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The pitfalls of using telerehabilitation and electronic activity monitoring for people with multiple sclerosis in a rural setting

Bahram Sangelaji[1]*; Catherine M Smith[1]; Gareth J Treharne[2]; Leigh A Hale[1]

[1]Centre for Health, Activity, and Rehabilitation Research (CHARR), University of Otago, Dunedin, New Zealand

[2]Department of Psychology, University of Otago, Dunedin, New Zealand

***Corresponding Author(s): Bahram Sangelaji**

Centre for Health, Activity, and Rehabilitation Research (CHARR), University of Otago, Dunedin, New Zealand

Email: bahram.sangelaji@otago.ac.nz

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Abstract

Background: Ongoing engagement in physical activity is known to be beneficial for people with multiple sclerosis (pwMS). Participation of pwMS in physical activity is however significantly lower than global recommendations.

Introduction: Technology-based Behavior Change Interventions (BCIs) may be effective in supporting pwMS to increase participation in physical activity. The perceptions and opinions of rurally living pwMS regarding the use of digital platforms and digital activity monitors have not been explored. This study explored perceptions of the use of technology for rurally living pwMS and investigates the pitfalls and problems of this technology.

Materials and methods: This proof-of-concept study involved thematic analysis of semi-structured interviews with a physiotherapist and four pwMS who participated in Web-Based Physiotherapy (WBP) and tested two digital activity monitors.

Results: Two themes of "using the activity monitors" and "using computers to access WBP" highlighted the personal and technological challenges of using digital activity monitors and web-based exercise platforms in a rural setting.

Conclusion: Although WBP showed promising benefits for increasing physical activity participation in pwMS, in a rural setting, there are both personal and technological barriers that need addressing for successful implementation of this form of telerehabilitation. More informed digital education, contemporary devices, and digital platforms (e.g., smartphone apps) need investigation for successful technology-based interventions and monitoring in a rural setting.

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Background

Multiple Sclerosis (MS) as a degenerative neurological condition causing fatigue and motor, sensory, and cognitive impairments that impact mobility and participation in physical activity and quality of life [1]. Participation in structured exercise programs and other forms of physical activity can reduce fatigue, increase cardiopulmonary health and improve quality of life in this population [2-5].

Encouraging the general population to engage and maintain participation in physical activity is challenging [6], and even more so for people with long-term health conditions such as MS who face many barriers to participation [7,8]. Barriers such as lack of suitable recreation facilities and, financial and transport limitations [9] are especially problematic for those living rurally [7]. Interventions are required to help mitigate these barriers and assist pwMS to adopt and sustain engagement in physical activity. Behavior Change Interventions (BCIs) are "coordinated sets of activities designed to change specified behavior patterns" (Michie 2011, page 1) and are effective in promoting physical activity behaviors in a range of long-term conditions [10-13]. BCIs may, therefore, help increase engagement in physical activity for pwMS.

There is some evidence that interventions using telerehabilitation platforms to deliver BCIs among pwMS can increase physical activity engagement [14]. In addition, user-worn digital devices are increasingly being used either as BCIs or as quantitative measures to track physical activity. Use of these devices can be challenging to the wearer, for example, attaching the device in the right location on the body, working with the technology of the device or using it consistently long-term [15-19]. However, the perception of pwMS about using various technological platforms and devices has not yet been fully explored, especially in those living rurally.

This paper reports a proof of concept study in which the perceptions of rurally living pwMS in the use of the two digital activity monitors and a computer-based platform technology (called Web-Based Physiotherapy [20]) to support physical activity engagement for pwMS living in rural New Zealand were explored.

Method

A qualitative case study design collecting data with semi-structured interviews was used. The observations of the researcher (BS) who briefed participants about use of the digital monitors and WBP were also used as a data source. The University of Otago Human Ethics committee (ID: H16/078) approved the study.

