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Original Paper

Exoskeletons With Virtual Reality, Augmented Reality, and Gamification for Stroke Patients' Rehabilitation: Systematic Review

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Abstract

Background: Robot-assisted therapy has become a promising technology in the field of rehabilitation for poststroke patients with motor disorders. Motivation during the rehabilitation process is a top priority for most stroke survivors. With current advancements in technology there has been the introduction of virtual reality (VR), augmented reality (AR), customizable games, or a combination thereof, that aid robotic therapy in retaining, or increasing the interests of, patients so they keep performing their exercises. However, there are gaps in the evidence regarding the transition from clinical rehabilitation to home-based therapy which calls for an updated synthesis of the literature that showcases this trend. The present review proposes a categorization of these studies according to technologies used, and details research in both upper limb and lower limb applications.

Objective: The goal of this work was to review the practices and technologies implemented in the rehabilitation of poststroke patients. It aims to assess the effectiveness of exoskeleton robotics in conjunction with any of the three technologies (VR, AR, or gamification) in improving activity and participation in poststroke survivors.

Methods: A systematic search of the literature on exoskeleton robotics applied with any of the three technologies of interest (VR, AR, or gamification) was performed in the following databases: MEDLINE, EMBASE, Science Direct & The Cochrane Library. Exoskeleton-based studies that did not include any VR, AR or gamification elements were excluded, but publications from the years 2010 to 2017 were included. Results in the form of improvements in the patients' condition were also recorded and taken into consideration in determining the effectiveness of any of the therapies on the patients.

Results: Thirty studies were identified based on the inclusion criteria, and this included randomized controlled trials as well as exploratory research pieces. There were a total of about 385 participants across the various studies. The use of technologies such as VR-, AR-, or gamification-based exoskeletons could fill the transition from the clinic to a home-based setting. Our analysis showed that there were general improvements in the motor function of patients using the novel interfacing techniques with exoskeletons. This categorization of studies helps with understanding the scope of rehabilitation therapies that can be successfully arranged for home-based rehabilitation.

Conclusions: Future studies are necessary to explore various types of customizable games required to retain or increase the motivation of patients going through the individual therapies.

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KEYWORDS

stroke; robot; exoskeleton; virtual reality; augmented reality; gamification; rehabilitation

Introduction

Background

Stroke refers to a sudden, often catastrophic neurological event that can lead to long-term adult disability. The American Heart Association (AHA) is responsible for providing up-to-date statistics related to heart disease and stroke. According to Benjamin et al [1], the AHA released a 2017 statistics report on heart disease and stroke that stated that approximately 795,000 stroke episodes occur in the US each year. With current advancements in medical technology there has been a decrease in the rate of stroke incidents, but it can still cause paralysis and muscle weakness. Such impairments can result in motor deficits that disturb a stroke survivor's capacity to live independently.

There are several reasons for stroke occurrence, which could be related to an increased risk of a collection of symptoms caused by disorders affecting the brain (eg, dementia) [2]. Various rehabilitation techniques have been used in the area of rehabilitation-based interactive technology to assist patients in recovering from impairments, and those techniques come under the umbrella of conventional therapy, exoskeleton or robot-aided therapy, virtual reality (VR) or augmented reality (AR) therapy, games-based therapy, or a combination of any of these. These forms of therapy can be done either in the clinic or in an in-home setting. In addition to these, there is a new technology known as telerehabilitation [3] that leverages the use of VR in home settings by providing patients access to real-time rehabilitation services through the internet while they sit at home.

One of the most effective techniques is robot-aided therapy, which has been gradually increasing in use primarily because patients may consider traditional rehabilitation therapy to be tiring and exhaustive. This may decrease their motivation and cohesion to the treatment, thus resulting in only minor improvement in the health of poststroke patients [4-6]. Various experimental evidence suggests that robot-assisted (or exoskeleton) rehabilitation has been effective in keeping patients motivated and interested in treatment for both upper or lower limb impairments [7,8]. With advancements in technology, there has also been an uptake of VR, AR, and Gamification for the purposes of rehabilitation [9], along with robotic rehabilitation [10,11], primarily to increase engagement, immersion and motivation on behalf of the patient. Both Colombo et al and Alankus et al [12,13] concluded and showed the positive effect of exoskeleton robots and games in poststroke rehabilitation. Wearable devices such as exoskeletons can also relay real-time feedback for any VR-based interactions [14].

Apart from these studies, Housman et al [15] showed user satisfaction survey results in which 90% of participants agreed to the fact that robot- or games-assisted therapies were less confusing, and improvements were very easy to track compared to traditional or conventional therapies. Further, it is thought that gamification can increase repetition, engagement, and range of care within the context of rehabilitation [16,17]. Games are not only useful for the field of rehabilitation, but they are also considered to be highly impactful and relevant in other medical and health fields. Russoniello et al [18] conducted a randomized controlled trial (RCT) study in which the effects of video games on stress-related disorders were tested, with the conclusion being that games were beneficial for their prevention and treatment. In another study, children who had cerebral palsy made use of a game (EyeToy) which was able to improve their upper extremity functions over time [19].

Virtual Reality, Augmented Reality and Gamification

VR is a virtual form of a real entity, object or environment. According to Schultheis et al [20], VR can be regarded as an enhanced version of human-computer interaction (HCI) in which the human interacts with a three-dimensional (3D) interface and is immersed in a synthetic environment comprised of digital objects. Various devices, such as earphones and head-mounted displays (HMDs), are used to support this form of technology. VR has already become popular in the fields of science, music, education and training, and healthcare, but in areas such as poststroke rehabilitation it has been an immense benefit. For example, Katz et al [21] described the effectiveness of VR in treating poststroke patients through their street program. In this study, the patients were suffering from Unilateral Spatial Neglect (USN), which happens because of right hemisphere—caused stroke. VR can provide the opportunity to create and customize a patient's training based on their interests. This could increase their motivation to continue training and increase their attention during their sessions, both of which are essential factors for effective rehabilitation.

As mentioned above, traditional methods of rehabilitation might lead to a patient's loss of interest in their therapy, as it often involves daily repetitive tasks. VR encourages patients to participate in their therapy by either incorporating games in the form of exercises or through other interactive means. With the current state of VR in rehabilitation services, a new form of therapy has gradually emerged that is known as Virtual Rehabilitation [22]. Virtual rehabilitation is defined as the ability of VR to provide therapy to patients using its hardware and simulation. Apart from a definition, Burdea also lists classifications and taxonomy for Virtual Rehabilitation [22]. Classification is done based on the area of study, the rehabilitation protocol, or the availability of a therapeutic team for the patient. Hardware used in VR is multipurpose and can be used for different patients suffering from different types of strokes (eg, a hand glove can be used to do strengthening exercises as well as other motor improvement exercises.) Therefore, VR provides an interactive and motivational environment, where patients feel encouraged to participate in clinical or home-based trials.

We must also consider the advancements in VR technology in recent years by the inclusion of sixth and seventh generation gaming systems, which include various popular systems such as the Xbox 360 Kinect and the Nintendo Wii. Yates et al [23] discussed various commercial gaming systems and gave extensive information regarding the features of these VR systems. When more realism (such as through the inclusion of tangible or physical objects in the virtual world) is added to VR, it gives rise to a new technology called AR. The user feels more realism as they receive more control over virtual objects by interacting with real objects. The virtual view of the world, or an environment, is superimposed in the real world, so therefore

VR and AR lie at the opposite ends of a reality-virtuality spectrum.

Slowly, AR is also gaining traction in the field of rehabilitation. According to Khademi et al [24], when a haptic device was used with AR in an experiment, there were improvements in hand stiffness that proved the potential of a haptic AR rehab system. In another study, Mousavi et al [25] trained and assessed subjects side by side with the help of multiple groups. One group used AR while the other one used traditional HCI via a personal computer and a mouse. The results of this study showed increased motor movements in the group using the AR technology as compared to the traditional means of interaction.

In addition to these two technologies (VR and AR), video games are often used in rehabilitation services these days as they play an essential part in encouraging patients to participate in therapeutic exercises. It should be noted that VR- or AR-interaction can be nongamified or nonplayful, which is why we prefer to delineate them. Games are used with specific hardware depending on the physical condition of the patients, and various game attributes are considered while developing games for rehabilitation purposes. There are several types of games used in rehabilitation services, such as two-dimensional (2D), 3D, VR and AR games, and other natural user interfaces such as Wii, PlayStation, Wii Balance, Xbox, and Kinect. Alankus et al [13] developed games for stroke-affected patients and identified three important attributes in this space: social context (multiplayer versus single player), motion type (single-muscle motion versus multiple-muscle motion) and cognitive challenge (easy versus difficult). Audio-visual cues and performance-related online information was also provided to patients as another means of boosting their motivation.

It should be noted that most of the games used in rehabilitation are commercial, off-the-shelf games. In a study conducted by Acosta et al [26], the feasibility of using the Nintendo Wii was assessed in a group of 20 patients, and it was concluded that use of computing gaming devices might be a benefit for rehabilitation. Burke et al [27] discussed various games (eg, *Rabbit Chase*, *Bubble Trouble* and *Arrow Attack*), and identified game design principles which were significant for upper limb stroke rehabilitation. However, the aim of our paper is to investigate and review the coupling of such gaming elements, or virtual reality, with an exoskeleton or robotic device.

Exoskeleton means an extension to the (human) skeleton, but in simplistic terms, some researchers have defined an exoskeleton as any transparent device that a user or patient may wear or attach upon themselves and that extends their natural motor capabilities by determining their intent [28]. They are popular for enhancing human strength and speed via their internal components, which is a composition of electric motors, levers, and hydraulics. There are many exoskeletons available, like Amadeo, HandCARE, ARMin IV, and CyberGlove, that are used to assist patients in participating in rehabilitation sessions.

To summarize, in our review we intended to ascertain the possible interactions of rehabilitation robotics or exoskeletons with AR or VR (forming the two major components considered within our review, that is, the hardware and the interfacing technology), that is, to use the intermediate interfaces employed as a means of supplementing the rehabilitation process using exoskeleton-based hardware. Therefore, we set out to perform an exploratory review of the field of rehabilitation robotics with an additive aspect of technical scope, focusing on solutions and prototypes in the area of exoskeletons that interfaced with software mediums. Our methodology focused on the common approach carried out when doing systematic reviews; however, our analysis and reflections were mainly based on qualitative grouping and meta-synthesis, due to the preliminary nature of our work and the heterogeneous and multidisciplinary character of our considered papers.

To further motivate our approach, work and research objectives, we scanned the literature to extract review articles like ours, and two recent studies emerged. The first focused primarily on the prospect of exoskeletons for stroke rehabilitation [29] and the second discussed the possibility of VR-based interactions for rehabilitation [30]. We essentially combined the two and investigated what would happen when both hardware-based rehabilitation aids and software interfaces depicting virtual reality or gaming mechanisms were merged.

Therefore, to conclude, the aim of this review was to examine the potential and latest trends in the area of exoskeleton- or robotic-aided therapy in combination with VR, AR, or gamification for the improvement of motor function for poststroke patients. Specifically, we aimed to determine: (1) if such a coupled approach or setting could provide positive outcomes for patients; (2) trends and popular configurations across both types of exoskeletons and software mediums; and (3) future challenges in the field of exoskeleton-based HCI therapy.

Methods

Databases Searched and Search Terms Used

We conducted this review according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [31]. The following databases were searched for relevant studies: MEDLINE, EMBASE, Science Direct and The Cochrane Library, and studies conducted between the years 2010 to 2017 were included. An electronic search of the literature was performed using search terms such as “post-stroke rehabilitation, exoskeleton, robotic device, virtual reality, or augmented reality, or gamification”.

Inclusion and Exclusion Criteria

Inclusion criteria were as follows: (1) experimental, explorative or RCT studies on poststroke rehabilitation, (2) VR, AR, or gamification visual feedback, (3) stroke-affected patients; and (4) use of an exoskeleton or robotic device. As per our interpretation for this review, a VR or AR environment in the field of robot-aided rehabilitation is a replica of the real-world environment that is achieved after using hardware devices and a wearable exoskeleton device in liaison with each other.

The exclusion criteria for our study were: (1) studies done without the use of any robotic device or exoskeleton; (2) studies with nonvirtual or nonaugmented environments, or an absence of games; and (3) publications or articles in languages other

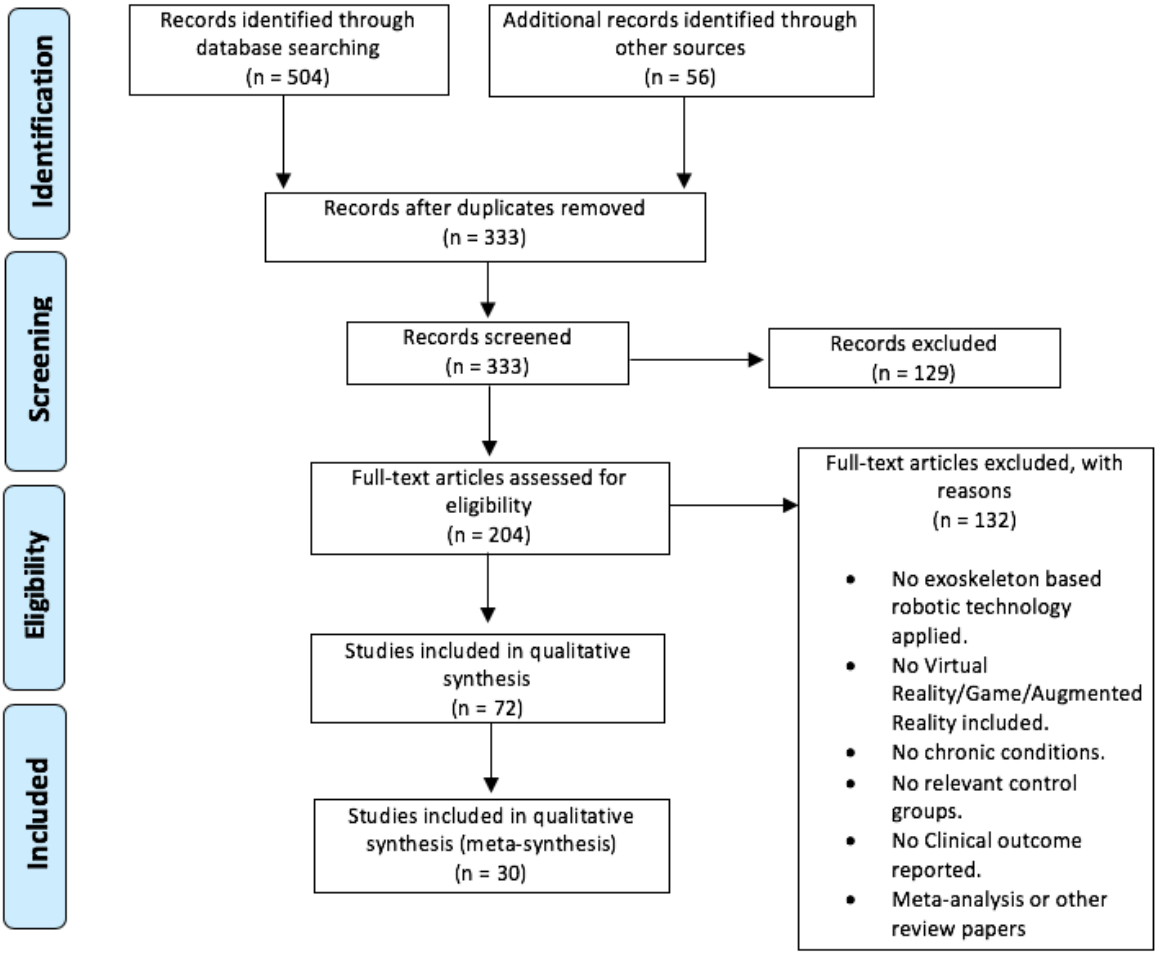
than English. As mentioned before, due to the heterogenous nature of the collated studies, data was synthesized qualitatively.

Results

Search Results

A total of 504 articles were identified from electronic searches and a total of 56 were identified through reference searches or other sources. We excluded 129 citations which were only at title and abstract stage, resulting in 204 full-text articles. Of these, 132 citations were excluded at the full-text stage, with reasons mentioned in Figure 1 as per the exclusion criteria for this paper. 30 studies reported across 30 publications were identified for inclusion in this review.

Figure 1. Selection of articles for review.



Overview of Included Papers

All articles published in English and in the years 2010 to 2017 were included. Four studies were published in the year 2010 and one in the year 2017, with size of the samples involved in the studies ranging from 1-47 participants per study; however, 13 studies had less than 10 participants. In two of the studies, healthy users of the devices were used as controls to compare the improvements of the patients [32,33]. Apart from this, one clinical study [34] was performed with just one patient who attended six sessions three times a week for two weeks, where it was found that the VR-based system resulted in effective upper-limb rehabilitation for this patient.

The average time poststroke for the participants involved in these studies, as mentioned in the articles, varied from less than six months to several years. Four studies did not mention the poststroke period at all [32,33,35-37], while three studies (10%) were held during the subacute (less than three months poststroke) stage [38-40]. All the other papers in our sample carried out their studies during the chronic stage (greater than three months poststroke). Most of the studies (28/30) considered designing rehabilitation therapies for upper limb while only two studies involved lower limb. Several measurement assessment scales were used in the studies that were used to assess improvements in motor functions which we then analyzed. Some of the scales included were the Chedoke-McMaster Stroke Assessment (CMSA), the Fugl-Meyer Motor Assessment (FMA), the Wolf Motor Function Test (WMFT), and the Modified Ashworth Scale (MAS), among others. An overview of some of the criteria used is provided as a summarized table below (see Table 1), whereas a detailed overview of the entire dataset is provided in Multimedia Appendix 1. The entire sample of 30 studies is also available in the reference list [26,32-36,38-61].

Table 1. Overview of some of the criteria of our review and their associated frequencies (N=30).

Criteria	Relative frequency, n
Limb Type	
Upper limb	28
Lower limb	2
Device	
Armin	2
Armeo	2
Bi-Manu	2
Other	24
Degrees of Freedom	
<10	15
>10	1
Not mentioned	14
Setting	
Clinic	25
Home	4
Both	1
Interaction Type	
Games	15
Virtual Reality	15
Sample Size	
<10	14
>10	16

Discussion

Key Findings

The studies were categorized into different fields, and of all 30 studies half of them used VR therapy while the other half used some gaming concepts. The studies that involved the use of an exoskeleton or robotic device along with VR, AR, or gamification were within the inclusion criteria of this review, so thirty exoskeletons or robotic devices were included. Of these devices, three exoskeletons emerged as slightly more popular in use: ARMin, Bi-Manu Track and ArmeoSpring. These devices each had repeated use in two studies while 24 studies made use of entirely different exoskeletons or robotic devices.

Klamroth-Marganska [41] made use of the ARMin exoskeleton in a 3D workspace with 7 degrees of freedom (DOF) for arm motor impairment in their study. This study was carried out among 38 poststroke patients who attended a total of 24 sessions (45 min/session) where they used VR Games that had their difficulty level adjusted by the therapist. This study resulted in improvement in the affected arm that was trained using ARMin, and audio-visual feedback was also provided to the patients through the VR games to elevate their motivation. Another lab-based empirical study [32] used the fourth version of the ARMin exoskeleton for 30 healthy and 8 impaired subjects, all of who played games with varying difficulty levels during the practice round. After that, feedback was taken from the participants using questionnaires. That study concluded that stroke-affected subjects were more interested in playing multiplayer games as compared to single player, as that allowed them to interact with peers or partners (dependent on the personality traits of the participants).

