Web apps to meet their needs and suggestions to include this in a Web app for patients with LBP.

A combination of text, photos, and videos was preferred. However, the content sets the bar as to how the information should be presented:

Sometimes when information is presented in text, people do not understand it the way it is intended. In these cases, videos and photos are useful. [Interview 3]

Additionally:

some exercises cannot be explained [with text]; they need to be demonstrated. [Interview 13]

Participants found text useful when it reinforced explanations in videos. It was likewise described as beneficial to have the opportunity to print out pictures of exercises. Videos were requested as a means to show and explain exercises, as one participant explained:

It would be nice to have someone who knows what he or she is talking about to show an exercise. [Interview 4]

Like photos, videos were also argued as a relevant method to make the presentation of information more interesting, especially for people who prefer to learn via visual impressions. It was suggested to let someone explain certain topics, ie, explaining while drawing on a whiteboard. Notifications on when to do exercises were suggested as a part of the HIT app:

I have actually considered setting an alarm on my phone to remind me to do my exercises. [Interview 3]

One participant said:

Send an email with the link. This would also serve as a reminder to me. [Interview 14]

Design

This theme comprised earlier experiences with the design of Web apps and suggestions to the design of a Web app for patients with LBP.

Aspects such as first impressions, customization, and certification were considered important to the design and appearance of an HIT app. The purpose of a webpage should be easy to detect at first glance, since participants described a webpage where the purpose is unclear as messy. Participants expressed how a messy front page could make them leave without further interaction with the content. Participants found it critical if Web apps were not suited for the target group:

They have just made a web app and presented the information they believe is relevant. [Interview 8]

Another participant suggested a front page prescribing the content and asking questions to guide the information delivered through the Web app. However, it was emphasized that if questions are asked, the reason to ask questions must be clear:

I am the one searching for information; why do they need information? [Interview 8]

It was suggested that all text should be presented on one page to avoid clicking around and ultimately getting lost. Others suggested a table of contents as seen in a book, which could provide an easy overview of the HIT app. One participant said:

The application should be user friendly – not too much confusion and use of different colors – it needs to be easy and simple. You do not want to spend too much time looking for the information relevant to you. [Interview 4]

Credibility

This theme comprised earlier experiences with the credibility of Web apps and suggestions to support the trustworthiness of a Web app for patients with LBP.

Participants expressed that layout and text should clearly indicate professionalism. One participant commented on presenting health care professionals as the source of information:

It could work as a certification mark, indicating that someone capable has been a part of it, thereby informing the user whether it is The Health Authority or somebody else certifying the application. It would be something I would look for if it existed. [Interview 8]

Participants agreed that other health care professions such as nurses and physiotherapists were reliable sources on equal terms as GPs when information should be presented on the Web. Participants found advertisements on an HIT app bad, as they could send mixed signals and be disturbing:

If advertisements are not related to LBP, it would be particularly strange to present them on the web page. [Interview 4]

Additionally:

If the page is stuffed with advertisements, then someone else has an interest in the page – one related to possible profit. [Interview 6]

It was argued that if a “wonder cure” had actually been found, why are people not receiving it from their GP already? However, one participant indicated that advertisements could be acceptable if they excluded people from paying for access. In addition to pop-ups, he did not mind advertisements:

Rather advertisements than having to pay for the content. [Interview 8]

Usability

This theme consisted of earlier experiences with the usability of Web apps, in particular the importance of avoiding the sense of getting lost.

Participants stated that a search function is desirable to have on an HIT app. However, one participant expressed when using search functions in general:

It is not something I do very often, though I know the possibility is there, simply because I don't want to spend my time on it, as I think I find a lot of information with no relevance to me. [Interview 9]

Additionally:

A good search function is one which understands what I mean, because I don't know all the Latin expressions to my back problems. [Interview 3]

Participants explained how a search function becomes crucial if the HIT app is hard to navigate. An alternative to a search was some kind of guide to what the HIT app contains.

Discussion

Principal Findings

Participants considered a Web app potentially useful in combination with advice and information regarding LBP provided by their GP. However, certain barriers prevent most patients from frequently using the internet as a source of health care information. The domains of readability, customization, design, credibility, and usability are all important for patient satisfaction with a Web app.