Participant recruitment and selection criteria

Participants were recruited via the Otago Multiple Sclerosis Society. Selection criteria included (1) to be 18 years or more (2) to be diagnosed with MS (3) to have a computer and internet access and be familiar with basic computer skills (or have a person who could help them to use a computer), and (4) to live in a rural area (in New Zealand area as defined by residential postal address). All participants gave written informed consent.

Participants were engaged in Web-Based Physiotherapy and wear a Vivoactive™ activity monitor for 12 weeks. Each participant also wore a SensWear™ activity monitor for one week prior to and one week after the 12 week intervention period. Following this semi-structured interviews were conducted by the researcher with both the participants and the physiotherapist delivering WBP.

Web-based physiotherapy

Web-Based Physiotherapy (WBP) is an exercise intervention prescribed and supported by a physiotherapist and delivered via a website platform. It was designed to enable participation in exercise [20-22]. The website contains a library of over 300 exercises, and each exercise page includes an exercise video clip, audio and text exercise description. In this study, a physiotherapist visited each participant at their home for an initial consultation and to collaboratively establish exercise goals and develop an individualized exercise program from WBP. Participants were asked to use a digital diary of exercise participation on the website. The physiotherapist could view the diary remotely and modify the participant's program if necessary. Participants were asked to use WBP for 12 weeks.

Digital activity monitors

Two digital activity monitors were chosen for trial in this study based on a range in: (1) type of data collected, (2) body site of monitor attachment, (3) validity and reliability of data collection and (4) price.

The SensWear™ monitor (BodyMedia Inc., Pittsburgh, PA, USA) was chosen as an "expensive" monitor, (about NZD 2000). SensWear™ is an armband triaxle accelerometer that has been used successfully to measure the short-term physical activity in ambulating pwMS [23], individuals with paraplegia [24] and healthy people who use wheelchair propulsion as an exercise [25]. The device uses AAA type batteries and can be connected to a personal computer (PC) with a Universal Serial Bus (USB) connection. The SensWear™ management software is installed on the PC and extracts the raw data and analyses it. The daily steps and consumed energy were the variables collected and analyzed. A study reported a 4% overestimation of energy expenditure rather than a gold standard measurement (of doubly labelled water), however, it displayed a better sensitivity in comparison with the other devices [26]. A good agreement exists between the device and step counting and energy expenditure in stroke participants (intra class correlation coefficient, ICC=0.702) when they used the armband on their intact upper limb, but only a fair relationship was detected when the affected upper limb was used (ICC=0.586) [27].

The Vivoactive™ monitor (Garmin Ltd., Olathe, KS, USA) was chosen as a commercial "cheaper" monitor (about NZD 350). It is a triaxial accelerometer with a built-in GPS, is lightweight and waterproof and also acts as a smart wristwatch. The battery is rechargeable, and connects to PCs, smartphones, and tablets via USB connection or Bluetooth. The raw data is sent to Garmin website located in San Francisco, USA. After six to 12 hours, analyzed results are released to an individual password-protected web page. Daily steps and energy expenditure were the variables collected and analyzed. However, we did not have sufficient data concerning the durability and reliability of this monitor, a recent systematic review about using other similar activity monitors in more healthy people, revealed a good validity of step counting (ICC=0.90), and an excellent validity for energy expenditure (ICC=0.95) on devices where their wearing site was the wrist [28]. There is no published evidence to measure Vivoactive in terms of physical activity measurement in pwMS.

Data collection and analysis

Interviews were conducted face-to-face by one researcher (BS), audio-recorded and then transcribed verbatim by a professional transcriptionist. The data were thematically analyzed using an inductive approach led by two researchers (BS, CS) following the phases described by Braun and Clarke [29]. In brief, the phases involved: 1) familiarisation with raw data by multiple readings, 2) generating and refining codes addressing the research question, 3) developing preliminary themes from the codes, 4) reviewing the themes, 5) defining and naming themes, and 6) producing a report describing the themes.

Results

Four female volunteers (age range 56-75) with MS were recruited from a rural region in the South Island of New Zealand. When reporting the findings, each participant is referred to by a pseudonym. Below the findings are reported in three sections. Firstly, the participants are introduced individually to provide insight into the technological issues faced by each individual. Secondly, a summary of the researcher's observations is reported. Finally, the thematic analysis of the interviews with pwMS and the physiotherapist is described.