Another exoskeleton device, Armeo Spring, was used in two other papers selected for analysis [42,43]. In the Grimm et al study, an Armeo Spring device with 7 DOF was used for a clinical study involving five subjects who attended 20 sessions of therapy over four weeks (20 min/session). A VR interface was used with the exoskeleton and the difficulty level of the exercise was adjusted as per a patient's performance, with a provision for feedback on movement quality. Improvements in kinematic parameters were observed, thus making this particular VR-exoskeleton setup an effective combination for poststroke rehabilitation. In the Gijbels et al article, the Armeo exoskeleton was used with VR-based, nongamified learning (domestic cleaning tasks) for 10 subjects performing exercises three times per week, for a total of eight weeks. Each session lasted for 30 minutes, and auditory-visual performance feedback was provided both before and after the practice. The main outcome of this study was that functional gains in motor movement were reached at the end of the two-month study period, even for patients with high levels of disability.

In the year 2011, several studies were published that made use of exoskeletons with other technologies, and here we summarize a few as case studies. Lambercy et al [44] had a study of 13 poststroke participants using HapticKnob and games which resulted in improvements in their hand and arm motor functions, while Acosta et al [26] used 3D arm coordination training alongside video games and concluded that the duo would be useful for stroke rehabilitation. Similarly, two other studies by da Silva et al and Stein et al [40,62] made use of Data Gloves and Amadeo alongside VR and games, which led to improvements in multiple measures of motor performance in the participants involved in the study. In addition, Bi-Manu-Track with games and Robotic Upper Extremity Repetitive Trainer (RUPERT) with VR were used for both clinical and home-based rehabilitation such as in [53]. In this study, out of the two patients the first showed improvement in movement smoothness on targets while the second did not experience any ascending or descending trend in smoothness.

The studies mentioned so far mostly involved one part of the human body (arm), but Connelly et al [35] discussed hand improvements in which the PneuGlove with 6 DOF (Servomotor actuator) was used in a clinical study that engaged 14 patients for six weeks (60 min/session). An HMD was used to measure haptic feedback in the study, and as a result, a great increase in FMA scores were achieved. In a different study, a home-based trial was done on hand motor function improvements [45] wherein Hand Mentor Pro (HMP) was used alongside video games. From this study, visual biofeedback about the quality and quantity of wrist movements was attained, which resulted in improvements in ARAT scores. In a more recent study, Khor et al [46] discussed the improvements in a 30 min, robot-assisted study for 7 participants who actively took part in clinical and home-based rehab therapy, and who showed improvements in both hand and arm functions. This therapy was assisted by the CR2-Haptic device alongside a VR game, and it was reported that all subjects were comfortable with the therapy. The study also reported on the low cost of its hardware due to a reduced number of sensors and actuators, but this had the negative effect of lowering the customization and scalability of the exoskeleton.

We noticed that there was less academic literature for lower limb rehabilitation compared to upper limb rehabilitation, but our review still included two studies that involved lower limb rehabilitation. Forrester et al and Mirelman et al [47,63] described the effectiveness of the use of the exoskeletons Anklebot (3 DOF) and Rutgers Ankle Rehabilitation System (RARS) (6 DOF), alongside VR and video games, for ankle and foot rehabilitation. Improvements in walking velocity and paretic ankle motor control, as well as an increase in peak plantarflexion moment and in ankle power generation, were observed. Through further snowballing searches after the primary search, we also located two additional studies that employed the Lokomat exoskeleton for leg rehabilitation [64,65]. Both of these studies utilized VR as their key interfacing medium, but the former was a study with adults where a racing game was the main object of interest, while the second was a study with children where games such as soccer were incorporated. Both studies reported generally increased levels of engagement from the participants and thus further outlined the potential of robot-aided rehabilitation for lower limbs using VR. An interesting observation was the absence of AR-based systems for stroke rehabilitation in our sample. The requirement of additional hardware over exoskeletons and real-time tracking might be a deterrent. With the current advancements in AR systems (such as HoloLens), we would expect their application in clinical and medical settings to grow.

Future Challenges in the Field of Rehabilitation

Although positive results and improvements in motor function were observed in most of the studies, the results from this systematic review also depict that most rehab services are carried out in groups in clinics while home-based rehab is rarely attempted using the current configuration of interactive technologies. Group therapies in a clinical or lab setting are done so that patients feel motivated by collaborating with, or competing against, each other. In home-based rehabilitation, it is possible that patients might feel overwhelmed or isolated with the advanced forms of technology necessary for their therapy. In this case, the technology and the therapy sessions need to be designed in a way such that patients feel motivated and confident during home-based rehabilitation sessions as well (such as through online-tailored gaming). Thus, game-based rehabilitation can play a key role and provide a suitable interfacing medium for VR or AR, with 10 of our sample of 30 papers associating gaming with virtual reality. Use of customized games should be encouraged so that games are designed to keep in mind a particular target user, which could drive motivation in those people who play these specialized games at home as a part of their rehabilitation process. Articles in our sample indicated the key considerations that researchers must focus on while designing games for rehabilitation (also known as serious games), with key elements of discussion including: whether the play is meaningful, if engagement or motivation is retained, the difficulty level of the game, the role of customization, the range and type of feedback acquired, and the overall usability of the gameplay. Lastly, the interaction technique used is also a key consideration in game-based rehabilitation, with what gestures result in what game event easily being dictated by the motor movements required (such as whether the game interaction will involve grasping, pinching or linear limb movements).

However, there are some limitations to this review. For example, different types of assessment scale and quality of collected data were used, which makes it difficult to compare the outcomes and results accurately or quantitatively against each other. In addition, some articles could have been missed in the review due to very specific search criteria.

Conclusion

This review was carried out to collect data from different clinical trials and then to categorize and explore them to find the effectiveness of VR, AR, or gamification when used in combination with an exoskeleton or robotic device for the rehabilitation of poststroke patients. It was found that very little work is done to make use of these technologies for rehabilitation of lower limbs when compared to upper limbs, and that there are a wide variety of exoskeleton-based devices currently in use. Apart from this, the review also states that these

exoskeleton-based devices are rarely available for home-based trials. This shows that there is a considerable gap in the transition of rehabilitation services from a clinical environment to a home-based setting. Future work should focus on the successful application of VR, AR, or gamification technology to engage poststroke patients in rehabilitation therapies done at their homes. In addition, commercial, off-the-shelf games may be deployed easily, but efforts must be dedicated to designing games for rehabilitation to keep in mind the user and allow for customization to facilitate their motivation.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Detailed overview of our dataset of 30 papers.
[PDF File (Adobe PDF File)333 KB - rehab_v6i2e12010_app1.pdf]

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Abbreviations

2D: two-dimensional
3D: three-dimensional
AHA: American Heart Association
AR: augmented reality
CMSA: Chedoke-McMaster Stroke Assessment
DOF: degrees of freedom
FMA: Fugl-Meyer Motor Assessment
HCI: human-computer interaction
HMD: head-mounted display
HMP: Hand Mentor Pro
MAS: Modified Ashworth Scale
MRC: Medical Research Council
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RARS: Rutgers Ankle Rehabilitation System
RCT: randomized controlled trial
RUPERT: Robotic Upper Extremity Repetitive Trainer
USN: Unilateral Spatial Neglect
VR: virtual reality
WMFT: Wolf Motor Function Test

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Original Paper

Real-Time Auditory Feedback–Induced Adaptation to Walking Among Seniors Using the Heel2Toe Sensor: Proof-of-Concept Study

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Abstract

Background: Evidence shows that gait training in older adults is effective in improving the gait pattern, but the effects abate with cessation of training. During gait training, therapists use a number of verbal and visual cues to place the heel first when stepping. This simple strategy changes posture from stooped to upright, lengthens the stride, stimulates pelvic and trunk rotation, and facilitates arm swing. These principles guided the development of the Heel2Toe sensor that provides real-time auditory feedback for each good step, in which the heel strikes first.

Objective: This feasibility study aimed (1) to contribute evidence toward the feasibility and efficacy potential for home use of the Heel2Toe sensor that provides real-time feedback and (2) to estimate changes in gait parameters after five training sessions using the sensor.

Methods: A pre-post study included 5 training sessions over 2 weeks in the community on a purposive sample of six seniors. Proportion of good steps, angular velocity (AV) at each step, and cadence over a 2- minute period were assessed as was usability and experience.

Results: All gait parameters, proportion of good steps, AV, and duration of walking bouts improved. The coefficient of variation of AV decreased, indicating consistency of stepping.

Conclusions: Efficacy potential and feasibility of the Heel2Toe sensor were demonstrated.

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KEYWORDS

angular velocity; auditory feedback; walking; older adults

Introduction

Background

Aging renders people vulnerable to gait deviations that impair efficient walking and limits the likelihood of achieving walking targets for health promotion. Physical activity guidelines for seniors recommend a target of 150 minutes of moderate intensity exercise accumulated over 1 week in bouts of 10 minutes [1]. Walking is the most practical exercise as it requires no equipment, or no specialized environment [2], and produces many physical and cognitive health benefits from the mental stimulation of exploring new avenues or neighborhoods [3]. Maintaining a level of physical activity is also critical to prevent secondary health conditions including cardiovascular disease, osteoporosis, obesity, and diabetes [4]. Despite capacity to walk at a health-promoting pace when tested clinically, it is rare for the North American seniors to do this in the real world for more than a few minutes a day [5,6]. It is hard to sustain walking without the capacity for an optimal stepping pattern indicating that quality drives quantity.

Reasons for failure to use walking capacity to achieve health-promoting walking targets include fear of falling or age-related gait abnormalities [6]. These are known to cascade into a slow, unstable, shuffling pattern that increases the work of walking, fatigue, and risk of falls and hip fracture [7]. There is a considerable evidence on how to improve seniors' gait [8,9], and evidence shows that gait training is effective in improving gait pattern [10] but effects abate with cessation of training [11]. Hence, gait training alone will not translate into the sustained behavioral change needed for physical activity guidelines to be met.

During gait training, therapists use many of verbal and visual cues to emphasize stepping with heel first. This simple strategy changes posture from stooped to upright, lengthens the stride, stimulates pelvic and trunk rotation, and facilitates arm swing [12]. However, once verbal cueing ceases, patients frequently revert to an inefficient foot-flat gait.

For walking to become more normalized, people must relearn the motor sequences of good walking and develop the needed adjuncts to efficient walking: flexibility, strength, power, core stability, balance, and trunk rotation indicated by arm swing. Therapy can work on the adjuncts, but motor learning requires instruction, practice, and feedback. The 2013 review by Sigrist et al [13] frames motor learning as a lasting change of motor performance caused by training in which the parameters of a *motor program* are developed, and there is a gradual reduction of the variability in the newly developed motor program stimulated by sensory feedback loops. The phenomenon underlying motor learning is neural plasticity [14]. A 2014 review of this topic indicates that motor learning takes place with active practice of a skill and that this activity-dependent neural plasticity can be induced by both lengthy-extensive and brief-intensive practice [14]. The literature supports the benefit of augmented or extrinsic feedback for motor learning [14]. In particular, sonification for correct movement sequences has been shown to enhance motor learning in athletes [13,15].

It is well established that knowledge of performance is strongly associated with skill acquisition and motor learning compared with knowledge of results [16,17]. Technology is poised to provide this feedback. For walking, there are emerging technologies that use footwear-based gait monitoring systems [18]. None of the reviewed technologies provided real-time feedback, and all needed considerable data processing to produce usable information on walking performance. There is evidence that gait can be modified in response to real-time auditory feedback, but currently, no technology provides this type of feedback.

These principles guided the development of the Heel2Toe sensor, a biofeedback device that provides auditory feedback for each *good* step, in which the heel strikes first. The aim of this project was to bridge this *feedback* gap that exists outside clinical settings and equip seniors to practice correct gait at convenience. The hardware and algorithm underlying generation of auditory feedback from the Heel2Toe sensor are described elsewhere [19,20]. Briefly, Heel2Toe is a modification of an off-the-shelf device from the Shimmer Motion Development Kit. The sensor is a combination of three-axis accelerometer, a three-axis gyroscope, and a microcontroller. The algorithm detects the rate of angular velocity (AV) in sagittal plane at the ankle joint and provides an auditory *beep* when the rate of foot deceleration after heel strike crosses a threshold. Pilot work on Heel2Toe has demonstrated that it is highly accurate to detect *good* steps in clinical setting [19,20]. Starting the gait cycle with a strong heel strike lengthens the stride and changes posture from stooped to upright [12,21], indicating the value of focusing on AV as a treatment target.

Objective

The aim of this study was to contribute evidence toward the feasibility and efficacy potential for home use of theHeel2Toe sensor that provides real-time feedback for good heel strike when walking. Specifically, the objectives were (1) to identify the extent of the immediate response to the feedback, carry over when walking without feedback, and peak response to feedback and (2) to identify pleasures and challenges in using the feedback sensor.

Methods

Study Design

A pre-post study design, with five sessions of training over 2 weeks, was employed to estimate the efficacy potential and identify feasibility issues of the Heel2Toe sensor when deployed for walking in the community.

Participants

A purposive sample of six people, four women and two men, over the age of 70 years, was identified from geriatric services at the Montreal General Hospital from September to October 2017. Participants were identified by a geriatrician or other health care professionals and included if they reported no limitation in walking without an aid and no cognitive impairments. The participants were selected to have a range of walking capacity from very limited to functional. Ethical approval was obtained from the Ethics Review Board of McGill University, Health Centre Research Institute.

Measures

Participants were assessed on physical performance tests and self-report measures. Physical performance tests included gait speed, 30-second chair stand, and 2-minute walk without and with auditory feedback. The self-report questionnaires included single item on perceived walking speed, lower extremity function scale (LEFS), life space mobility scale, and activity-specific balance confidence scale. LEFS scoring is based on fit to the Rasch Model, and therefore, not all items have to be administered to derive a legitimate total score [22]. Posttraining outcomes additionally included questions about the system usability and a semistructured interview on challenges and pleasures of using the Heel2Toe sensor. The interview was conducted separately with each participant.

Intervention

The intervention involved a therapist visiting a participant's residence to provide walking training with the Heel2Toe sensor, for five sessions over 2 weeks (Figure 1). The training involved

walking in the participant's neighborhood with the sensor. Care was taken that they walked on an obstacle-free path. The duration of the training was determined by the participants themselves based on interest and tolerance. On each training day, participants were instructed to walk for at least 15 minutes with the sensor at a comfortable pace and taking rests when needed. The training was accompanied with home exercises targeting flexibility and strength at ankle, knee, and hip joints with a particular focus on core strength and trunk rotation. At the end of the training, a semistructured interview was conducted with all participants.

Figure 1. Flowchart of the study method and assessment time points.

Analysis

The gait signals recorded with the Heel2Toe sensor were analyzed using MATLAB (MATLAB and Statistics Toolbox Release 2017b, The MathWorks, Inc, Natick, Massachusetts). The gait parameters extracted for each person over the entire walking period were proportion of good steps (%), total walking time (seconds), and average cadence (steps per minute). AV (degrees per second) in sagittal plane at ankle joint during heel strike was extracted for each step and averaged over the walking duration yielding mean, SD, and coefficient of variation (an indicator of consistency of stepping).

Results

Table 1 shows the characteristics and level of physical activity of the participants before the training. There were two men and four women (age range: 73-87 years). The results are presented as single subjects, as it is not meaningful to aggregate data across six participants.

The score on 30-second chair rise test ranged from 0 to 12 for the six participants. Of the six participants, four exceeded their 30-second chair rise normative value. The self-reported walking speed ranged from normal to very slow walking. LEFS scale is a self-report questionnaire on difficulties with activities of daily living related to lower limb problems. The maximum score of LEFS is 32, with lower scores indicating difficulty in activities. The LEFS scores ranged from 11 (participant A) to 26 (participants D and F). Life space mobility scores ranged from 48 (participant A) to 126 (participant E) out of a total 140 days. A score of 28 days indicates no movement outside of home in the past 28 days, and a score of at least 56 indicates mobility outside of house but within the yard, porch, or apartment building.

Table 2 shows an immediate response (pre without and with feedback) and carry over effects after five training sessions (pre to post) to auditory feedback on proportion of good steps, AV, cadence, and coefficient of variation.

Posttraining gait was assessed within 1 week of the last training session. Important gains are indicated by the values in italics in Table 2. Participant A showed an immediate response to feedback producing, at first exposure, 0 good steps without any feedback and 56% good steps with feedback. This immediate response did not impact cadence, but AV showed a large effect (−48°/sec to −102°/sec). However, the coefficient of variation of AV was very large and remained so throughout. Posttraining, participant A showed some carry-over effect, as posttraining good steps without feedback changed from 0% to 29%.

Participant B produced almost twice the proportion of good steps with an increase in AV and no loss in cadence. A total of four of six participants showed only a small increase in the proportion of good steps with feedback, but all already had a high proportion (80%) of good steps without feedback. Nevertheless, they showed an improvement in AV while maintaining cadence. Overall, five of six participants showed important gains on gait parameters. The one person who did not was very good at study entry.

Table 1. Characteristics and physical activity level of the participants at study entry.

Characteristics/activity level	Identification					
	A (Man)	B (Woman)	C (Woman)	D (Woman)	E (Woman)	F (Man)
Age (years)	80	73	87	83	85	86
Physical performance tests						
Self-report walking speed[a]	Very slow	Stroll	Stroll	Normal	Very slow	Normal
30-second sit to stand (n)	0	12	7	9	10	12
Age norm (n)[b]	10	10	8	8	8	8
Self-report questionnaires						
LEFS [c] (scored from 0=extreme difficulty to 4=no difficulty)						
Walking a mile	1	2	0	4	0	3
Running on even ground	0	0	2	1	0	2
Squatting	2	2	1	3	4	3
Standing for 1 hour	2	1	0	4	2	3
Climbing 10 stairs	2	3	3	4	4	3
Heavy household activities	0	1	1	4	2	4
Getting in and out of bath	3	0	4	2	4	4
Light household activities	2	2	4	4	4	4
Total score (0-32)	12	11	15	26	20	26
Life space mobility (number of days out of the past 28 days)[d]						
Other rooms besides the bedroom	28	28	28	28	28	28
Areas outside home	6	28	28	28	28	15
Places in neighborhood	6	28	15	28	28	5
Places outside neighborhood within town	6	28	10	28	28	2
Places outside town	2	2	2	10	14	2
Total days (max 140 days)	48	114	83	122	126	52
Activity Specific Balance Confidence Scale (0%=no confidence to 100%=full confidence)						
Walk around the house	90	60	80	100	95	100
Walk across a parking lot	90	50	100	100	100	100
Walk in a crowded mall	95	50	75	90	100	100

[a]Self-reported walking speed: unable to walk, very slow, stroll at an easy pace, normal speed, fairly brisk, fast.

[b]As per Bennell et al [23].

[c]LEFS: Lower Extremity Function Scale (selected items).

[d]A score of 28 days indicates no movement outside of the home in the past 28 days; score of 56 indicates mobility outside of the house but within the yard, porch, or apartment building; score of 84 indicates going to places in neighborhood; score of 112 indicates going to places outside the neighborhood but within town; and score of 140 indicates going to places outside the town.

Table 2. Immediate response and carry-over effect after five training sessions with the Heel2Toe sensor on gait parameters measured without feedback (values in italics indicate clinically important changes after five days of training based on a change of ≥10%).

Outcomes and assessment		Participants' identification					
Gait parameters and time points	Feedback	A	B	C	D	E	F
Good steps (%) (closer to 100 is better)							
Pre	–[a]	0	43	80	84	92	93
Pre	+[b]	*56*	*82*	83	97	92	99
Post	–	29	*80*	*89*	*97*	95	99
Post	+	*66*	*90*	*92*	*94*	93	100
Cadence (steps/min) (closer to 100 is better)							
Pre	–	70	95	97	110	113	96
Pre	+	69	102	95	95	110	95
Post	–	77	104	100	121	105	110
Post	+	*84*	96	99	122	111	109
Heel strike angular velocity (°/second) (typical values are −300 to −500; the more negative, the better) [24]							
Pre	–	−48	−97	−147	−145	−165	−163
Pre	+	*−102*	−128	−157	−186	−173	−213
Post	–	*−80*	−126	−163	*−227*	−176	*−250*
Post	+	*−102*	*−147*	−159	*−208*	−173	*−263*
Gait regularity (angular velocity coefficient of variation; <10%) [25]							
Pre	–	59	39	40	31	24	24
Pre	+	41	33	39	*17*	23	14
Post	–	52	33	*24*	*20*	17	*11*
Post	+	50	21	*21*	*24*	22	*10*

[a]No feedback (auditory beep was absent).