Comparison With Prior Work

The credibility of the provider was found to be a key determinant for considering Web-based health information to be trustworthy, which was also identified by Eysenbach et al [27]. Most of the requested information or content, such as seeking a diagnosis (also if the diagnosis is nonspecific LBP), information about possible prognosis, advice about how to stay active, and advice on how to perform exercises, is in accordance with international guidelines for what is recommended to be delivered by health care professionals [28,29]. However, in this study, people with LBP also preferred receiving more individualized information, especially on how to cope with pain, and how to choose and perform exercises. In a Web app, this could be achieved by integrating advice on pain and exercises according to the principle described by Silbernagel et al [30]. They proposed a continuous pain monitoring model to motivate and guide the rehabilitation of patients with Achilles tendinopathy [30]. Combining guideline-concordant advice with the tailoring of content to fit users' preferences and interests can be an effective tool in self-management of LBP [28]. This has previously been found to be a useful tool to achieve the initial use of the technology; however, as also previously reported, it is unclear whether this leads to satisfied users and continuous user engagement [31].

Clinical Implications

In this study, patients expressed the need for Web-based information for LBP. Some patients had problems with understanding the content, whereas patients understanding the content found the content on existing Web apps irrelevant to them. Therefore, an effort to involve patients in the development of Web apps, include patients' preferences, and thereby increasing satisfaction with Web apps for LBP, have a large potential to increase the use of Web apps. An increased use can lead to improved functional outcomes for patients with LBP, the condition most prevalent among all health care conditions worldwide [1].

Strengths and Limitations

The 15 patients in this study were interviewed when they had an appointment to see their GP; therefore, they were at a point in time when they actively sought information regarding LBP. Furthermore, interviewing took place at the patients' homes, thereby reflecting the settings, where patients normally seek

information on the Web. Timings combined with settings are unique and strengthened this study. Patients were sampled with the purpose to reach maximum variation in bio-psycho-social profiles by use of the SBT [22], which strengthens the generalizability of findings to other primary health care settings.

Only one-third of the responders sought information monthly or on a more frequent basis, which may have restricted the findings regarding Web app usage and thereby weakened parts of the analysis. It had been planned to describe differences between the 3 SBT groups; however, based on this material, it was not possible to draw any conclusions. A larger sample size may be needed to identify differences. This study was performed to inform the development of informational material to supplement routine care. Participants were informed of this before the interviews. Consequently, this strategy does not

support transferability to settings in which the purpose of the information is a stand-alone intervention.

Conclusions

This study identified important issues to consider when developing and supplementing existing general practice treatment with Web-based information and advice to patients with LBP. Important domains to address in the development of a Web app for people with LBP are readability, customization, design, credibility, and usability. Some of the findings were consistent with our expectations. However, the inability among eHealth providers to inform in language suited to the patients surprised us. The authors were also surprised that patients often felt that the available information did not relate to their condition.

Acknowledgments

This work was supported by The Danish Rheumatism Association and The Novo Nordisk Foundation. They played no role in formulating the research questions, data collection, interpretation of the results, writing of the paper, or decision to publish.

Authors' Contributions

All authors have contributed to the conception of this study. Research questions and interview questions were developed by AR, DMH, and LDV. DMH and LDV conducted the interviews and transcribed the data. AR, DMH, and LDV performed the data analysis. Translations were performed by AR, DMH, and LDV. All authors participated in interpreting the results. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Interview guide.

[[PDF File \(Adobe PDF File\), 27KB - rehab_v5i1e7_app1.pdf](#)]

Multimedia Appendix 2

Themes for coding and analysis.

[[PDF File \(Adobe PDF File\), 296KB - rehab_v5i1e7_app2.pdf](#)]

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Abbreviations

GP: general practitioner

HIT: health information technology

LBP: low back pain

STarT: Stratified Targeted Treatment

SBT: STarT Back Tool

Edited by G Eysenbach; submitted 25.08.17; peer-reviewed by A Geraghty, M Alshehri; comments to author 02.12.17; revised version received 16.01.18; accepted 02.02.18; published 02.04.18.

Please cite as:

Riis A, Hjelmager DM, Vinther LD, Rathleff MS, Hartvigsen J, Jensen MB

Preferences for Web-Based Information Material for Low Back Pain: Qualitative Interview Study on People Consulting a General Practitioner

JMIR Rehabil Assist Technol 2018;5(1):e7

URL: <http://rehab.jmir.org/2018/1/e7/>

doi: [10.2196/rehab.8841](https://doi.org/10.2196/rehab.8841)

PMID: [29610108](https://pubmed.ncbi.nlm.nih.gov/29610108/)

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