Participants

Mary (75 years) reported a 21-year history of MS (type unknown) and moderate to severe osteoarthritis in her hip, knee and shoulder areas. Mary was retired and lived alone in a suburb of a small rural town. Despite adequate access to the broadband internet, her computer and mobile phone did not meet the minimum hardware requirements of Vivoactive™ activity monitor software and she was, therefore, unable to use this device. She was able to successfully access and use WBP and, wore SensWear™ without any complaint.

Kate (65 years), a retired woman with secondary progressive MS, lived with her husband in a rural area. Kate had access to broadband internet, and, based on researcher observation, had a basic knowledge of computer operation. She was not however able to complete advanced activities such as updating her computer's operating system or using web browser to lunch a website such as the WBP website or installing an application such as the Garmin administration application. Synchronization of Vivoactive™ was not possible as her computer RAM and processor were too old to support the software. Data transfer between the activity monitor and her mobile phone was also not possible. She reported that the SensWear™ armband was "scratching" however, she used it according to instructions. Like Mary, Kate was also able to successfully access and use WBP.

Lora (56 years) had a three year diagnosis of relapsed remitting MS. She was undertaking post-graduate studies whilst working simultaneously. Lora lived with her partner on a farm. She had access to broadband internet and an up-to-date laptop. Her computer's operating system and hardware were compatible with the Vivoactive™ and the WBP website. Lora was the only participant for whom the Garmin administration software could be successfully installed and who could also use the device properly. Also, Lora successfully used SensWear™.

Margo (56 years), a retired woman with secondary progressive MS diagnosed in 1986 (two years after first experiencing signs and symptoms), lived with her husband in a rural area. Her access to the broadband internet was reliable, and her computer was compatible with the Garmin activity monitor and for accessing and using WBP. After the first session, Margo said she did not like the technological devices and stated that she had problems trying to use them. The researcher attempted to help via emails and text messages, but Margo ended up refusing to use the Garmin. Also, Margo complained that the SensWear™ affected her "biorhythms." As a result, she stopped using the SensWear™.

Researcher observations

The researcher noted three technological issues in this study: 1) age of participants' computer systems, 2) low internet speed 3) participants' limited computer knowledge.

Two participants' computers were old, and although some systems were still working correctly, these participants could not install the support software for the Garmin devices. Also, the software of both of these computers was not up to date, and updating of hardware was not possible. Surprisingly, some of the devices such as tablets or mobile phones were not very old. For example, in the case of Kate's mobile, although the model was introduced to the market in 2011 and the handset was manufactured in 2013, it was unable to support the Garmin application.

In the rural areas where participants lived the low-speed internet was problematic despite all participants having broadband internet. For example, when the physiotherapist tried to show a video clip to Mary in the first face-to-face session at her home, it took 10 minutes to enable the clip to download and run.

Whilst all participants had some computer operational knowledge, they did not have the in-depth knowledge required to assess compatibility or solve unexpected problems, and the researcher was frequently consulted to solve issues at a distance. This limited computer knowledge led to one participant (Margo) declining further use of the activity monitors.

Qualitative findings

Analysis of participant and physiotherapist interviews resulted in two themes: 1) Using the activity monitors, and 2) Using computers to access WBP.

Using the activity monitors

The first theme addresses participant views of the activity monitors. All four participants expressed dissatisfaction with using SensWear™. Complaints about this activity monitor included bulkiness, noise, and soreness at the site where the SensWear™ was worn (usually the upper arm). For example, Margo explained: "it is very uncomfortable, especially when you are sleeping." Kate expressed that the monitor is: "Very bulky and heavy." Mary said it was: "Very intrusive." Lora complained about the rashes that using the SensWear™ caused.