[b]Feedback provided (auditory beep was present).

Figure 2 shows the duration (minutes) of intervention time over 5 training days. To illustrate, participant A, who was the most disabled, walked with the sensor for 4.5, 3.7, 9.4, 7.4, and 5.6 minutes on days 1 through 5, respectively. However participant D, who walked for about 12 minutes on day 1, had 2 days in which she walked for 30 min. All participants increased the time spent walking with the sensor over the intervention period. Out of the 30 intervention days, continuous walking bouts of 10 minutes or more were observed on 21 of the intervention days.

The information collected on system usability and on challenges and pleasures of using the Heel2Toe sensor was helpful in identifying areas for improvement. The results from the System Usability Scale are given in Table 3.

Only 8 of the original 10 questions were applicable, as 1 question was not understood and 1 question referred to their impression of how other people would be able to use the sensor. Overall, 38 item responses were available: 25 favorable, 4 neutral, and 9 unfavorable. No one feature was consistently rated *unusable*, but one issue raised concerned the intrusiveness of the sound while walking in public. This issue can be easily resolved by using earphones. The question on confidence was inconsistently answered because the trainer was always present during these training sessions.

The aim of semistructured interviews was to capture the experiences of the participants while walking with the Heel2Toe sensor in the community and recommendations for subsequent sensor development and upgrading. All participants expressed that the sensor was enjoyable, stimulating, beneficial, and easy to use while training outside the home. The participants had a few recommendations to make the sensor more user friendly. First, clipping the sensor to the shoe was recommended over a strap to accommodate older adults with back pain and limited trunk mobility. The clip also offers flexibility of use with any shoe. Second, the sensor should be available to connect via an iPad that offers a larger display for an app. Third, the sensor and app combination should be affordable and accompanied by an exercise manual.

Figure 2. Time (minutes) spent walking with the sensor during each training day.

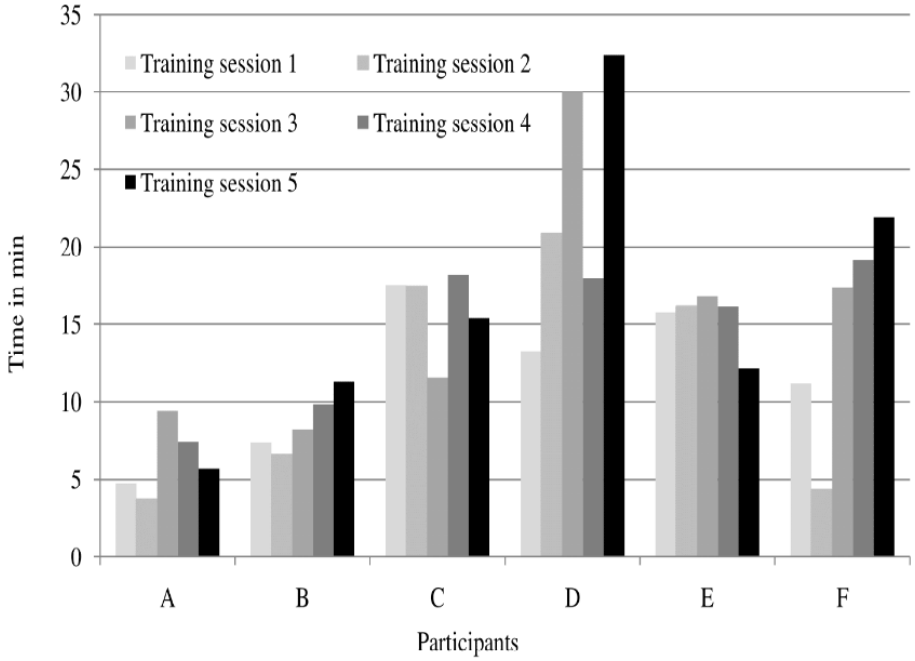

Table 3. Item scores on the System Usability Scale.

Item (8/10 original questions)[a]	Response scores across participants					
	A	B	C	D	E	F
Higher is better						
Use it frequently	4	3	5	__[b]	5	4
Easy to use	4	1	1	—	5	5
Functions integrated	5	1	3	—	1	—
Confidence in using	5	1	—	—	1	4
Lower is better						
Too complex	1	1	1	—	1	1
Need assistance to use	1	1	1	—	1	1
Cumbersome or awkward	1	1	5	—	2	1
Need to learn a lot before using	1	5	1	—	2	5

[a]Two questions were omitted because of understanding (too much inconsistency with sensor) and applying what other people might think (I would imagine most people would learn to use this very quickly). Of the 18-item responses for the four questions where higher is better, 10 were at the two highest agreement levels and 6 were at the lowest levels. Of the 20-item responses for four items where lower is better, 15 were at the best level and 3 were at the poorest level.

[b]Not available.

Discussion

Principal Findings

We found that the Heel2Toe sensor was feasible to use in the community setting with older adults and that they improved on gait quality after the planned five training sessions, averaging 73 minutes (range: 43-114 minutes) in total. The proportion of good steps and AV improved without any detriment to cadence. All six participants showed longer duration of time spent in walking from the initial training days. However, the most dramatic effect was seen for duration of walking bouts which frequently exceeded 10 minutes (Figure 2) such that most (five of six; Table 2) participants would now be capable of meeting the Canadian Physical Activity Guidelines of 150 minutes of moderate to vigorous activity (required walking cadence ≥100 steps per minute) per week in bouts of 10 min.

Posttraining, five of six participants showed a reduction in the coefficient of variation of AV, a parameter indicating

inconsistency of stepping pattern. Before training, the coefficient of variation ranged from 23% to 59%. Previous studies have shown a higher coefficient of variation in step width, and stance and stride time among older adults is associated with increased occurrence of falls [26-28], with the suggestion that a treatment target is to reduce the coefficient of variation with exercise interventions. After 5 days of training, the range was 9% to 49%.

We purposely chose a sample of people diverse in physical function. In all, two people were quite frail (A and B). Participant A was severely limited in mobility (Table 1), yet he improved on the proportion of good steps and degree and consistency of AV (Table 2 and Figure 2). Participant B also improved on these parameters. The most functional walker, participant D, showed no change as she was high on all parameters but enjoyed the experience of the sensor and could see how it would prevent deterioration. In a definitive trial, these data can be used to optimally select people for intervention.

How did the sensor achieve these outcomes? One hypothesis is that the auditory feedback acts as a positive reinforcement to a rhythmic stepping pattern. With symmetrical walking, each good step produces a *beat* that is repeated with periodicity. To produce the rhythmic pattern (the *beat*), the participants modified their stepping pattern to maintain the rhythm. In the long run, auditory cues could enhance cortical motor excitability. This has previously been studied with upper limb movements and walking tasks that required persons synchronizing to an external auditory cue [29]. The underlying basis of auditory motor synchronization is that brain poses anticipatory tendency for a rhythm, and this anticipation guides subsequent movements [29].

The Heel2Toe sensor provides direct positive auditory feedback, which could be perceived as rewarding stimulating neural plasticity and increasing the pleasure in walking, stimulating behavior change. Ultimately, the aim is to improve health-promoting walking rather than just functional walking, so that older people can derive pleasure and health benefit from walking. The sensor is not designed to be worn all the time but to be worn to practice optimal walking with the aim that this would carry over into other walking activities. As it is linked to a smartphone and the sensor is very small (size of a matchbox), it could be worn for longer periods of time.

Fear of falling and age- or illness-related changes co-occur in most seniors and can induce an inefficient and dangerous gait pattern [30,31]. To normalize walking, people must relearn motor sequences of good walking and develop needed adjuncts to efficient walking: flexibility, strength, power, core stability, balance, and arm swing. Therapy targets adjuncts but motor learning requires instruction, practice, and feedback. Motor learning is framed as a lasting change of performance occurring with training in which parameters of a *motor program* are developed and consolidated. Early on, formation of the motor program of the *to-be-learned task* can occur rapidly but demands high levels of attention. Later, the motor program is refined, improving error detection or correction mechanisms, reducing movement variability. Finally, movements become highly automatized, skilled, and consistent, and the motor program is now relatively permanent [32].

The phenomenon underlying motor learning is mostly because of neural plasticity [33]. A review of this topic [33] indicates that motor learning takes place with active practice of a skill and that this activity-dependent neural plasticity can be induced by both lengthy-extensive and brief-intensive practice. The literature supports the benefit of augmented feedback for motor learning. In particular, sonification for correct movement sequences has been shown to enhance motor learning in elite athletes [34] but is less useful for novices who have no idea of the correct movement. Walking is a natural way to get about [35], and as older persons are not novices to walking but have lost the expertise with age, their walking pattern should respond to auditory feedback. This type of *positive* feedback has been shown effective in the short term to improve gait pattern in people poststroke [36]. It is superior to auditory alarms signaling incorrect movements as feedback because good movement is more motivating [34].

This solution to poor gait is unique in that there is positive reinforcement, in real time, which stimulates motor learning of correct gait. The Heel2Toe sensor provides information in real time, in other words, knowledge of performance and not just knowledge of after-the-fact results, which is provided by most other technologies in the field today. This is a completely novel and original approach to gait enhancement. There have been other approaches to monitor step counts, but these have not attempted to improve gait quality. The review of the literature conducted by our team did not find any study focusing on feedback related to gait quality and ankle kinematics.

Finally, debriefing interviews suggested readiness of seniors to adopt technology as long as it is simple and user friendly. This project is timely and relevant to increasing the proportion of older population and builds upon the potential of technology to stimulate innovation, thereby advancing Canadian economic and social development. An increasing proportion of older adults use smartphones [37,38], and this proportion is likely to increase as technologically savvy cohorts age.

This sensor could be on the foot of every person who needs to maintain or improve optimal gait. By formally practicing gait improvement with positive auditory feedback, people could develop the habit of walking better leading to walking more often and for longer.

Through the use of the Heel2Toe device, every step becomes therapeutic, engaging large muscle groups, which improves peripheral and core muscle strength and through this improves balance, allows the person to walk at a faster pace. Our data also support changes to gait consistency (lower coefficient of variation with training), making walking more rhythmical, which, in the long run, is more sustainable [35].

The sensor is in development, and refinements to the algorithm will be made, such as to provide different thresholds for the feedback to occur (low, medium, and high AV). An instructional manual and video are in production to optimize the participants' capacity to use the Heel2Toe sensor. The plan is to develop a

full-scale trial, now that there are some data that people can change their gait with the device.

Limitations

This was a very small study focusing on proof-of-concept only. On the basis of the results that short-term intensive training with positive auditory feedback produced changes in gait quality, a full pilot study is warranted including the second motor learning phase and longer-term practice to estimate sustainability.

Implications and Conclusions

The results of this study have future implications in exploring the neural basis of auditory-motor synchronization during walking, application of motor learning principles to enhance walking performance, and technology design of wearable sensors for older adults. Understanding the neural basis of auditory motor synchronization will help design interventions to use auditory feedback to improve walking symmetry. The application of motor learning principles to enhance walking performance based on movement-generated auditory feedback and long-term effects on skill acquisition is an area yet to be explored. Debriefing interviews conducted after the intervention concluded that an optimal wearable device for seniors needs to be simple and easy to use, provide real-time meaningful feedback, have a software program that requires minimal preprocessing (zero effort) before use, and have the option for technical support or supervision from a rehabilitation professional [39].

Acknowledgments

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Conflicts of Interest

KKVM, AA-S, and NEM are cofounders of a start-up enterprise Physio Biometrics Inc. The Heel2Toe sensor is one of the products that will be commercialized.

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Abbreviations

AV: angular velocity
LEFS: lower extremity function scale

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Original Paper

Wrist-Based Accelerometers and Visual Analog Scales as Outcome Measures for Shoulder Activity During Daily Living in Patients With Rotator Cuff Tendinopathy: Instrument Validation Study

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Abstract

Background: Shoulder pain secondary to rotator cuff tendinopathy affects a large proportion of patients in orthopedic surgery practices. Corticosteroid injections are a common intervention proposed for these patients. The clinical evaluation of a response to corticosteroid injections is usually based only on the patient's self-evaluation of his function, activity, and pain by multiple questionnaires with varying metrological qualities. Objective measures of upper extremity functions are lacking, but wearable sensors are emerging as potential tools to assess upper extremity function and activity.

Objective: This study aimed (1) to evaluate and compare test-retest reliability and sensitivity to change of known clinical assessments of shoulder function to wrist-based accelerometer measures and visual analog scales (VAS) of shoulder activity during daily living in patients with rotator cuff tendinopathy convergent validity and (2) to determine the acceptability and compliance of using wrist-based wearable sensors.

Methods: A total of 38 patients affected by rotator cuff tendinopathy wore wrist accelerometers on the affected side for a total of 5 weeks. Western Ontario Rotator Cuff (WORC) index; Short version of the Disability of the Arm, Shoulder, and Hand questionnaire (QuickDASH); and clinical examination (range of motion and strength) were performed the week before the corticosteroid injections, the day of the corticosteroid injections, and 2 and 4 weeks after the corticosteroid injections. Daily Single Assessment Numeric Evaluation (SANE) and VAS were filled by participants to record shoulder pain and activity. Accelerometer data were processed to extract daily upper extremity activity in the form of active time; activity counts; and ratio of low-intensity activities, medium-intensity activities, and high-intensity activities.

Results: Daily pain measured using VAS and SANE correlated well with the WORC and QuickDASH questionnaires (r=0.564-0.815) but not with accelerometry measures, amplitude, and strength. Daily activity measured with VAS had good correlation with active time (r=0.484, *P*=.02). All questionnaires had excellent test-retest reliability at 1 week before corticosteroid injections (intraclass correlation coefficient [ICC]=0.883-0.950). Acceptable reliability was observed with accelerometry (ICC=0.621-0.724), apart from low-intensity activities (ICC=0.104). Sensitivity to change was excellent at 2 and 4 weeks for all questionnaires (standardized response mean=1.039-2.094) except for activity VAS (standardized response mean=0.50).

Accelerometry measures had low sensitivity to change at 2 weeks, but excellent sensitivity at 4 weeks (standardized response mean=0.803-1.032).

Conclusions: Daily pain VAS and SANE had good correlation with the validated questionnaires, excellent reliability at 1 week, and excellent sensitivity to change at 2 and 4 weeks. Daily activity VAS and accelerometry-derived active time correlated well together. Activity VAS had excellent reliability, but moderate sensitivity to change. Accelerometry measures had moderate reliability and acceptable sensitivity to change at 4 weeks.

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KEYWORDS

shoulder; wearable sensors; activity count; validation; test-retest; sensitivity to change

Introduction

Shoulder pain is a frequent problem in adults of all ages [1]. A large proportion of shoulder pains is caused by rotator cuff tendinopathy [2,3], a chronic degenerative disease affecting rotator cuff tendons in the shoulder [4]. Patients with rotator cuff tendinopathy generally experience pain when performing activities of daily living [5]. Shoulder pain is often accompanied by stiffness and weakness that can degenerate into declining shoulder function, diminished work capabilities, and overall decreased quality of life [5,6]. Conservative treatment for rotator cuff tendinopathy usually starts with nonsteroidal anti-inflammatory medications (NSAID) and physical therapy to regain full range of motion and restore scapular control [7,8]. Corticosteroid injections (CSI) in the subacromial space are also used in conjunction with NSAIDs and physical therapy to further alleviate the pain symptoms by reducing the inflammatory response, and facilitate mobilization of the shoulder. As a last resort, a surgical option such as bursectomy or acromioplasty can be offered to patients with persistent rotator cuff tendinopathies [9]. Currently, evaluation of the response to treatment is based on patient-reported outcomes using subjective measures, such as questionnaires and pain scores [7], which do not necessarily correlate with real-life function of the shoulder and do not capture efforts made by the patients in mobilizing their shoulder during daily activities.

Up to 40 different questionnaires have been proposed as outcome measures for the follow-up of shoulder pathologies [10]. The Disability of the Arm Shoulder and Hand (DASH), its short version (QuickDASH), the Shoulder Pain and Disability Index, the American Shoulder and Elbow Society score, and the Constant-Murley scores have been well validated, but none are consistently recommended in the literature [11]. Some questionnaires, such as the Western Ontario Rotator Cuff Index (WORC), have also been developed to assess patients with rotator cuff tendinopathy specifically [12]. However, all these activity and function questionnaires assess perceived capacity and activity, which have different bias inherent to this type of evaluation. Other simpler measures such as pain or activity (measured with visual analog scales [VAS]) and the Single Assessment Numeric Evaluation (SANE) have, however, rarely been studied in the context of patients with rotator cuff tendinopathy. Objective clinical examinations such as strength and range of motion are rarely correlated with patients' subjective assessment of function and have usually poor sensitivity to change in the context of rotator cuff tendinopathy [13-15].

Objective outcome measures based on wearable motion sensors could prove useful in the clinical evaluation of real-life shoulder activity and mobilization of patients with rotator cuff tendinopathy as well as an outcome to measure the effect of different treatments on shoulder activity and function. Multiple authors have used raw sensor data from inertial sensors (accelerometers and gyroscope) or orientation data from Attitude and Heading Reference Systems positioned on different segments to capture shoulder activity. Numerous techniques and algorithms have been proposed, such as the range of angular velocities and linear accelerations measured during a set of standardized tasks [16-18], detection of active time [19,20], measurement of shoulder elevation angles in clinic or daily life [21-28], and movement classification algorithms [29,30]. Most of these methods are not suitable for continuous monitoring over long periods, as they require either many devices on the same arm or one on each limb, or that the device be positioned at the humerus, all of which affect long-term adherence of wearing the devices by the participants. Consequently, the data collection for all the methods presented above was limited to short periods of 8 hours at most or to standardized evaluation in the clinic, which is not a valid representation of the patient's real-life activities.

Activity counts (ACs), a manufacturer-specified unit obtained from raw accelerometer output [31,32], could prove useful as a way to quantify upper extremity use during a longer follow-up period. ACs were initially used to quantify whole-body physical activity using accelerometers worn at the waist or wrist [33], but have been since adapted to assess upper extremity impairments associated with different pathologies and to monitor the impact of rehabilitation. They can be obtained in three broad ways: (1) counting how many times the raw accelerometer data cross a predetermined threshold, (2) a rolling window method where the count is determined as the highest acceleration in that window, or (3) calculating the area under the curve of the acceleration signal for each window [31,32]. Acuna et al [34] measured ACs derived from humerus-worn and wrist-worn accelerometers and observed a good correlation between both approaches. This could justify the wrist positioning as a valid position to quantify shoulder activity, which can improve participant acceptability of a continuous monitoring protocol in their own environment [35]. Lawinger et al [36] used wrist-based accelerometers to analyze different shoulder rehabilitation exercises and activities of daily living involving

the upper extremity in a clinical setting. They demonstrated that ACs were sensitive enough to detect low-velocity exercises and that a good correlation could be found between the amount of movement performed and the measured AC (r=0.93, *P*<.001). To our knowledge, however, ACs have not been validated in the setting of patients with rotator cuff tendinopathy and their convergent validity, fidelity, and sensitivity to change are not known in this population.

Hence, the aims of this study were (1) to evaluate and compare convergent validity, test-retest reliability, and sensitivity to change of known clinical assessments of shoulder function to wrist-based accelerometer measures of shoulder activity during daily living in patients with rotator cuff tendinopathy and (2) to determine the acceptability and compliance of using wrist-based wearable sensors, which is an outcome measure to study the effects of CSI on rotator cuff tendinopathy.