Participants differed in their views about Vivoactive™. This activity monitor was not compatible with Mary and Kate's computers and so they could not comment on its use. Margo declined ongoing use of all technology, including this activity monitor, and commented: "Technology, and I just seem to be incompatible". Lora, however, it was very positive about how the Vivoactive™ was able to monitor her physical activity: "you'd reached your goal for the day, it buzzed, and it was all the fireworks on the screen, and it made you feel really good ……… I think the watch, it was like somebody was there keeping an eye on me."

Using computers to access WBP

The second theme addressed participants' opinions about using a web-based approach to support their exercise. Some expressed frustration with having to use a computer interface, such as forgetting the password of the website or forgetting to tick the completion box in the WBP website that showed whether the participant had completed the exercise or not: "I kept forgetting to go onto the website" (Kate) or "I lost the piece of paper, I forgot my password." (Margot).

Once on the website, however, mostly participants were satisfied. They reported being easily able to access the website and use its contents: "Easy, yeah no problem" (Mary) or "it was easy to load onto and get onto I just used to put it on my iPad and prop it up on the sofa and um, go ahead." (Lora).

All participants tried the WBP diary as a method to make contact with the physiotherapist. However, because of the one-way nature of the diary (it is readable only at the researcher and physiotherapist end), communication between participants and physiotherapists defaulted to email or text messages as faster and easier method of communication. Therefore, Email or text was the preferred method of contact as participants felt that the telephone would be inconvenient: "Someone like [the physiotherapist] wouldn't want to ring just in case that person is resting or whatever." (Kate)

Most participants found the idea of using the technology to increase their physical activity acceptable and feasible with statements such as: "I think the idea is really good especially for rural people." (Kate) or "Good as gold, yes yes, it was fine." (Mary). Participants felt that technology could overcome some of the barriers that they faced to be more active. For example, three participants complained about transportation problems despite two being able to drive. Transportation barriers could be classified in two different ways. Firstly, dependency on other people: "I can't get into town you know without my husband." (Kate) And secondly, the long distance from traditional rehabilitation centers: "Face to face would probably work for those closer to Dunedin, but I'm a three-hour drive from Dunedin so at this stage either Skyping or telephone." (Margot)

Regardless to the technical problems, participants all expressed that they required more motivation to engage with the WBP intervention. At first, participants found the intervention interesting, but as the weeks progressed, it became *"boring," "tedious,"* or "*monotonous.*" Also, "*Scottish*" accent of WBP and "*old fashion*" nature of the clips, lack of "*oomph*" (as Margot said) and "*music*," and "*very slow and robotic-like*" (Margot) were also complaints. It seemed that one of the problems was that despite the exercise archive of the WBP website having more than 200 different exercise clips, participants felt that the physiotherapist restricted the number of exercises she prescribed them. For example, as Margot said: *"I'm limited in the number of exercises" or "…was the same old exercises repeating all the time…"*

Also, participants expressed their need for social support via WBP which was unmet due to one-way nature of WBP. Margo said: *"It would be also a good idea to be able to have a contact where, if you feel you can so a bit of exercise you have got some advice, ah that you can either drop an email or text somebody who knows, who you know has got your best interest at heart".* Mary suggested: *"I suppose like a Facebook page…"* Likewise, Kate said: *"I like the idea of support. I have got a good support group around me … when I need them, I can contact them… so that is good."* For example, Margo would like to have a personal relationship with the other participants to compare herself with them: *"How well they were doing and what they were feeling."* Also, she thought that this relationship might be helpful to have to provide more motivation: *"…because I know when I talked to Mary at one of the meetings that she was doing it every day, and I thought oh I'm a bit slack here I better get cracking more."*

Discussion

This study trialed a Computer-Based platform Technology (WBP) as a BCI to support physical activity engagement for pwMS living in rural New Zealand and, two digital monitors to this track this engagement. We explored the use of these technologies from researcher, physiotherapist and participant perspectives. We found WBP to be conceptually acceptable to pwMS living in a rural setting, in that they volunteered for the study. In reality, however, it was not that easy to use. Using WBP presented some software and hardware issues and this combined with participants' limited computer knowledge to create some challenges.