Methods

Participants

Patients with unilateral or bilateral rotator cuff tendinopathy who were candidates for receiving a CSI were recruited from the orthopedic clinic of the Sherbrooke University Hospital Centre (Centre Hospitalier Universitaire de Sherbrooke [CHUS] - CIUSS de l'Estrie) and by referral from local physiotherapists and general practitioners. Rotator cuff tendinopathy was confirmed by a clinical diagnosis based on examination (presence of a painful arc of movement and positive impingement tests) and symptom duration of at least 9 months. The patients were screened by a medical student, and the diagnosis was confirmed by a fellowship-trained shoulder surgeon. Participants were excluded if they presented any other painful pathology of the shoulder (shoulder osteoarthritis, capsulitis, cervical pain radiating to the shoulder, rheumatic disease, etc), had a history of fracture or surgery on the affected shoulder, or received a shoulder CSI in the last 3 months. Significant rotator cuff tears were excluded by physical examination and diagnostic imaging, if available. The Ethics Review Board of the CIUSSS de l'Estrie-CHUS approved the protocol, and informed consent was obtained from each participant prior to his/her inclusion in the study.

Study Design and Assessments

This is an embedded methodological study within a pilot randomized controlled trial on the effect of CSI and the addition of a sham or real treatment of transcranial direct current stimulation (tDCS) on shoulder function and activity in patients with rotator cuff tendinopathy. tDCS is an experimental treatment currently being investigated for chronic pain [37]. As part of this main study, participants were randomized 2 weeks after receiving a CSI to additionally receive tDCS treatment, placebo tDCS, or no intervention. Participants were followed up for a total of 5 weeks after CSI with assessments on patient-reported outcomes from questionnaires and clinical examinations at 0-, 1-, 3- and 5-week endpoints.

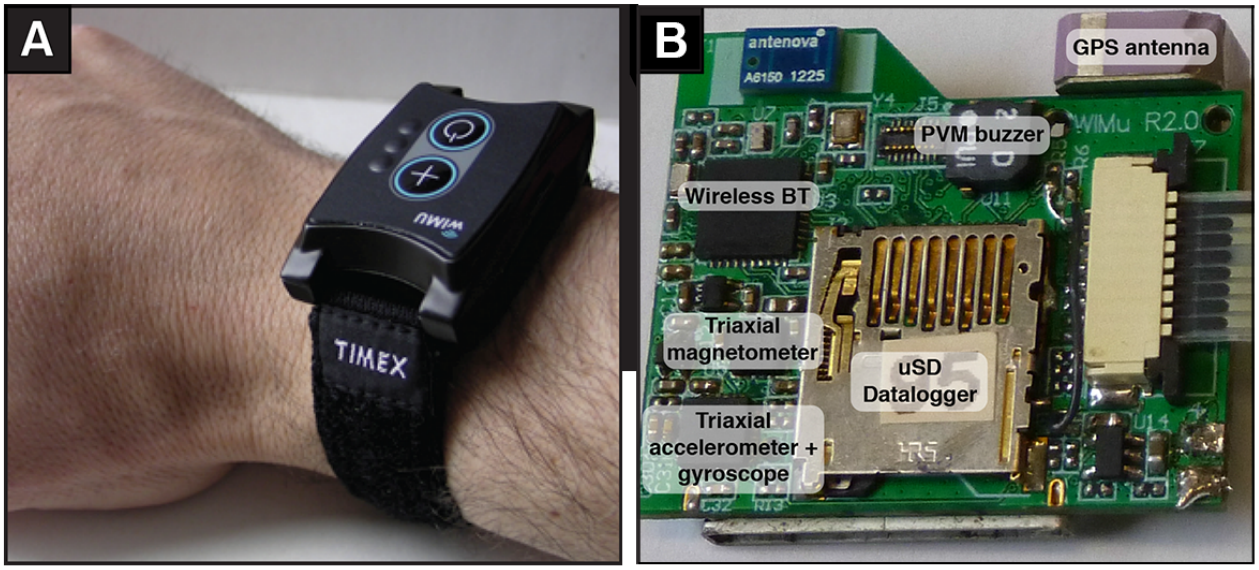
For this study, the participants were asked to wear an accelerometer logger called the WIMU-GPS (Wireless Inertial Measurement Unit with GPS) on the wrist of the affected shoulder for the whole duration of the study, from morning to bedtime. Participants were asked to answer daily questionnaires on shoulder pain levels and the relative usage of their upper extremity in the form of two VAS. At the 1-week evaluation endpoint, participants received a CSI in the affected shoulder. The CSI (1 ml of 40 mg/mL methylprednisolone and 4 mL of 1% [10 mg/mL] xylocaine injected using a 25-bore 1.5-inch needle) was performed in the subacromial space using the posterior approach by the same fellowship-trained orthopedic surgeon for all participants. Finally, at the 5-week evaluation endpoint, participants completed a short questionnaire about satisfaction and adherence to wearing the WIMU-GPS.

Outcome Variables and Measures

Upper Limb Activity Measured Using Wrist-Based Accelerometry

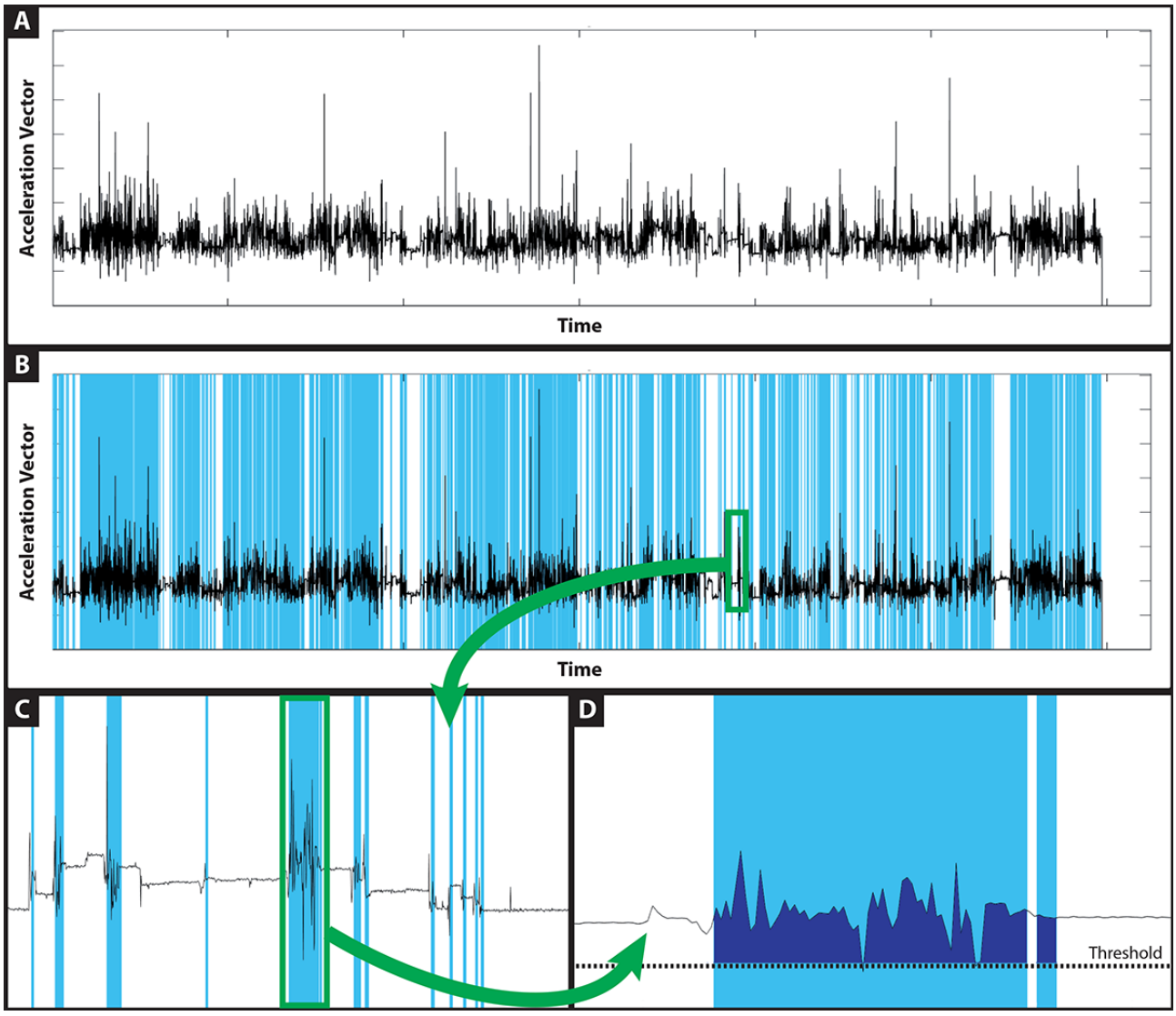
Upper limb activity was measured using 3D accelerometers embedded in a wearable activity monitoring system worn on the wrist. The WIMU-GPS [38] (Figure 1) is an activity-monitoring system developed at the Research Centre on Aging of the CIUSS de l'Estrie – CHUS to be used as a multisensor data-logging device with a small form factor to capture mobility and activity of individuals in their home environment over long-term recording periods. The third generation of the device currently consists of a triaxial accelerometer (2/4/8/16 g), a triaxial gyroscope (250/500/1000/2000 degrees/s), a triaxial magnetometer (0.8 Ga to 8.1 Ga), all sampled at 50 Hz, and a GPS (SiRFstarIV, 48 Channels) sampled at 1Hz. The data stream is then stored on an 8 GB microSD memory card. By using a 400 mAh Li-ion battery, the WIMU-GPS is able to record data continuously over a period of 10-14 hours on a full charge. The activated device was provided to participants at the beginning of the project. They were instructed to wear it on the wrist on the same side of their affected shoulder for all waking hours and to charge it at night. They were instructed to take it off during water-based activities. No instructions were given on how to turn on or off the device, as recordings are automatically paused when the battery is low or charging and are set to restart once it is disconnected from the power supply. At each endpoint, data were downloaded from the microSD chip onto a portable computer and the WIMU-GPS was reset. Data from each visit day were deleted, as these days would have been incomplete and the data would have possibly been invalidated by observation bias and patients disturbing their usual routine to attend the appointments.

Figure 1. Overview of the WIMU-GPS (WIMU-GPS [Wireless Inertial Measurement Unit with GPS]) platform: (A) device worn on the wrist, and (B) printed circuit board and components. PVM: Pulse Variable Modulator buzzer chip; BT: Bluetooth chip; uSD: Micro-USD chip.



For this study, raw data from the three accelerometers were first low-pass filtered (Butterworth, 1 Hz, 2nd order) to remove sensor noise, full-wave rectified and high-pass filtered (Butterworth, 5 Hz, 2nd Order) to remove the gravitational acceleration vector, and combined into a unique vector using square root sums [39]. Periods of "active time" in the recordings were identified in areas of the vector where 50% of the data values over a 10-second window were over a fixed threshold (0.015 g) [40]. ACs were then computed using the integration method (Figure 2). Four variables are derived from this AC: *active time*, reported as a ratio with total recorded time; mean *AC* per minute of active time, the proportion of *low-intensity* (LIA) and *medium-intensity* (MIA), and *high-intensity* activities (HIA). Activities with an AC below the 33rd percentile of all activities recorded during the project were classified as LIA, while the 33rd-66th percentiles were defined as MIA, ACs above the 66th percentile were defined as HIA. The two thresholds separating these three activity levels are an AC of 90.0 and 180.0 (for LIA-MIA and MIA-HIA, respectively). To obtain a better representation of the participants' upper extremity daily usage and to allow easier comparison with other outcome measures, data are reported as a mean for each week of follow-up (preinjection week and second and fourth week postinjection). Weeks with less than 3 days of valid data were eliminated from the analysis.

Figure 2. Processing of accelerometer data into active time, activity count, low-intensity activity, medium-intensity activity, and high-intensity activity. (A) Combined acceleration vector. (B, C) Periods of active time are identified in areas where 50% of the data values over 10 seconds rolling windows are over a fixed threshold of 0.015 g. (D) Acceleration vector in active periods is integrated to produce activity count. A distribution of the activity count of all activities detected in the sample was created and with activities count below the 33rd percentile (activity count 90.0) was classified as low-intensity activity; activities between the 33rd and 66th percentile, as medium-intensity activity; and activities above the 66th percentile (activity count 180.0), as high-intensity activity.



Daily Activity and Pain Measured Using Visual Analog Scale and Single Assessment Numeric Evaluation

Participants were also given daily questionnaires to complete at home every day for the duration of the study. The short questionnaire included a 100-mm VAS evaluating their perceived level of pain in the last 24 hours (VAS_{pain}), and another 100-mm VAS for the perceived level of upper extremity use in the last 24 hours ($VAS_{activity}$). The SANE is a new short questionnaire that simply asks, "How would you rate your shoulder today as a percentage of normal (from 0 to 100% being normal)?" [41]. It has not been previously validated for patients with rotator cuff tendinopathy, but shows good convergent validity with Rowe and American Shoulder and Elbow Society scores (r=0.72 and 0.66, respectively) in a young population with shoulder instability [41]. Scores for the daily questionnaires are reported for three items as an arithmetic mean for each follow-up week as per the accelerometry measures (Multimedia Appendix 1).

Perceived Shoulder Function and Quality of Life

The WORC and the QuickDASH are two health-related quality of life questionnaires, which were completed by participants at each of the four visits. Both questionnaires have been validated for follow-up of rotator cuff tendinopathy and upper extremity pathologies and show excellent test-retest reliability and sensitivity to change [12,42-46]. The scores are reported on a scale of 0 to 100. On the WORC, a higher score indicates better quality of life, while it is the opposite for the QuickDASH.

Physical Measures

Shoulder strength and amplitude were measured at each visit by either one of two standardized evaluators: a medical student or physical therapist. A hand-held dynamometer was used to measure shoulder strength in movements preferentially involving the three major rotator cuff muscles: scapular plane elevation

with thumb pointed down (Jobe maneuver) for supraspinatus muscle, external rotation at the side for infraspinatus, and internal rotation at the side for subscapularis [13]. An inclinometer was used to measure active shoulder range of motion amplitude in all planes of shoulder movement: abduction, flexion, scapular plane elevation, external rotation with shoulder at 90° of abduction, external rotation with arm at the side, and internal rotation with shoulder at 90° of abduction [47]. Internal rotation was also evaluated using the maximal vertebral level reached by the thumb with the hand at the back [47].

Global Rating of Change

The *Global Rating of Change Scale* (GRCS) is a 15-point scale that asks participants to rate their global perceived improvement ranging from "*a very great deal worse*" (–7) to "*a very great deal better*" (+7). Change from +4 ("moderately better") to +7 is considered moderate to important change [48]. The GRCS was handed to participants at the 3- and 5-week endpoints.

Compliance, Reliability of Data, and Acceptability of Wrist-Worn Accelerometry

A short questionnaire at the end of the study asked participants to estimate the number of times they forgot to wear or charge the WIMU-GPS. Discomfort and disturbance secondary to wearing the device was measured using the 100-mm VAS, and free space was given for any additional comment (Multimedia Appendix 2). Log data from the WIMU-GPS were also used to determine how many days the accelerometer was not charged or malfunctioning. Compliance and reliability are reported as the percentage of missing days over the total number of participant-days of the study.

Statistical Analyses

All statistical analyses were performed using SPSS statistics (v24.0 for Windows, IBM Corporation, Armonk, New York). An α value of 0.05 was used as the threshold for statistical significance. Normal distribution of variables was tested using a Shapiro-Wilk test. Currently, there is no gold standard to measure shoulder function in the setting of rotator cuff tendinopathy or shoulder pathologies [10]. Therefore, *convergent validity* was assessed by correlating accelerometry variables from the first week with scores from questionnaires and physical tests at the first evaluation (before the CSI). Normally distributed variables were correlated using a Pearson test, and Spearman correlations were used in the other case. *Test-retest reliability* of questionnaires and accelerometry and *intrajudge reliability* of clinical measures were computed using an intraclass correlation coefficient (ICC) between assessment done a week prior to the injection and the one done immediately before the injection. For daily measures, the mean of the three days following the first assessment was correlated to the mean of the 3 next days. To determine *sensitivity to change* of the instrument, we used a method to discriminate between participants with meaningful improvement and those who showed unchanged results [49]. Hence, participants were dichotomized into two groups using the GRCS at the 3- and 5-week evaluations as either perceiving a moderate to important change (improved group, GRCS≥4) or perceiving a mild change or less (stable group, GRCS>–4 and <4). This limit was used by Mintken et al [45] to determine clinically important change for shoulder questionnaires [45]. Standardized response means (SRM) [50] were calculated for both groups to compare sensitivity to change for each outcome variable. An SRM<0.2 is considered a minimal effect, while one between 0.2 and 0.49 is small, between 0.5 and 0.79 is moderate, and ≥0.8 is large [50]. Sensitive and specific instruments for change should show good SRM for the improved group and an SRM approaching zero for the stable group [51].

Results

Patients' Characteristics

Thirty-eight participants aged 25-65 years (mean 48.8 years, SD 10.4 years) were included in the study. Sociodemographics and baseline scores on patient-reported outcome of shoulder function, pain, and clinical exam results before CSI are shown in Table 1. All participants received the CSI and attended the preinjection, intervention, and 4-week follow-up visits. One participant was unable to be present at the 2-week visit and was instead asked to send in completed questionnaires by mail.

Table 1. Participant characteristics and scores at the first visit.

Parameter	Value
Number of participants	38
Sex, n (%)	
Female	18 (47.4)
Male	20 (52.6)
Age (years), mean (SD)	48.8 (10.4)
Body mass index (kg/m^2), mean (SD)	27.9 (5.0)
Smokers, n (%)	5 (13.2)
Dominant hand, n (%)	
Right	32 (84.3)
Left	6 (15.7)
Affected shoulder, n (%)	
Dominant	20 (52.6)
Nondominant	18 (47.4)
Time since onset of symptoms (months), mean (SD)	71.4 (79.3)
Questionnaire scores (out of 100), mean (SD)	
WORC[a]	46.88 (18.86)
QuickDASH	42.85 (18.07)
Pain VAS[b,c]	54.94 (18.76)
Activity VAS[c]	58.24 (20.82)
SANE[d]	53.42 (17.92)
Strength (kg), mean (SD)	
Jobe	8.11 (3.45)
External rotation	9.27 (3.69)
Internal rotation	13.60 (5.34)
Range of motion (°), mean (SD)	
Abduction	161.86 (22.30)
Flexion	159.49 (18.78)
Scaption	163.75 (17.17)
Internal rotation 90°	73.68 (14.22)
Spinal level	8.68 (3.40)
External rotation 90°	76.68 (14.22)
External rotation 0°	61.57 (17.15)

[a]WORC: Western Ontario Rotator Cuff.

[b]VAS: Visual Analog Scale.

[c]Arithmetic mean for the first week.

[d]SANE: Single Assessment Numeric Evaluation – arithmetic mean for the first week.

Convergent Validity

Although all questionnaires and clinical exams were completed at the first visit, only 24/38 accelerometers had valid data in the first week. The Shapiro-Wilk test confirmed normal distribution of all the data, and a Pearson test was used to calculate convergent validity between the different variables (Table 2). As expected, WORC and QuickDASH were well correlated (r=0.821, P<.001, data not shown in table). Both questionnaires had a moderate-to-strong correlation with the pain VAS (r=–0.815 and 0.637, respectively) and SANE (r=0.613 and –0.564, respectively), but showed no significant correlation with the activity VAS. None of the four accelerometry variables (AT, AC, LIA, MIA, or HIA) showed any significant correlation

with the WORC, QuickDASH, pain VAS, SANE, or clinical measures. However, there was a moderate correlation between the activity VAS and AT (r=0.484, *P*=.02). This correlation was significative at *P*<.05, but this statistical significance was lost following Bonferroni correction for multiple comparisons. Generally, acceleration measures correlate well with each other.

Table 2. Convergent validity.

	Pain VAS[a,b]	Activity VAS[b]	SANE[b,c]	Active time[b]	Activity count[b]	LIA[b,d]	MIA[b,e]	HIA[b,f]
WORC[g] (n=38)	–0.815[h]	–0.062	0.613[h]	0.327	0.353	–0.235	–0.199	0.229
P value	<.001	.71	<.001	.12	.09	.27	.35	.28
QuickDASH[i] (n=38)	0.637[h]	0.177	–0.564[h]	0.024	-0.170	–0.033	–0.023	0.015
P value	<.001	.30	<.001	.92	.45	.88	.92	.95
Jobe strength (kg) (n=38)	–0.303	-0.173	0.271	0.155	0.065	0.062	0.272	–0.237
P value	.06	.30	.10	.47	.76	.77	.20	.26
Abduction range of motion (°) (n=38)	–0.175	0.326[j]	0.210	0.386	0.317	–0.251	–0.262	0.275
P value	.29	.05	.21	.06	.13	.24	.22	.19
Pain VAS (n=38)	—[k]	0.326[j]	–0.583[h]	–0.128	-0.327	0.170	0.033	–0.071
P value		.05	<.001	.55	.12	.43	.88	.74
Activity VAS (n=38)	—	—	–0.110	0.484[j]	0.195	–0.369	–0.341	0.364
P value			.51	.02	.36	.08	.10	.08
SANE (n=38)	—	—	—	–0.013	–0.020	0.072	0.302	–0.262
P value				.95	.93	.74	.15	.22
Active time[b] (n=24)	—	—	—	—	0.469[j]	–0.761[h]	–0.439[j]	0.529[h]
P value					.02	<.001	.03	.01
Activity count[b] (n=24)	—	—	—	—	—	–0.621[h]	–0.674[h]	0.699[h]
P value						<.001	<.001	<.001
LIA[b] (n=24)	—	—	—	—	—	—	0.676[h]	–0.772[h]
P value							<.001	<.001
MIA[b] (n=24)	—	—	—	—	—	—	—	–0.990[h]
P value								<.001

[a]VAS: Visual Analog Scale.

[b]These values are presented as the arithmetic mean for the first week.

[c]SANE: Single Assessment Numeric Evaluation.

[d]LIA: low-intensity activity.

[e]MIA: medium-intensity activity.

[f]HIA: high-intensity activity.

[g]WORC: Western Ontario Rotator Cuff.

[h]Significant correlations with Bonferroni correction at *P*<.008

[i]QuickDASH: short version of the Disability of the Arm, Shoulder, and Hand questionnaire.

[j]Significant correlations at *P*<.05.

[k]Not applicable.

Test-Retest and Intrajudge Validity

One-week test-retest and intrajudge reliability for all of the outcomes measured are presented in Table 3. All participants were present for the second visit (intervention visit) and completed the questionnaires; however, 11 did not receive standardized range of motions and strength testing on that date. ICCs were used to derive the fidelity of all outcome measures, except for internal rotation measured from the spinal level (not a continuous variable), for which we used a weighted Kappa coefficient. There was enough data in 24 WIMU-GPS to proceed. All questionnaires had excellent reliability (ICC=0.883-0.950), and clinical measures had good to excellent

reliability (ICC=0.601-0.960). Accelerometry measures such as AT (ICC=0.724), AC (ICC=0.621), MIA (ICC=0.674), and HIA (ICC=0.661) had good reliability. However, MIA (ICC=0.104) showed very weak reliability in comparison.

Table 3. Test-retest reliability. Values provided are intraclass correlation coefficient unless indicated otherwise.

Questionnaires (n=38)	Reliability
WORC[a]	0.902
QuickDASH[b]	0.883
Pain VAS[c]	0.924
Activity VAS	0.908
SANE[d]	0.950
Strength (n=27)	
Jobe (kg)	0.770
External rotation (kg)	0.960
Internal rotation (kg)	0.952
Range of motion (n=27)	
Abduction (°)	0.812
Flexion (°)	0.932
Scaption (°)	0.886
Internal rotation 90° (°)	0.786
External rotation (spinal level)	0.93[e]
External rotation 90° (°)	0.601
External rotation 0° (°)	0.845
Acceleration data (n=24)	
Active time	0.724
Activity count	0.621
LIA[f]	0.104
MIA[g]	0.674
HIA[h]	0.661

[a]WORC: Western Ontario Rotator Cuff.

[b]QuickDASH: short version of the Disability of the Arm, Shoulder, and Hand questionnaire.

[c]VAS: Visual Analog Scale.

[d]SANE: Single Assessment Numeric Evaluation.

[e]Weighted Kappa coefficient.

[f]LIA: low-intensity activity.

[g]MIA: medium-intensity activity.

[h]HIA: high-intensity activity.

Sensitivity to Change

Global Rating of Change Scale

GRCS was completed by all participants at the 2- and 4-week evaluations. At 2 weeks, 31 patients (81.6%) felt improvements, six (15.8%) felt no change, and only one (2.6%) deteriorated following the injection. In addition, 25 of the 31 improved subjects (73.7%) classified their improvement as large on the GRCS scale (from “A good deal better” to “A very great deal better”). At 4 weeks, the number of participants who still described an improvement dropped to 26 (68.4%), while 11 did not feel better than the preinjection phase (28.9%). Only one participant (2.6%) felt worse at the 4-week evaluation (the same participant at the 2-week evaluation).

Sensitivity to Change at 2 Weeks and 4 Weeks

Sensitivity to change at 2 weeks and 4 weeks for all the outcomes measured are presented in Table 4. All patients filled the questionnaires at 2 weeks, but one could not attend the physical examination. Seventeen accelerometers contained enough data at the preinjection week and at the second week postinjection to allow for analysis. Of the participants who

described a large improvement on the GRCS, the WORC, QuickDASH, pain VAS, and SANE all showed a very strong effect (SRM=1.384-1.508). A moderate effect was also seen for activity VAS (SRM=0.568) and clinical measures. In contrast, only a small effect was seen with all accelerometry measures (SRM=0.017-0.246). Patients who described small or absent improvement generally showed a small effect on questionnaires (SRM=0.108-0.621) and clinical measures (SRM=0.010-0.419) with the exception of a large effect at the Jobe strength testing (SRM=1.067). Activity measures had a variable range of specificity to change.

Questionnaires and clinical examinations were completed for all patients at 4 weeks. Enough valid data were available in 13 accelerometers. AC, LIA, MIA, and HIA showed a large SRM (0.802-1.032) for participants who felt a significant improvement on the GRCS. However, AT only had a weak effect (SRM=0.064). For patients with a slight to nonexistent improvement on the GRCS, all accelerometer variables showed a weak effect (SRM=0.010-0.176). In a similar fashion to the 2-week data, WORC, QuickDASH, and SANE questionnaires, all showed a strong effect (SRM=1.039-2.094) on improved patients and a small to moderate effect on others. The activity VAS showed a moderate effect (SRM=0.507) on improved participants and a very small effect on participants without improvement. Clinical measures had very variable sensitivity and specificity to change at 4 weeks.

Table 4. Sensitivity to change at 2 and 4 weeks.

Outcome measure	Standardized response means from 0 to 2 weeks		Standardized response means from 0 to 4 weeks	
	Large improvement (n=25)	Slight or no improvement (n=13)	Large improvement (n=20)	Slight or no improvement (n=18)
WORC[a]	1.412	0.108	1.039	0.544
QuickDASH[b]	1.384	0.138	1.245	0.056
Pain VAS[c,d]	1.508	0.610	2.094	0.788
Activity VAS[d]	0.568	0.228	0.507	0.012
SANE[d,e]	1.395	0.621	1.712	1.214
Strength (kg)				
Jobe	0.101	1.067	0.057	0.553
External rotation	0.473	0.228	0.866	0.474
Internal rotation	0.594	0.168	0.674	0.357
Range of motion (°)				
Abduction	0.230	0.010	0.349	0.191
Flexion	0.456	0.087	0.510	0.048
Scaption	0.119	0.172	0.093	0.419
Internal rotation 90°	0.420	0.081	0.740	0.136
External rotation 90°	0.240	0.419	0.016	0.010
External rotation 0°	0.251	0.097	0.040	0.008
Accelerometry[d]				
Active time	0.082	0.103	0.064	0.176
Activity count	0.246	1.050	0.888	0.010
LIA	0.068	0.091	0.885	0.087
MIA	0.026	0.733	0.802	0.012
HIA	0.017	0.767	1.032	0.019

[a]WORC: Western Ontario Rotator Cuff.

[b]QuickDASH: short version of the Disability of the Arm, Shoulder, and Hand questionnaire.

[c]VAS: Visual Analog Scale.

[d]Calculated from the arithmetic mean of the pre-injection week, second week post, and fourth week post.

[e]SANE: Single Assessment Numeric Evaluation.

Patient Compliance and Data Loss

Recording days had a mean of 9 hours 59 minutes (SD 2 hours 44 minutes) of data on the accelerometers. Participants reported having forgotten to wear the device for a total of 6.2% of the recording days and forgotten to charge it 2.0% of these days. In comparison, WIMU-GPS data log show that participants forgot to charge or wear the device on 7.4% of the recording days. A software malfunction unfortunately caused a data loss for 31.2% of the recording days, increasing the total loss of recording days to 38.6%. As such, 57.0% of the follow-up weeks' accelerometry data were valid as per our predefined criteria. At the end of the study, participants reported minimal discomfort while wearing the device (mean 20.58 mm on a 100-mm VAS, SD 19.16 mm) and minimal inconvenience (mean 21.69 mm on a 100-mm VAS, SD 20.41 mm). Four participants voiced that the device tended to catch with their clothes, and three participants would have preferred it to be smaller and more discreet.

Discussion

The primary objective of this study was to validate wrist-based accelerometer measures and VAS of shoulder activity during daily living in comparison to other known measures for patients with rotator cuff tendinopathy. Daily pain VAS and SANE showed good convergent validity compared to previously validated questionnaires, while activity VAS and accelerometer data did not. However, activity VAS and AT correlated well together prior to correction for multiple comparison. Reliability was excellent for pain and activity VAS and SANE, but moderate for accelerometry measures. Sensitivity to change was excellent for pain VAS and SANE at 2 and 4 weeks and moderate for activity VAS and accelerometry measures at 4 weeks only. Evaluating the acceptability and compliance to wrist-based sensors was a secondary objective, and the accelerometers were shown to be easily accepted by patients who reported high adherence to wear.

The convergent validity of already validated questionnaires (WORC, QuickDASH, pain VAS, and SANE) was excellent and alike what has been already reported [12,14,52,53]. There was no significant correlation between questionnaires and range of motion, but there was a significant correlation between WORC and external and internal rotation strength and between SANE and strength in the Jobe test. Since the pathology mostly affects the tendon [4], but not the other structures in the shoulder, it would be logical that strength had some correlation with reported function, while range of motion did not. Although activity VAS was correlated with AT, reported and recorded shoulder activity did not correlate with any questionnaire or clinical measures. This is in contrast with correlations shown between accelerometry measures and DASH, Simple Shoulder Test, and pain VAS obtained by Jolles et al [18] and Korver et al [54]. These were obtained using multiple accelerometers and a standardized protocol of movements in a clinical setting, differing significantly from our protocol of unrestricted home usage. In both studies, patients were affected by a mix of pathologies (rotator cuff tendinopathy, shoulder osteoarthritis, etc), and a control group was used. Upper extremity activity might also represent a much different construct than that tested in questionnaires such as the WORC and DASH, and pain and subjective function are not necessarily linked with activity and use of the upper extremity. The correlation between AT and activity VAS suggests that accelerometry can still be used as a proxy for upper extremity activity. This correlation has not been described in the literature earlier. The significance of this correlation is, however, lost after correction for multiple comparisons. There are issues with correcting for multiple comparisons, with some statisticians recommending against this practice [55,56].

The excellent test-retest validity of WORC and QuickDASH has already been reported [12,42-45,52,57,58]. Our study adds new data on the excellent reliability of the SANE, pain VAS, and activity VAS in the context of shoulder pathologies. Similarly, the good intrajudge reliability of dynamometer-obtained shoulder strength and inclinometer-measured range of motion is confirmed in our study and resembles what has already been reported [13,59]. AT, AC, MIA, and HIA showed strong test-retest validity, which has not been reported in the literature in the context of shoulder pathology followed in an unrestricted home environment. Bruder et al [60] followed 15 distal radius fractures using wrist accelerometry and standardized tasks. Compared to our study, they obtained superior reliability for certain tasks such as classifying objects (ICC=0.83) and operating a lever (ICC=0.91), but similar or worse reliability for floor (ICC=0.69) and table cleaning (ICC=0.77) tasks and use of a keyboard (ICC=0.15). We hypothesize that the low reliability of LIA could be secondary to interference from other undesired movements detected by the accelerometers, but this remains to be tested.

As previously reported, WORC, QuickDASH, and pain VAS had excellent sensitivity to change and improvement in rotator cuff tendinopathy symptoms, both at 2 and 4 weeks after the intervention [46,52,53,61-66]. The SANE also showed excellent sensitivity to change, but only acceptable specificity to change. The activity VAS had moderate sensitivity to change at 2 and 4 weeks, and its low SRM on patients with low GRCS score indicated good specificity to change. Sensitivity to change of both SANE and activity VAS had not been previously reported in patients with shoulder pain or rotator cuff tendinopathy. As expected, sensitivity to change of clinical measures was low [15]. Sensitivity to change of all accelerometry measures was mediocre at 2 weeks, but acceptable at 4 weeks for AC, LIA, MIA, and HIA. This could be explained by a delay between the improvement in pain seen in questionnaires and patients increasing their use of the upper extremity. This delay could be secondary to previously acquired shoulder protective reflexes, slow improvement of a chronic condition, or no significant change in the patients' daily routine following the intervention. Knowing this, wearing the accelometry device for longer period of time, for example, 6-8 weeks, might have shown better sensitivity, as patients may have increased their function over time. Sensitivity to change of wrist accelerometry in shoulder pathology has not been previously studied.

With a compliance of above 90%, participants seem to have had no issues in integrating the device in their daily routine. This adherence ratio is similar or superior than that reported in

previous studies on the use of wrist accelerometers [35]. Very few complaints were voiced over the device and subjective acceptability seemed high. However, it is impossible to estimate how many potential participants declined the project because of the device. In a study on physical activity, 8.3% of participants refused to wear a wrist accelerometer for a duration of 9 days [67].

Data loss was larger than expected. Comparisons with other commercially available accelerometers show that these usually report between 3.3% and 10.8% of data loss [68-70]. Despite this setback, we were able to obtain enough data to calculate convergent validity, test-retest validity, and sensitivity to change of the wrist accelerometer. However, we recognize that this is an important limitation of the article, leading to possibly important bias in the data obtained, especially at the 4 weeks' follow-up, where only 13 participants had enough combined data preinjection to allow analysis. The software malfunction has since been corrected for future studies, now yielding less than 1% data loss. Other improvements to the device could include better power management to increase recording time, miniaturize the device, and make it water resistant in order to increase comfort and adherence to accelerometer use in all activities. Low battery life of the device might have led to a bias where possibly important activity data at the end of the day was lost. Usability issues encountered in this embedded study with the activity and monitoring platform used have since been addressed by using smartwatches with motion sensors as a data logging platform for the proposed measurement approach. Possible uses of such a system could be the development of an app that allows clinicians and surgeons to follow the rehabilitation and progress of their patients in real-time, potentially allowing for less frequent clinical visits. The patient could also track his own progress to determine if more home physical therapy work is needed to remain in the correct recovery pathway. This could lead to decreasing health care cost for the patient, while allowing the clinician to free up more clinical time to see additional patients and decrease wait lists.

This study has multiple strengths. First, it is the first to report and compare metrological qualities of accelerometers in patients with shoulder pain or rotator cuff tendinopathy. Second, our strict inclusion criteria ensured internal validity of the study. Third, although we report similar data as those reported for the WORC and QuickDASH, we added significant information on pain and activity VAS, SANE, shoulder strength, range of motion, and accelerometry in the context of rotator cuff tendinopathy following a CSI. However, since we included only one pathology, the external validity of the study is diminished. The physical examination was performed by two different examiners, which might be a source of bias in this validation study.

Conclusions

Daily pain VAS and SANE showed good correlation with validated questionnaires, excellent reliability at 1 week, and excellent sensitivity to change at 2 and 4 weeks. Daily activity VAS– and accelerometry-derived AT were well correlated. Activity VAS showed excellent reliability, but moderate sensitivity to change. Accelerometry measures have moderate reliability and moderate sensitivity to change at 4 weeks.

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Authors' Contributions

SL conceived the study, assisted with recruitment of the participants and the data collection, performed the statistical analyses, and wrote the original version of the manuscript. FB participated in the design and coordination of the study, recruited patients, performed CSI, and assisted in the interpretation of the data. SB assisted with recruitment of the participants, data collection, coordination of the study, and interpretation of the data. GL participated in the design and coordination of the study and assisted in the interpretation of the data. MT was involved with the development of WIMU-GPS devices and participated in the interpretation of the data. PB participated in the study conception, design and coordination, development of WIMU-GPS devices, accelerometer data processing, revision of the statistical analyses, interpretation of the data, and the drafting of the manuscript. All authors read, revised, and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Daily questionnaire provided to participants, including a pain Visual Analog Scale, an activity Visual Analog Scale, and the Single Assessment Numeric Evaluation.
[PDF File (Adobe PDF File), 120 KB - rehab_v6i2e14468_app1.pdf]

Multimedia Appendix 2
Accelerometer satisfaction questionnaire provided to participants.
[PDF File (Adobe PDF File), 120 KB - rehab_v6i2e14468_app2.pdf]

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Abbreviations

AC: activity count
AT: active time
CHUS: Centre Hospital Universitaire de Sherbrooke (Sherbrooke University Health Center)
CSI: corticosteroid injection
GRCS: Global Rating of Change Score
HIA: high-intensity activity
LIA: low-intensity activity
MIA: medium-intensity activity
NSAID: nonsteroidal anti-inflammatory drug
PRO: patient-reported outcome
QuickDASH: short version of the Disability of the Arm, Shoulder, and Hand questionnaire
SANE: Single Assessment Numeric Evaluation
SRM: standardized response mean
tDCS: Transcranial Direct Current Stimulation
VAS: Visual Analog Scale
WIMU-GPS: Wireless Inertial Measurement Unit with GPS
WORC: Western Ontario Rotator Cuff index

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Original Paper

Amputees' Attitudes Toward Participation in Amputee Support Groups and the Role of Virtual Technology in Supporting Amputees: Survey Study

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Abstract

Background: Acquiring information about and living with an amputation (or limb differential) is a lifelong endeavor. Although medical institutions address the immediate medical needs of amputees, information regarding how to live life as an amputee is provided from numerous sources, one of which is amputee support groups.

Objective: This study aimed at understanding why amputees join support groups, leave support groups, and possibly return to support groups as well as how technology, specifically virtual reality, might play a role in supporting patients' needs. The results are intended to provide data for support groups, to increase their impact on amputee participants.

Methods: A 38-item online survey was developed based on the findings of a previous randomized trial. The survey was administered between April and September 2018 and divided into four sections: Demographics, Limb Loss History, Amputee Support Group Participation, and Technology Usage. Items used multiple-choice, drop-down menu, check-box formats with explanation boxes for open-ended responses. Descriptive analyses were performed for both qualitative (open-ended questions) and quantitative data.

Results: Of the 59 amputees enrolled, 54 completed the survey. All the respondents were aged 20-39 years, and nearly half of the older respondents thought audio and video teleconferencing or avatar-based technology would increase participation in support groups. The results suggest that an early goal for amputees who join support groups is to focus on regaining mobility and functionality in order to return to their normal life. Once achieved, the goal transitions to one of social connection with other amputees, although there is a caveat: Simply being an amputee may not provide sufficient connections for developing long-term social relationships. The strongest reason for joining a support group was to learn about living with an amputation, followed by networking and learning new skills.