Participant computer knowledge was insufficient to easily use this technology. For example, knowing how to install and update computer software. A possible reason for these difficulties may have been age [230]. The age range in our study was 56 to 75 years old. Based on the findings of a cross-sectional study in rural and urban setting in USA with healthy participants (n=283, mean 67.46 years), being older is associated with significantly lower technological literacy [31].

Also, a systematic review showed moderate evidence of reverse relationship between age and digital literacy in all industrial countries [32]. A second reason for participants' lack of computer knowledge may be due to their lack of experience in using computers due to the current poor access to reliable internet in rural Otago [33].

Computer technology and internet communication are promising mediums to facilitate patient and physiotherapist interactions. However, the therapeutic role of WBP in a population who are not skilled in advanced computer operation is debatable. Our results along with other findings [34,35] recommend a smarter platform may be needed to facilitate therapist-patient interactions. Bert et al. in 2013 suggested the use of Smartphone Applications rather than computer-based interventions [32], and this maybe a more viable option in rural areas where internet access is poor. Smartphone technology is more user-friendly and potentially more accessible than computer-based programs. In addition, mobile internet coverage (3G or 4G) might be better than broadband in rural areas [32].

Of the digital activity monitors, SensWear™ had practical limits and was considered by participants to be "bulky," "scratchy," and "noisy." In line with this finding, Giggins et al. recommended a more appropriate attachment method (belt or adhesive) to prevent long-term discomfort [36]. The Vivoactive™ was also not optimal. It demonstrated compatibility issues with some computers, tablets, and mobile phones even though some were not old models and thus two of our participants could not use it. Two participants were able to use the Vivoactive™, however one participant did not like using electronic "gadgets" while the other was very positive about using it. This discrepancy in the use of electronic gadgets can be explained by the social identity theory [37]. Technology users can be categorized socially based on their age, community, gender, purposes for using technology and technology awareness [30,38]. Therefore, learning new digital skills or using new technologies may be influenced by social identity. The participant who liked the Vivoactive™ was a postgraduate student and thus may have been more exposed to the use of technology. Digital activity monitoring should be chosen carefully based on participants' age, education, their cognitive situation, and their socioeconomic situation. More research is needed regarding the practicalities and acceptability of long-term physical activity monitoring (> 1 month). Using social media [39], radio frequency technology [40], and smartphone activity monitoring [41] might be the solution.

The other critical issue was the participants motivation. It seems that some factors identified in the WBP component such as different accents on the clips (Scottish accent), lack of music and oomph in the clips, caused disappointment in some but not all the participants. The motivational problem was not reported in the BP section. More social support was another issue that identified. Participants spoke about their need for support from the other participants or specialists. Michie's taxonomy identifies "Social Support" as one type of BCIs [42]. In line with this finding, Duff et al. in their systematic review mentioned that "Social support" is the third common BCI (46%) among physical activity telerehabilitation interventions for cardiovascular people [43]. Similarly, Williams et al. pointed to a significant effect from the use of this BCI to increase physical activity in more healthy people [12]. Embedding a form of social support to support people into physical activity may be extremely important when people use telerehabilitation interventions in their homes as this could increase the sense of *"isolation"* (Mary). Demiris et al. in 2004 mentioned that the social supports that are provided by E-health methods could decrease the participant's isolation for those who lived in rural areas [44]. They stated that these supports can be conducted via telephone, text, or telemeetings [44]. Bearing all this mind it seems that an improvement in the degree of connection with the participants is needed in my intervention.

As our study was a proof of concept study it is limited by its small sample and our findings should only thus be used to guide future research.

Conclusion

Whilst WBP appears conceptually acceptable as a telerehabilitation intervention to increase physical activity participation in pwMS living rurally, personal, technological, and educational barriers need addressing before it can be practically acceptable. SensWear™ was not acceptable to any participant and the Vivoactive™ was only acceptable to one participant. Digital education, more user friendly devices or platforms (e.g., smartphone apps) need investigation for successful technology-based interventions and monitoring in a rural setting.

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