Conclusions: The results suggest four key takeaways regarding amputee participation in support groups: (1) the needs of participants in amputee support groups change over time; (2) meeting content needs to be relevant to agendas primarily driven by participants; (3) support group participation is also driven by the desire to increase functionality by developing skills, become familiar with prosthetic technology, have more than amputation in common with other participants, and participate at the designated meeting time and location; and (4) the use of technology should support patients' needs.

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KEYWORDS

amputation; amputee; survey; support; support group; technology; virtual; virtual reality

Introduction

Acquiring current and evolving prosthetic and health-related information is an ongoing process throughout the lifespan of an amputee. Although the availability of global data regarding the incidence of amputation is varied and nonstandardized, it is estimated that there are nearly 2 million people living with limb loss in the United States, [1] with approximately 185,000 amputations occurring here each year [2]. Worldwide, peer support is a viable venue for acquiring and sharing this information. A support group is defined as a group of people with common experiences and concerns who provide emotional and moral support for one another [3]. The concept of patient support groups dates back to the late 18th century France, where "The governor of Bicêtre Hospital in Paris, Jean Baptiste Pussin, recognized the value of employing recovered patients as hospital staff. The chief physician at the hospital, Philippe Pinel praised these peer staff for being 'gentle, honest, and humane', 'averse from active cruelty', and 'disposed to kindness'" [4].

The power and impact of support groups were demonstrated by one of the earliest support groups, Alcoholics Anonymous, in 1935. Alcoholics Anonymous showed how self-help groups could do what the medical profession had, for the most part, been unable to do, which was to help alcoholics successfully manage their addiction [5]. In the latter half of the 20th century, support groups in both the mental health field and medical profession proliferated. Support groups were created to help those affected by numerous conditions, from addictions to heart disease, cancer, and grief support. One such group—the Amputee Coalition—was founded in 1986 when "a small group of amputee support group leaders recognized the need for an organization dedicated to the needs of people with limb loss, their families and healthcare providers" [6]. Peer support for amputees can assist with adjustment to amputation; psychosocial healing [7]; and sharing information about medical support, adaptive tools, and mental health resources.

Although traditional peer-to-peer support groups have functioned in face-to-face, real-time meetings, a limitation of face-to-face peer support groups is the lack of access due to distance, time, transportation, etc. This is especially true for individuals with disabilities, chronic illness, or mental illness [8]. These populations may not have the physical or social resources to participate in face-to-face support groups. As a result, virtual health care support groups are a potential alternative. Virtual health care support groups utilize the communication technology of virtual worlds. The growth and positive impact of virtual worlds has created many new possibilities for amputee support groups. A 2013 study of 196 individuals with physical or mental disabilities who actively participated in Virtual Ability in the Second Life virtual world found an increase in self-esteem, social support, and life satisfaction [9].

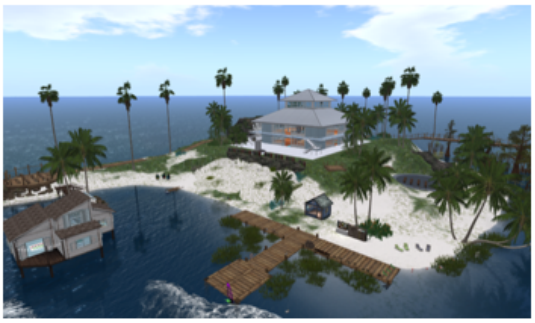
Characteristics of virtual worlds include persistence, anonymity, 24/7 access to individuals globally, and virtual embodiment [8]. Persistence is the ability of the virtual environment to continue to operate, use, and collect data irrespective of whether individuals are interacting with it via their avatars [8]. Virtual worlds are anonymous because the use of avatars allows the user to mask their identity, which includes the ability to alter their age, gender, physical appearance, and other characteristics including disabilities. Virtual worlds allow amputees to interact globally, overcoming geographic limitations and isolation. Virtual embodiment allows users to interact with their virtual geography including other individuals and objects in the environment and in the virtual world [10]. In other words, the virtual world environment may allow people to participate in support group sessions with a level of access and anonymity that is not possible in a face-to-face support group setting.

Winkler et al [11] tested the use of a virtual environment to provide self-management information including skill development to amputees. Figure 1A shows how a computer is used to access the virtual world via the internet. Figure 1B shows the virtual world built for Winkler's previous study [11]. Amputees had the opportunity to view themselves as an avatar, practicing desired behaviors such as balance (Figure 1C) and providing information on the history of prosthetics (Figure 1D). Figure 1E and F show virtual support groups. Some participants performed activities wearing a prosthetic limb and socialized with other amputees virtually, before having a prosthetic limb and interacting with other amputees in real life. Attempts at convening a virtual support group within the virtual world infrastructure developed by Winkler et al [11] were not sustained, which was the impetus for the survey study reported in this paper. Thus, the purpose of the survey study was to understand what amputees seek in a support group and to measure the acceptability of using technology to increase access to support groups. More specifically, the study sought to answer four research questions:

1. Why do amputees join support groups?
2. Why do amputees not participate in support groups?
3. Why do amputees rejoin support groups?
4. Is there a role for virtual technology in improving amputee support group engagement?

Figure 1. (A) User engaging with a virtual world via computer, (B) the virtual island, (C) practicing balance activities, (D) a virtual museum, and participating in regularly scheduled (E), and holiday virtual support groups (F).

A. Using a computer to access a virtual world.



B. The virtual world build for Winkler's previous study.

C. Amputees using avatars to practice behaviors.

D. Virtual museum providing a history of prosthetics.

E. One setting for an amputee virtual support group.

F. Another setting for an amputee support group.

Methods

This study was approved by the Nova Southeastern University Institutional Review Board. A cross-sectional survey design was used to survey a sample of amputees with an email address, as the survey was administered by email and required internet access. Using convenience sampling, amputees were recruited using an institutional review board–approved flyer distributed on the Amputee Coalition website and Facebook page; InMotion magazine; and at the 2018 Amputee Coalition annual conference in Tucson, AZ. Interested participants were instructed to contact the first author by phone or email. Study data were collected and managed using Research Electronic Data Capture (REDCap) electronic data capturing tools hosted at Nova Southeastern University. REDCap is a secure, Web-based app designed to support data capture for research studies, providing an intuitive interface for validating data entry; audit trails for tracking data manipulation and export procedures; automated export procedures for seamless data downloads to common statistical packages; and procedures for importing data from external sources [12]. Subjects who decided to participate in the study provided their name and email to the first author. They were then sent an email via REDCap with a link to the closed survey. A statement of consent preceded the survey. Respondents were able to review and change their answers.

The 38-item survey administered between April and September 2018 was divided into four section headers: Demographics, Limb Loss History, Amputee Support Group Participation, and Technology Usage. The Demographic section of the survey had four demographic questions including gender, race-ethnicity, age, and military service. The Limb Loss History section had seven questions including type, cause, and number of participant amputations. The Amputee Support Group Participation section included questions about the number, type, and frequency of support group participation. The Technology Usage portion of the survey asked participants about the type, frequency, and access to various types of technology. The formats of the items were multiple-choice, drop-down menu, check boxes (designated for single and multiple answers). Explanation boxes were also provided for some questions to give participants a chance to choose the "other" option and provide open-ended responses.

There were additional comments sections for respondents to provide further, optional information. Qualitative descriptive analyses were used for open-ended questions. Quantitative statistical analysis was applied to the numerical data captured from the survey.

Results

Fifty-nine amputees were enrolled in the study. Data were analyzed for the 54 amputees who completed the survey, although most, not all, items were completed for all participants. Tables 1 and 2 present the demographic composition of the participant group.

The first research question asked why amputees join support groups. Table 3 shows how many participants belong to support groups and other information about support group participation.

Table 1. Demographic data.

Variable	Sample (N=54)
Age (years), mean (range)	58.6 (20-82)[a]
Sex, n (%)	
Male	35 (65)[b]
Male LGBT[b]	1 (2)
Female	18 (33)
Race, n (%)	
Caucasian/White	50 (93)
Black/African American	3 (6)
Native American	1 (2)
Ethnicity, n (%)	
Latino/Latina	2 (4)
Not Latino/Latina	52 (96)
Military service, n (%)	
Yes	8 (15)
No	46 (85)
Number of amputations, n (%)	
1	41 (76)
2	8 (15)
3	2 (4)
>4	3 (6)

[a]Continuous variable in age (range).

[b]LGBT: lesbian, gay, bisexual, transgender.

Table 2. Amputation data.

Variable	Value, n (%)
Number of amputations (54 subjects)	
1	41 (76)
2	8 (15)
3	2 (4)
≥4	3 (6)
Amputation type (total of 64 amputations, as some subjects had more than one amputation)	
Below knee	35 (55)
Above knee	11 (17)
Finger(s)	6 (9)
Below elbow	3 (5)
Shoulder disarticulation	1 (2)
Above elbow	1 (2)
Elbow disarticulation	1 (2)
Hip disarticulation	1 (2)
Knee disarticulation	1 (2)
Foot	1 (2)
Toe(s)	1 (2)
Amputation side	
Left	28 (52)
Right	20 (37)
Bilateral	4 (7)
Quadrimembral	2 (4)
Amputation cause (total of 64 amputations, some subjects had more than one cause)	
Trauma	18 (28)
Infection	14 (22)
Diabetes related	10 (16)
Other	8 (13)
Vascular disease	4 (6)
Cancer	4 (6)
Disease related	3 (5)
Congenital/birth	2 (3)
Unknown	1 (2)
Time since most recent amputation (years; N=53, as one participant did not respond	
<1	4 (8)
1-2	9 (17)
2-3	8 (15)
3-5	8 (15)
5-10	11 (21)
≥11	13 (25)

Table 3. Amputee support group experience.

Experience	Participants, n (%)
Belong to at least one support group	
Yes	45 (83)
No	9 (17)
Number of years belonged to support group (45 responses)	
<1	11 (24)
1-2	9 (20)
2-3	8 (18)
3-5	9 (20)
5-10	6 (13)
≥11	2 (4)
Number of support groups participated in the past 12 months (one missing value, N=53 respondents)	
0	14 (26)
1	23 (43)
2	10 (19)
3	4 (8)
>3	2 (4)
Frequency of support group meets (47 responses)	
Once a month	30 (64)
Once every 2 months	4 (9)
Once every 3 months	2 (4)
Twice a year	1 (2)
Other	10 (21)
Number of meetings attended past 12 months (primary group; 47 responses)	
0	9 (19)
1-3	17 (36)
4-6	5 (11)
7-9	5 (11)
10-12	11 (23)

Questions 22, 24, and 26 in the 38-item participant survey asked respondents to select all applicable choices; therefore there could be multiple responses per participant.

Table 4 shows seven defined reasons (plus "Other") for amputees' participation in support groups, stratified by sex and military experience. The top reasons for all participants to join their support group were to obtain information about living with an amputation and to network with other amputees and health care professionals. For the group of military respondents, the top reasons were to obtain information about living with an amputation, to learn new skills as an amputee, and to network with other amputees and health care professionals.

Table 5 presents 13 reasons why amputees do not participate in support groups, stratified by sex and military experience. The top two reasons for all participants not to participate in support groups were because they did not know there was a support group close to them or the support group was not close enough. For the group of military respondents, the top reasons they did not participate was that they did not know there was a support group close to them, the support group was not close enough, or they did not feel they had anything in common with other members of the group. The "Other" option was the most frequent selection. Textbox 1 groups the "Other" reasons by theme.

Table 4. Reasons why participants decided to participate in their amputee support group (total responses=160).

Reason	All responses, n (%)	Male responses, n (%)	Female responses, n (%)	Military responses, n (%)
Obtain info about living with an amputation	34 (21.3)	23 (20.4)	11 (23.4)	7 (29.2)
Network with other amputees & health care professionals	30 (18.8)	20 (17.7)	10 (21.3)	4 (16.7)
Make new friends	21 (13.1)	14 (12.4)	7 (14.9)	2 (8.3)
Learn about new prosthetic technologies	19 (11.9)	16 (14.2)	3 (6.4)	1 (4.2)
Learn new skills as an amputee	19 (11.9)	12 (10.6)	7 (14.9)	5 (20.8)
Learn about new amputee support services	16 (10.0)	12 (10.6)	4 (8.5)	1 (4.2)
Learn about new amputee support technologies	13 (8.1)	10 (8.8)	3 (6.4)	2 (8.3)
Other	8 (5.0)	6 (5.3)	2 (4.3)	2 (8.3)

Table 5. Reasons for not participating in an amputee support group (total responses=69).

Reason	All responses, n (%)	Male responses, n (%)	Female responses, n (%)	Military responses, n (%)
I don’t know if there are any support groups near me	9 (13.0)	7 (16.7)	2 (7.4)	4 (23.5)
No amputee support groups are reasonably close to where I live	8 (11.6)	3 (7.1)	5 (18.5)	2 (11.8)
I don’t feel I have a lot in common with the other participants	7 (10.1)	6 (14.3)	1 (3.7)	2 (11.8)
The amputee support group meeting time does not work for me	7 (10.1)	5 (11.9)	2 (7.4)	0 (0.0)
Usually, not enough people show up	5 (7.2)	3 (7.1)	2 (7.4)	1 (5.9)
It’s always the same people who attend	5 (7.2)	3 (7.1)	2 (7.4)	1 (5.9)
The meeting topics are usually not relevant to my needs	5 (7.2)	3 (7.1)	2 (7.4)	1 (5.9)
Most of the participants are not in my age group	5 (7.2)	3 (7.1)	2 (7.4)	0 (0.0)
The meeting topics are usually not interesting to me	3 (4.3)	1 (2.4)	2 (7.4)	1 (5.9)
I do not like the amputee support group leadership	3 (4.3)	1 (2.4)	2 (7.4)	1 (5.9)
The healthcare professionals take up most of the meeting time	2 (2.9)	2 (4.8)	0 (0.0)	1 (5.9)
There is/are amputee support group(s) close to me, but I have no way to get there	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Usually there are too many people	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Other	10 (14.5)	5 (11.9)	5 (18.5)	3 (17.6)

Textbox 1. Other reasons for not participating in support groups.

Time:

- Meetings are held every other month and I lose track of which month they are held on also I have many doctors' appointments at the same time they are held on too.
- Wasn't able to make last one
- Limited time
- The support group for upper extremity amputees is only held twice a year. Unfortunately, I have missed meetings because the days did not work because of other obligations, or timing

Gender:

- I am the only woman except sometimes the wives of some amputees
- Being an above the elbow amputee and a women, I have found that most support groups are made up of primarily leg amputees and men

Need:

- Don't need support, can make this adjustment on my own, too proud, shows signs of weakness, won't help
- We had so many below 40 amputees we helped and convinced a few to start a "young" amputees support group and had joint meetings occasionally
- Never really thought about joining one.

Fear:

- I'm still embarrassed of my situation.

Distance:

- The support group for upper extremity amputees is 2 hours from my home

Leadership and group process:

- There is little, if any, opportunity provided for interchange of experience among the amputees. All of us, occasionally, wonder about this or that and if others have had similar experiences. The group does not even go around the table each time to introduce oneself and, perhaps, indicate the reasons for their amputation. In short, we know almost nothing about each other. The professionals make presentations and don't even ask if there are questions or how the presentation might be relevant to anyone in the room.

Commonality:

- I found my local support group to be a lot of older amputee people who were very negative and who is me type people who complained a lot instead of going out and doing things. I lead a much more active lifestyle than they do.

Table 6 shows 10 possible reasons why participants would return to a support group. The top reasons were that members of the group should have more in common with the respondent, the group should be closer geographically, and the topics should be more relevant. For the group of military respondents, the top reasons were that the group should have more in common with the respondent and the topics should be more relevant. Reasons specific to men were a preference that health care professionals not dominate support group meetings.

An ad hoc analysis looked at the relationships between the duration of participation in support groups and time since amputation for a cohort of 34 amputees who had a single amputation and belonged to a support group (Table 7). The data show that while about half the amputees dropped out of support groups as time since amputation increased, others joined support groups ≥5 years after their amputation.

Table 8 shows the confidence level of using technology by age group. The majority of respondents rated themselves as "Very Confident" in using technology and used technology daily. Nearly 100% of all age groups used technology daily (not graphed). Only one respondent used technology "Weekly" (≥60 years) and one responded, "Not at all" (40-59 years).

All the participants in the 20-39 years age group and less than half of the older groups reported that they thought technology (teleconferencing, videoconferencing, and virtual environments) could increase participation in amputee support groups (Table 9).

Tables 10-12 compare the likeliness of joining a support group using teleconferencing, videoconferencing, and avatars by age group: 20% of the respondents aged 20-39 years were very likely to participate in support groups that use teleconferencing and videoconferencing. In comparison, 40% of those aged 20-39 years were very likely to participate in support groups that used avatars. Only 20% of those aged 40-59 years and ≥60 years responded that they were not at all likely to use teleconferencing or videoconferencing; 30% said they were not at all likely to use avatars.

Table 6. Reasons to participate in a support group (total responses=52).

Reason	All responses, n (%)	Male responses, n (%)	Female responses, n (%)	Military responses, n (%)
Participants that have more in common with me	13 (25.0)	7 (23.3)	6 (27.3)	3 (18.8)
An amputee support group closer to where I live	7 (13.5)	4 (13.3)	3 (13.6)	1 (6.3)
More relevant topics to my needs	7 (13.5)	3 (10.0)	4 (18.2)	3 (18.8)
Participants who were closer to my own age	6 (11.5)	3 (10.0)	3 (13.6)	1 (6.3)
Healthcare professionals who support the meetings without dominating the meetings	5 (9.6)	5 (16.7)	0 (0)	2 (12.5)
Other	5 (9.6)	3 (10.0)	2 (9.1)	1 (6.3)
The availability of technology like teleconferencing , videoconferencing, etc to be able to meet virtually	4 (7.7)	2 (6.7)	2 (9.1)	2 (12.5)
A larger group of participants	4 (7.7)	2 (6.7)	2 (9.1)	2 (12.5)
A smaller group of participants	1 (1.9)	1 (3.3)	0 (0)	1 (6.3)
If I could access low cost reliable transportation to get me to the meeting	0 (0)	0 (0)	0 (0)	0 (0)

Table 7. Relationship between time since amputation and duration of support group participation (total=34 hours).

Number of years since amputation	Number of years in support					
	<1	1-2	2-3	3-5	5-10	>11
<1	2	—[a]	—	—	—	—
1-2	3	3	—	—	—	—
2-3	0	2	4	—	—	—
3-5	3	0	2	3	—	—
5-10	0	1	0	3	1	—
>11	0	2	1	0	3	1

[a]Not applicable.

Table 8. Confidence in using technology (N=54).

Level of confidence	All participants, n (%)	Group: 20-39 years, n (%)	Group: 40-59 years, n (%)	Group: 60-82 years, n (%)
Very confident	25 (46.3)	3 (60.0)	12 (57.1)	10 (35.7)
Confident	17 (31.5)	1 (20.0)	7 (33.3)	9 (32.1)
Slightly confident	11 (20.4)	1 (20.0)	1 (4.8)	9 (32.1)
Not confident at all	1 (1.9)	0 (0.0)	1 (4.8)	0 (0.0)

Table 9. Responses to the question, “Can technology increase participation in amputee support groups?” (N=51).

Response	All participants, n (%)	Group: 20-39 years, n (%)	Group: 40-59 years[a], n (%)	Group: 60-82 years[b], n (%)
I think technology will increase the level of participation in amputee support groups.	23 (45.1)	5 (100)	9 (45.0)	9 (34.6)
I am not sure whether technology will increase the level of participation in amputee support groups.	17 (33.3)	0 (0)	7 (35.0)	10 (38.5)
I don't think technology will increase the level of participation in amputee support groups.	11 (21.6)	0 (0)	4 (20.0)	7 (26.9)

[a]One person did not respond.

[b]Two people did not respond.

Table 10. Likelihood of using teleconferencing to participate in an amputee support group (N=54).

Likelihood	All participants, n (%)	Group: 20-39 years, n (%)	Group: 40-59 years, n (%)	Group: 60-82 years, n (%)
Very likely	9 (16.7)	1 (20.0)	3 (14.3)	5 (17.9)
Somewhat likely	16 (29.6)	2 (40.0)	6 (28.6)	8 (28.6)
Neutral	13 (24.1)	2 (40.0)	5 (23.8)	6 (21.4)
Somewhat unlikely	6 (11.1)	0 (0)	3 (14.3)	3 (10.7)
Not at all likely	9 (16.7)	0 (0)	4 (19.0)	5 (17.9)
Don’t know what teleconferencing is	1 (1.9)	0 (0)	0 (0.0)	1 (3.6)

Table 11. Likelihood of using videoconferencing to participate in an amputee support group (N=54).

Likelihood	All participants, n (%)	Group: 20-39 years, n (%)	Group: 40-59 years, n (%)	Group: 60-82 years, n (%)
Very likely	7 (13.0)	1 (20.0)	3 (14.3)	3 (10.7)
Somewhat likely	15 (27.8)	1 (20.0)	4 (19.0)	10 (35.7)
Neutral	16 (29.6)	3 (60.0)	7 (33.3)	6 (21.4)
Somewhat unlikely	5 (9.3)	0 (0.0)	2 (9.5)	3 (10.7)
Not at all likely	10 (18.5)	0 (0.0)	5 (23.8)	5 (17.9)
I don’t know what teleconferencing is	1 (1.9)	0 (0.0)	0 (0.0)	1 (3.6)

Table 12. Likelihood of using avatars to participate in avatars in a virtual amputee support group; response to the question, “If you had access to the internet how likely would you be to join a virtual support group using avatars?” (N=54).

Likelihood	All participants, n (%)	Group: 20-39 years, n (%)	Group: 40-59 years, n (%)	Group: 60-82 years, n (%)
Very likely	9 (16.7)	2 (40.0)	5 (23.8)	2 (7.1)
Somewhat likely	5 (9.3)	1 (20.0)	2 (9.5)	2 (7.1)
Neutral	19 (35.2)	1 (20.0)	8 (38.1)	10 (35.7)
Somewhat unlikely	7 (13.0)	0 (0.0)	2 (9.5)	5 (17.9)
Not at all likely	13 (24.1)	1 (20.0)	4 (19.0)	8 (28.6)
I don’t know what teleconferencing is	1 (1.9)	0 (0.0	0 (0.0)	1 (3.6)

Discussion

Principal Findings

The purpose of this study was to understand why amputees do or do not participate in support groups and whether there is a role for technology in improving amputee support group engagement. The authors speculated that with the growing prevalence of virtual technology, there was an opportunity for virtual technology to supplement the amputee support group experience. After a failed virtual support group in a previous study [11], it became clear that additional information on support group participation and attitudes toward a “spectrum of increasingly more complex technology” was needed. In the early 1980s, when the use of computer-based training (CBT) was in its infancy, instructors had to take time in a class to provide basic computer literacy—how to turn on and off the computer, save and transfer data, how to use a mouse, etc—skills that are ubiquitous today. We believe that one day, customizing an avatar and navigating a virtual reality environment will also be ubiquitous. Our data show that 100% of amputees in the youngest age group (20-39 years) believe that technology would improve participation in support groups, a finding supported by Taylor et al [13] who used virtual technology with respiratory patients. Although it is important to understand how best to deliver health care, including support to the next generation of health care consumers, we had some unexpected findings.

When examining the text-based participant feedback in Table 4 and the duration of participation in Figure 1D, we learned that participants had two reasons for joining a support group. The first was to learn skills and improve functionality to regain as much mobility as possible (which includes familiarity with new prostatic technology), and the second was to connect with other people who have had similar experiences. While further research is needed, once the functional goals of a participant are attained, the social aspect seems to become more critical, and if there is no sense of connectivity between participants, amputee support group participation drops over time. The implications of this observation will be examined further in this paper.

Although the survey covered a lot of ground, there seemed to be four key takeaways regarding amputee participation in support groups:

- The needs of participants in amputee support groups change over time.
- Meeting content needs to be relevant with agendas primarily driven by participants.
- Support group participation is also driven by the desire to
  - Increase functionality by developing skills
  - Become familiar with prosthetic technology
  - Have more than amputation in common with other participants
  - Participate at the designated meeting time and location
- The use of virtual technology should support patients' needs.

A more detailed discussion of each takeaway is presented below.

The Needs of Participants in Amputee Support Groups Change Over Time

It should come as no surprise that amputee support group participants' needs change over time. In cases where the initial challenge of living with a prosthesis is met, participants look for deeper connectivity to the other members of the support group. If that does not happen, group participation can be waned.

Just as the Amputee Coalition describes phases of recovery for amputees [14], the data in the study suggest that participation in amputee support groups may follow phases based on time as an amputee and functional capability. Reviewing both the text-based responses in Table 3 and the duration of participation observed in Textbox 1, it may be reasonable to assume that there are phases in support group participation: a short-term phase (≤1 year) with a primary focus on improving functionality and a longer-term phase (>1 year) where connecting with the shared experience of other amputees becomes the primary focus. Table 13 describes how amputee support groups' goals may vary over time.

From early on, the primary focus of amputees is to learn the life skills needed to return to as normal a life as possible and meet with other amputees who have a shared experience. Over a longer time, as the functional goals are achieved, the primary purpose of continuing participation seems to focus on friendships and relationships with others because of their shared experience, and secondary purpose is to obtain new information on functional issues and prosthetic technology as they become available. If this observation proves to be valid, the implications for support group content and agendas may be significantly impacted, as that agendas should provide content or activities to meet the needs of participants based on where they are in their experience as an amputee.

Table 13. Proposed phases of goal priority for amputees in support groups.

Phase	New amputees (≤1 year)	Experienced amputees (>1 year)
Primary goal	Increase functional skills and familiarity with prosthetic technology	Connect with the shared experiences of other amputees
Secondary goal	Connect with the shared experience of other amputees	Enhance existing functional skills and learn about new prosthetic technology

Meeting Content Needs to be Relevant With Agendas Primarily Driven by Participants

The decision to participate in an amputee support group is based on the perceived value of what the group has to offer as well as the logistical ability to participate in the meetings. Following the perceived value, or perhaps, as part of that perceived value, the relationships between participants and the meeting content become an important factor for continuing to be engaged in a support group.

For respondents who choose not to participate in a local support group, a common reason for not doing so was feeling disconnected from the content of the meetings. Either the health care professionals drove too much of the agenda or the content was not sufficiently explained, or the reason was relevant to the participants' needs. While additional research could help gain a better understanding of the opportunity, not surprisingly, it appears that amputees want to be empowered and engaged in their support group meetings by helping to drive the meeting content. This may seem like common sense, but in a number of support group situations, this is not perceived by amputees as common practice.

Additionally, trying to be "all things to all people" with regard to meeting content pits the needs of new amputees against those of seasoned amputees. The data suggest that there may be a need for amputee support groups that provide focus for new amputees as well as a separate focus for "seasoned" amputees. Creating a single agenda for every meeting that serves both groups' needs may be a significant challenge, but unless there is a large enough population of each category of amputees to support two groups, the meeting agenda may need to have a portion of time dedicated to the needs of the new amputee and a portion of this agenda focused on the more experienced amputee.

These observations also tie into the descriptor we used to label a support group "participant." Considering that support group participation may occur over time, from starting as a new amputee to becoming an experienced amputee, the label of "patient" may not apply to a "seasoned" amputee support group participant. In the article "What should we call the people we work with?" Author John Brinkman observed that early on in the journey of limb loss, individuals are often referred to as "patients" because they may be recovering from an actual illness [15]. The use of the descriptor "patient" also suggests a dependent relationship between amputee and health care providers/prosthetists. However, over time, that relationship changes, where the individual may no longer be "sick," so, perhaps, they should no longer be viewed as "patients."

If the leadership of an amputee support group is largely comprised of health care providers who view its members as "patients" as opposed to "participants," health care providers may feel justified to be the ones driving the support group agenda and content, that is, they know best what should be covered in a support group meeting. However, once the health care community considers experienced amputees as partners or participants instead of patients, the goals and content of support group meetings can be mutually agreed to. This requires further study but it is possible that participation and engagement in support group meetings could increase with a change in meeting philosophy based on how group participants are defined—as patients or partners.

Support Group Participation Driven by Several Factors

Support group participation was driven by the need to improve functionality by developing skills, becoming familiar with prosthetic technology, having more than amputation in common with other amputees, and being available to participate in support group meetings at the designated time and location.

As stated earlier, the research suggests that many people initially join amputee support groups primarily to learn how to live life as an amputee. This can be done through gait clinics and other group activities ranging from swimming to bowling, golf, and many other sport- and hobby-based activities. Once these needs are met, having something in common with the other support group members is important to most amputees' continued participation in the support group. Although this study only skimmed the surface of elements of commonality, some of the feedback indicated that gender, age, socioeconomic background, and educational background impact the perception of commonality between members of a support group and consequently a connection that may drive continued participation. While support group leaders can easily control meeting content, it is far more challenging to manage the demographic of amputees that participate in support group meetings. Additional research in this area may prove helpful to support group leaders.

Learning about prosthetic technology can be overwhelming for new amputees. Support groups can help when experienced amputees share their experiences with certain technologies. Additionally, product manufacturers and prosthetists might be invited to support group meetings as long as it is understood that the purpose is to objectively inform the audience and not simply promote their products.

In addition, of importance to many amputees was the timing and location challenges of attending amputee support group meetings, which can impact respondents' level of participation. Trying to find an optimal meeting time and location for all amputees connected to a support group can be very challenging for group leaders. Depending on the size of the group, varying the meeting times or location or the use of communication technology may help with this issue.

Virtual Technology Should Support the Participants' Needs

Respondents indicated a general belief that technology may be used to overcome some of the meeting logistical limitations that were a challenge to some respondents. However, it was also clear that at an individual level, such openness to the use of technology was strongly influenced by the respondents' comfort level and understanding of specific technology options.

Based on the earlier observations regarding focus on improving amputee functionality, it seems that if communications technology (teleconference, videoconference, or avatar-based virtual world) can assist with improving participant functionality, there is a place for these technologies to supplement support group activities. For example, virtual reality technologies can help amputees by visually demonstrating new skills, safely practice those skills through avatars, gain confidence, and assess functional progress. A limitation of this study was that the technology options included were limited to teleconference, videoconference, or avatar-based virtual world.

In Textbox 1, which presented other reasons for not participating in support groups, participants provided open text responses regarding why they do not participate in amputee support groups. These reasons could be grouped together in several categories such as time, gender bias, perceived value, fear, distance, leadership in the group process, and a sense of commonality. The technology used to create virtual worlds could address a number of these issues.

The issue of time can be addressed by the possibility of offering a variety of meeting times from which support group members could sign up. By not having to travel to participate, the possibility of a larger geography from which to draw participants becomes viable for a virtual group. It may also permit greater flexibility around frequency and timing of meetings.

While no one should have to hide who they are, the anonymous environment afforded by virtual worlds and the wider reach of a support group in a virtual world could allow more members of both genders to participate. According to the Amputee Coalition, male amputees outnumber female amputees by two-thirds [16]. As per the survey results, it is not uncommon for a woman to find herself to be the only female in a face-to-face support group, which may then not focus on her specific gender needs. The potentially wider reach of a virtual environment may allow more women to participate.

In terms of "Perceived Value," for amputees who feel they do not need support and can make the adjustment on their own or are simply too proud or afraid of showing weakness, the anonymous nature of a virtual support group might open the door to these individuals to encourage them to participate. The same would be true for people who are afraid or embarrassed about their appearance and new situation. The anonymous nature of a virtual environment might make it easier for them to participate.

One of the common themes for not participating in a support group beyond improving one's functionality with a prosthesis is the social disconnect they feel with other members of the support group. Several respondents said they do not feel they have enough in common with other support group members beyond being amputees. As stated earlier, the use of avatars can provide a level of anonymity that might diminish some of the more obvious differences between participants, at least at the

physical level. Being engaged in specific activities like windsurfing or swimming in an online virtual support group setting may provide an environment to help overcome some of those barriers. With the wide range of ages one sees in the survey results, age becomes less significant in an avatar-based environment since the physical limitations that come with age are not restrictive or visible in a virtual world.

Additional research with a stronger focus might provide additional insights regarding the optimal circumstances in which technology, in general, and virtual reality, specifically, may increase amputee support group participation.

Recommendations to Support Group Leaders

Our recommendations are as follows:

- View your group participants as partners, not just as patients.
- Ask participants what they want to achieve by participating in the group. Do this periodically (not just when a new person joins), since participant goals change over time.
- Engage with support group participants to develop meeting agendas.
- Have meetings to support the development of functional skills for all participants.
- Depending on group size, develop meeting content for both new amputees and experienced amputees:
  - When possible, a portion of each meeting can be used for the needs of new amputees and another portion can be used for the needs of experienced amputees.
  - Alternate meetings where one meeting focuses on the new amputee and the next meeting focuses on experienced amputees can be conducted.
  - Experienced amputees can be used to help and encourage new amputees.
- Look at the support group demographics and brainstorm ways to find common ground between group participants where possible.
- Determine if and how various communication technology options can supplement the support group experience:
  - Make training available to teach participants how to use the technology selected.
  - Develop activities that are engaging for participants using the technology and helps them achieve their goals.
  - Where needed and possible, provide technology support to participants (equipment, financial support, tech support, etc)

While these recommendations will not resolve all issues regarding support group participation, they are based on feedback from a range of support group participants from all walks of life. We believe they can go a long way in enhancing the amputee support group experience as well as improving outcomes for participants.

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Conflicts of Interest

None declared.

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Abbreviations

REDCap: Research Electronic Data Capture

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Original Paper

Development of a Web-Based Monitoring System for Power Tilt-in-Space Wheelchairs: Formative Evaluation

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Abstract

Background: In order to prevent pressure ulcers, wheelchair users are advised to regularly change position to redistribute or eliminate pressure between the buttocks region and the seat of the wheelchair. A power tilt-in-space wheelchair (allowing simultaneous pivoting of the seat and the backrest of the wheelchair toward the back or front) meets many clinical purposes, including pressure management, increased postural control, and pain management. However, there is a significant gap between the use of tilt as recommended by clinicians and its actual usage. A Web-based electronic health (eHealth) intervention, including a goal setting, monitoring, reminder, and feedback system of the use of power tilt-in-space wheelchairs was developed. The intervention incorporates behavior change principles to promote optimal use of tilt and to improve clinical postprocurement follow-up.

Objective: This study aimed to conduct a formative evaluation of the intervention prototype to pinpoint the functionalities needed by end users, namely, power wheelchair users and clinicians.

Methods: On the basis of an evaluation framework for Web-based eHealth interventions, semistructured interviews were conducted with power wheelchair users and clinicians. A content analysis was performed with a mix of emerging and a priori concepts.

Results: A total of 5 users of power tilt-in-space wheelchairs and 5 clinicians who had experience in the field of mobility aids aged 23 to 55 years were recruited. Participants found the Web interface and the physical components easy to use. They also appreciated the reminder feature that encourages the use of the tilt-in-space and the customization of performance goals. Participants requested improvements to the visual design and learnability of the Web interface, the customization of reminders, feedback about specific tilt parameters, and the bidirectionality of the interaction between the user and the clinician. They thought the current version of the intervention prototype could promote optimal use of the tilt and improve clinical postprocurement follow-up.

Conclusions: On the basis of the needs identified by power wheelchair users and clinicians regarding the prototype of a power tilt-in-space wheelchair monitoring system, 3 main directions were defined for future development of the intervention. Further

research with new wheelchair users, manual tilt-in-space wheelchairs, various age groups, and family caregivers is recommended to continue the formative evaluation of the prototype.

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KEYWORDS

wheelchairs; eHealth; health behavior; pressure ulcers; self-help devices; remote sensing technology; technology assessment

Introduction

Background

Globally, about 65 million people need a wheelchair [1]. In North America, an estimated 15% of wheelchair users living in a community use a power wheelchair [2,3]. Pressure ulcers represent a major problem for power wheelchair users [4]. The loss of mobility and lack of sensitivity are important risk factors in the formation of pressure ulcers [5]. For example, over 50% of Americans with spinal cord injuries develop at least one pressure ulcer during their lifetime [6]. The risk of developing pressure ulcers also affects other wheelchair users with central neurological conditions (eg, multiple sclerosis and cerebral palsy) [7,8] and elderly people who experience fragility associated with a major loss of mobility [9,10]. In addition to causing pain and infections and increasing mortality risk, a pressure ulcer may require hospitalization of 6 to 14 days [11,12] along with extended bedrest. Consequently, the presence of a pressure ulcer may not only limit an individual's capacity to participate in significant activities [13] but may also detract from their quality of life [14,15]. In addition, pressure ulcers have a major financial impact on the health care system: the estimated cost of their treatment ranges from Can $2000 to Can $20,000, depending on their severity [16].

Scientific studies [17,18] and the best-known practice guides [19,20] recommend that users increase blood flow to the buttocks region by regularly changing position to redistribute or eliminate pressure between the buttocks region and the seat of the wheelchair, while avoiding sliding on the seat surface. To do so, depending on the individual's capacities, several strategies can be used to reduce pressure on the buttocks region (eg, pushing up, leaning forward and sideways, and positioning oneself on the back wheels) [21]. However, some users are unable to complete these maneuvers and, therefore, need to activate power tilt on their wheelchair to compensate for their inabilities. Power tilt allows simultaneous pivoting of the seat and the backrest of the wheelchair toward the back (or front). The constant seat-backrest angle keeps the user at the back of the seat, preventing friction and sliding during a change of position. Depending on the angle of the tilt, the pressure on the seat decreases by 11% to 55% [22-24]. To optimize the benefits of power tilt in reducing pressure, it is recommended that wheelchair users tilt every 30 min, for at least 1 to 2 min [19] at a minimum angle of 30 [22,25].

Therefore, the use of power tilt is an effective means of changing the pressure distribution between the buttocks region and the seat, as needed, because it redistributes pressure largely to the backrest of the wheelchair [26]. In fact, the use of power tilt provides benefits beyond prevention and treatment of pressure ulcers. On the basis of a literature review followed by focus groups, Lacoste et al [27] identified the main reasons that power wheelchair users use tilt daily: (1) comfort and pain, (2) rest and relaxation, (3) posture, (4) functional independence, and (5) physiological functions. The participants claimed that they used tilt for comfort purposes (95%), rest (92%), relaxation (70%), or pain reduction (77%). Only 30% of the participants reported tilting during the day to prevent or treat pressure ulcers, and 20% of them used tilt to avoid sliding on the seat of their wheelchair. They also reported that they tilted at small (0°-15°) and medium (16°-30°) angles much more often than at large angles (31°-45°). This observation has been corroborated by several other studies [18,28-30] that all reached the same conclusion: there is an important gap between the usage recommended by clinicians and the actual use of power tilt.

Personalized instruction in the proper daily use of tilt is indeed part of the care continuum of power wheelchair users. However, recently documented clinical practices demonstrate that little or no time is dedicated to training sessions and practice using various wheelchair components [31-36]. Furthermore, given that the conceptualization of reasons for the use of power tilt is complex and differs greatly between clinicians and users [30], it may be difficult for both parties to reach a common understanding of the recommended use of tilt during power wheelchair procurement. Under these circumstances, it is understandable that the lack of postprocurement follow-up of the use of mobility aids is one of the main concerns of wheelchair users [37].

To date, several studies have examined monitoring technologies to gather objective data regarding the use of mobility aids. The scoping review by Routhier et al [38] pertaining to the use of monitoring technologies by power wheelchair users found that activities associated with the prevention and treatment of pressure ulcers are the most frequent research topic. Among the 43 studies compiled, only 1 proposed an intervention involving interaction between clinicians and users where clinicians could objectively monitor the daily use of power tilt and other wheelchair components (reclining backrest, elevating leg rest, and seat) [39]. Recently described by Wu et al [40], this intervention, which is offered in the form of a mobile app, is intended to prompt users to adopt the repositioning behaviors recommended by their clinicians by issuing reminders and personalized alerts. Nonetheless, although this intervention is on the market, only a very small number of users and clinicians can benefit from it because it is compatible with power wheelchairs from only 1 manufacturer. A portable monitoring system that could be installed on various models of power wheelchairs would reach a wider range of users.

Objectives

Consequently, our research team has developed a Web-based electronic health (eHealth) intervention that integrates technology and professional advice. The prototype includes a monitoring system that can be installed without complex manipulation or permanent modification on all models of power wheelchairs. The data gathered are transmitted to the user and to the attending clinician via a Web interface. This intervention aims to favor optimal use of tilt among users of any power wheelchair model and to improve the postprocurement monitoring offered by clinicians. Our study's objective was to perform a formative evaluation of our monitoring system prototype to clarify the functionalities needed by end users (power wheelchair users and clinicians) and thus increase the likelihood that healthy behaviors targeted by the intervention are adopted. Formative evaluation of a system by end users is typically performed when a product is in the early stage of its development to identify and solve problems that influence the end user's experience [41,42].

Methods

Prototype Description

The proposed intervention was developed by a multidisciplinary team of researchers, clinicians, students, and business partners working in the fields of rehabilitation and electrical and computer engineering. The Behavioral Intervention Technology (BIT) model [43] illustrates the components of the intervention (Table 1). Already commonly used in the eHealth domain [44-46], the BIT model has the advantage of reconciling principles issuing from behavioral change theories with different concepts in electrical and computer engineering. This model describes 2 conceptual components and 3 technical components to consider during the development of eHealth interventions, namely, the aims of the intervention, behavioral change strategies, elements, characteristics, and workflow.

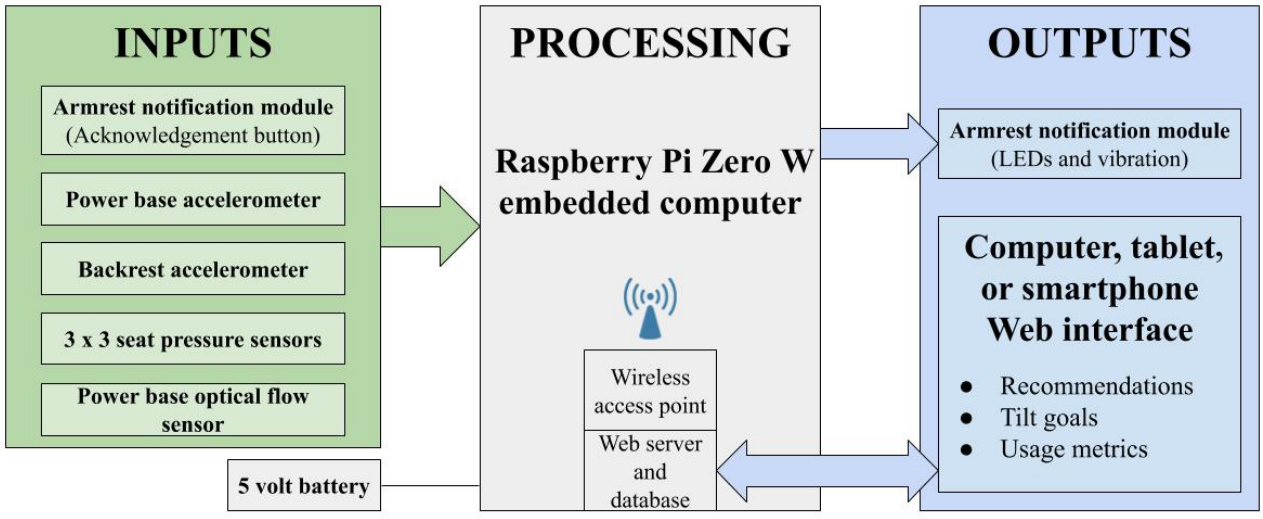
The literature was reviewed to compile the clinical goals associated with the use of tilt. In addition, identification of the needs and priorities of stakeholders [47] enabled us to select behavioral change strategies (eg, feedback on performance), elements (eg, transmission of data concerning the use of tilt), and characteristics (eg, graphics and text results) to include (Table 1). The reference framework proposed by Webb et al [48] on effective behavioral change strategies used in eHealth interventions has also guided the choice of behavioral change strategies.

Figure 1 presents the prototype of the developed monitoring system. The system includes 2 accelerometers (InvenSense MPU-6050) installed at the power base and backrest of the wheelchair. Each of them measures the tilt angle relative to the direction of gravity, then the difference of both angles provides the effective tilt angle, independent from the surface unevenness. A matrix of 3 × 3 sensors (Interlink Electronics FSR 400) measures pressure on the seat to activate the monitoring system when someone sits on the wheelchair, and the information is used to calculate time spent in the wheelchair. An optical flow sensor (PMW3901) detects movement of the wheelchair to send alerts when stationary only. An embedded computing system (Raspberry Pi Zero W) calculates the time seated in the wheelchair and the tilt time. The computer analyzes the results, archives them in a database, and displays them on a Web interface accessible by a local wireless network. The system also includes a notification module equipped with indicator lights emitting diodes and a vibration motor that serves as a tilt reminder. No personal data are stored in the embedded computing system as it is linked to an external secured server for data management and security.

Table 1. Monitoring system of the use of the power tilt wheelchair according to the Behavioral Intervention Technology model.

Conceptual and technical components of the Behavioral Intervention Technology model	Power tilt-in-space monitoring system
Aims of the intervention (conceptual "Why")	• Favor optimal use of power tilt • Allow clinicians to offer users more effective postprocurement follow-up of power tilt
Behavioral change strategies (conceptual "How")	• Provide information on the outcomes in general: inform users of tilt parameters (frequency, angle, and duration of tilt) associated with recommended tilt goals • Provide information on the outcomes for individuals: inform users about reasons linked to recommended tilt goals • Action planning: allow users to create their own personal tilt goals • Reinforcing effort toward behavior: recognize users' efforts to attain recommended and personal goals • Provide rewards for behavior: congratulate users on attainment of goals • Prompts/cues: issue tilt reminder when necessary • Provide feedback on performance: transmit results on daily and monthly use of tilt according to recommended and personal goals
Elements (technical "What")	• Collection, analysis, and passive transmission of data regarding the use of tilt to the user and clinician • Reminder (indicator lights and vibration motor) aligned with tilt parameters of personal goals • Data entry field
Characteristics (technical "How")	• Medium: text, images, and graphics • Complexity: tasks are easy to perform and have simple instructions • Aesthetics: simple and discreet
Workflow (technical "When")	• Automatic transmission of results on the use of tilt at specific intervals (eg, at the end of each day or start of each month)

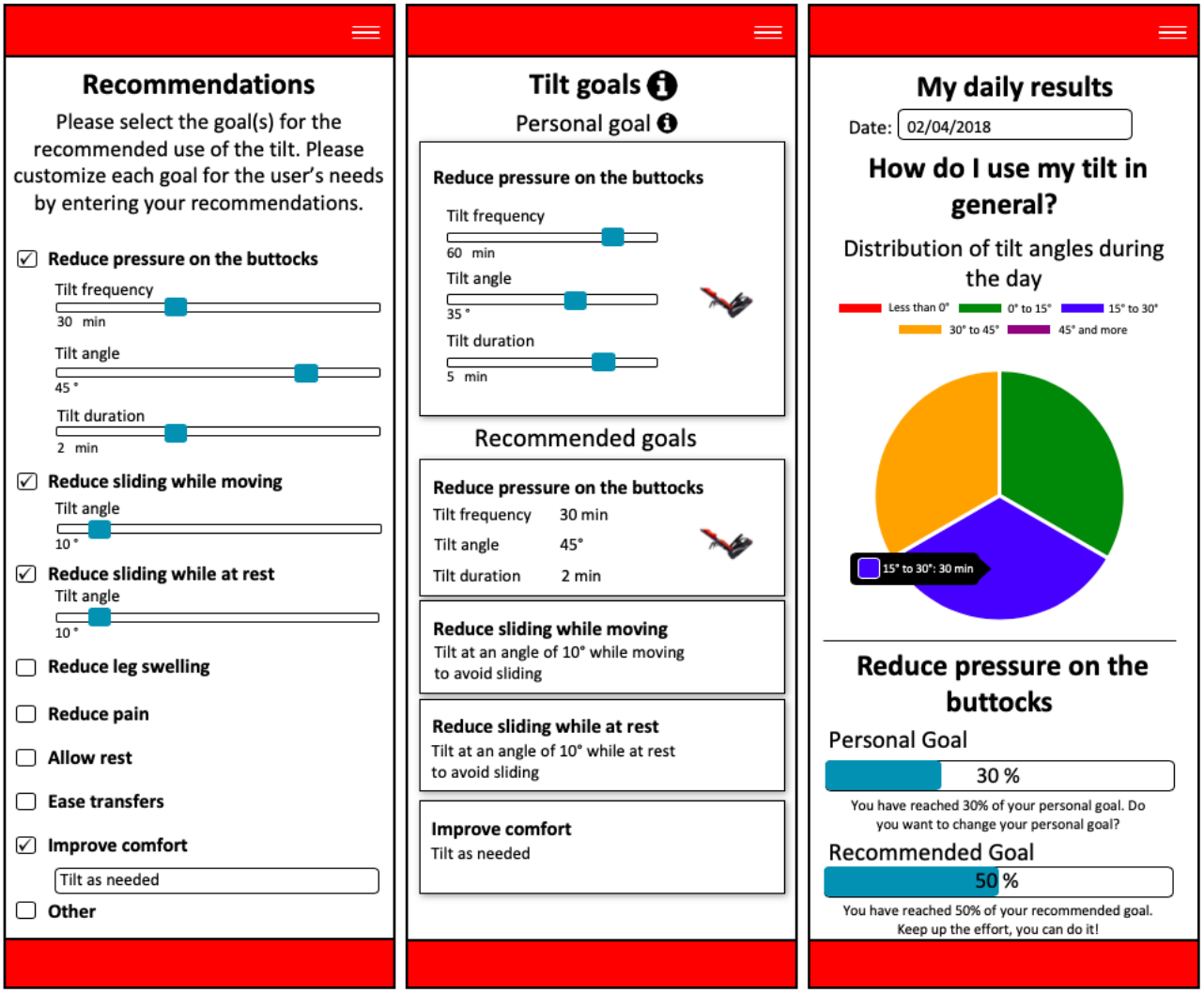
Figure 1. Embedded computing system architecture performing data acquisition, storage, and processing on a power tilt-in-space wheelchair.



As shown in Figure 2, the monitoring system's Web interface is optimized for computers, tablets, and smartphones. The Web interface includes separate pages to input recommendations and displays tilt goals and feedback on the use of tilt. On the recommendation page, attending clinicians can specify recommendations from among the proposed tilt goals: (1) prevention and treatment of pressure ulcers, (2) postural control at rest, (3) postural control during movements, (4) edema, (5) pain management, (6) comfort, (7) transfers, and (8) rest. Users can also create personalized tilt goals to add to the list of recommendations. Once the recommendations are saved, they are automatically available to users in the form of recommended tilt goals. These goals are configured to provide information on the positive outcomes of the use of tilt. In addition, at all times, users can personalize their own performance targets and tilt parameters (frequency, angle, and duration of tilt) associated with the goal of prevention and treatment of pressure ulcers. The term *personal goals* refers to new targets set by the user, as opposed to the *recommended goals*, initially set by the clinician. The Web interface also included a section where users

and attending clinicians can view daily and monthly data on tilt usage in real time. These data are displayed in the form of graphics and text results that show the user's performance relative to the recommended and personal tilt goals. A message encouraging users to keep up with their efforts or to try to attain their tilt goals is also displayed. Another element intended to motivate users to use tilt, specifically to prevent and treat pressure ulcers, is the tilt reminder (Multimedia Appendix 1). This reminder is activated each time the user sits in the wheelchair for a period longer than the tilt frequency specified in the user's personal goal. In addition, indicator lights change color when users reach or exceed the angle and duration of tilt specified in the personal goal to inform users that they have achieved the desired behavior.

Figure 2. Screenshots of main pages of the Web interface of the power tilt usage monitoring system.



Recruitment

A formative evaluation was performed with 5 users of power tilt-in-space wheelchairs and 5 clinicians who had experience in the field of mobility aids. To ensure that they could easily navigate a Web interface, all participants had to have basic knowledge of how to use a computer, tablet, or smartphone. Users had to be at least 18 years old and use a power tilt-in-space wheelchair as their main mobility aid. There were no exclusion criteria for the 2 groups of participants.

The project received ethical approval from the institutional review board of the Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal (CRIR-1090-0715). The coordinators of clinical research at 3 rehabilitation centers in the Greater Montreal Area (Canada) identified all potential participants. Participants provided written consent to participate in the study.

Interview Guide Development

To ensure that all concepts that influence the quality of the Web-based intervention were developed and the users' experience were covered, the conceptual framework by Baumel et al [49] was used to build the interview guide. Accordingly, the following concepts were examined: usability, visual design, content, user engagement, therapeutic persuasiveness, therapeutic alliance, and general subjective evaluation. The interview consisted of 2 parts. First, after having briefly described the prototype and the intervention goals, realistic task-based scenarios were presented to the participants. Specifically, power wheelchair users (1) viewed photos of the physical components of the system installed on a power wheelchair, (2) consulted tilt goals and set a personal goal

according to their preferences in the Web interface, (3) viewed a tilt reminder on video, and (4) consulted and interpreted results linked to daily and monthly use of tilt directly in the Web interface. Clinicians viewed the same scenarios, with the addition of a fifth scenario on the entry of recommendations regarding the use of tilt. During the scenarios, participants were asked to think aloud, a process that encouraged participants interacting with a product to verbalize their thoughts, reactions, and emotions, which provided an insight into their experience as a user [41]. Participants were asked open-ended questions after each scenario. The second part of the interview contained questions concerning the prototype in general. A preliminary version of the interview guide was tested with a family caregiver and clinician, both familiar with the mobility aids domain. The comments served to improve and refine the guide (contact CA to obtain a copy).

Data Collection Procedure

Each of the participants was met individually for a session that lasted about 1.5 hours, which was recorded in a digital audio format. The participants' sociodemographic data, including their level of perceived experience with technologies and the internet, their reasons for using tilt, and their history of pressure ulcers, were also obtained. Observation notes (eg, participants' nonverbal reactions) were taken throughout the session.

Data Processing and Analysis

Interview transcriptions were subject to content analysis with a mixed coding approach. The coding guide was based on the key concepts by Baumel et al [49] (main themes and subthemes), and the emerging themes were linked to these concepts until a final coding guide was developed. Coding was done with QDA Miner v5.0 (Provalis Research) software by the first author (CCV), and a second author (DGB) coded transcriptions independently. Divergence in coding was discussed with the last author (CA) to reach consensus.

Results

Study Participants

Participants' characteristics are presented in Tables 2 and 3. Power wheelchair users' ages ranged from 23 to 49 years, and clinicians' ages ranged from 34 to 55 years. Each of the 2 groups of participants comprised 3 men and 2 women. All power wheelchair users had a neurological condition, and 3 of them had pressure ulcers in their buttocks region. They lived in the community and used their device daily as their main mobility aid for at least 8 years. Regarding their current usage of the tilt, they all reported using it for either comfort or to prevent and treat pressure ulcers. Moreover, 3 out of 5 users also mentioned that they used tilt to avoid sliding on their wheelchair, and 1 person mentioned easing transfers. The 5 clinicians interviewed were all occupational therapists. One of them worked in a neuromuscular disease program and the other 4 worked in technical aid programs and services. Perceived experience with technologies and the internet varied within the sample.

Table 2. Sociodemographic characteristics of power wheelchair users (N=5).

Sociodemographic characteristics	Value
Age (years), range	23-49
Gender, n	
Male	2
Female	3
Principal diagnosis, n	
Cerebral palsy	3
Quadriplegia	2
Occupation, n	
Employed	2
Unemployed	2
Student	1
Level of perceived experience with technology and the internet, n	
Inexperienced	1
Somewhat experienced	1
Very experienced	3

Table 3. Sociodemographic characteristics of clinicians (N=5).

Sociodemographic characteristics	Value
Age (years), range	34-55
Gender, n	
Male	2
Female	3
Level of perceived experience with technology and the internet, n	
Inexperienced	1
Somewhat experienced	3
Very experienced	1

Evaluation Outcomes

The 7 main themes of the conceptual framework by Baumel et al [49] captured the viewpoints of users and clinicians. We identified only 4 emerging subthemes, all of which represented the clinical perspective, and they were regrouped under the therapeutic persuasiveness and the general subjective evaluation concepts. Table 4 summarizes the participant's comments regarding the Web-based monitoring system. These results are presented in detail in the following paragraphs.

Table 4. Main participants' comments about the power tilt usage monitoring system.

Baumel concepts	Users (n=5)	Clinicians (n=5)	Interview results
Usability (ease of use and ease of learning)	4	5	Physical components are convenient for daily use of the wheelchair
	4	5	Web interface is easy to use
	5	5	Some interactive functions of the Web interface are not intuitive
Visual design (appearance and visual quality)	4	4	System looks discreet on the wheelchair
	3	1	Web interface could have more colors
	4	2	Web interface could have larger fonts
Content (content provided or learned during the use of the Web intervention)	5	5	Web tilt goals are well presented to the user
User engagement (extent that the Web intervention employs strategies to attract and encourage its adoption)	3	5	Personal tilt goal for the prevention and treatment of pressure ulcers is appreciated
	4	5	Reminder settings are not appropriate in certain contexts
Therapeutic persuasiveness (extent to which the Web intervention encourages users to make positive behavior change)	5	—[a]	Users felt that the tilt reminder would encourage them to tilt more often
	5	5	Color of the indicator lights according to the angle and the duration of the tilt is appreciated
	5	5	Feedback on the goal associated with the prevention and treatment of pressure ulcers should not take the form of a global analysis
Therapeutic alliance (ability of the intervention to create an alliance with the user to bring about positive change)	4	4	Web interface is missing a space where users can share their experience regarding the use of tilt with their clinicians
General subjective evaluation (potential anticipated benefit of the intervention for the target audience and to the possible usage contexts)	5	5	Participants felt that the goal of the Web intervention was met by the current system
	—	5	Clinicians considered that the Web intervention would improve postprocurement follow-up of tilt use

[a]Not applicable.

Usability

Regarding ease of use of the physical components of the system, nearly all participants mentioned that the current configuration of components allowed adequate daily use of the wheelchair. However, they also mentioned several aspects that should be considered during the configuration and installation of components (eg, minimize the overall width of the wheelchair and preserve the possibility to hang personal effects on the backrest). Regarding the Web interface, most users claimed that

the entire Web interface was easy to use and navigate. Similarly, all clinicians reported that it was easy to enter the recommendations within a reasonable time. Regarding learnability, all users and clinicians had difficulties with exploring some of the interactive functions of the Web interface at some point, particularly during consultation of their tilt goals and their results. The participants attributed these difficulties to the unintuitive aspect of the functions in question. Almost all the participants (users: n=5 and clinicians: n=4) thought that a training session that included a demonstration would be necessary to learn how to use the system.

Visual Design

Almost all participants described the system as discreet when installed on the wheelchair owing to its small size and the black color of its physical components. All the participants appreciated the general structure of the Web interface. However, some participants would have liked to see more colors, particularly during the consultation of the tilt goals, and others would have preferred a larger font.

Content

Overall, 4 clinicians found that the reasons for the use of tilt that were displayed in the recommendation entry screen corresponded to those they would normally recommend, whereas 1 clinician mentioned that his practice was restricted to a few on the list. All the participants found that the tilt goals available to users online were presented clearly and appropriately. All the participants also appreciated the clarity of the content of the daily and monthly results of the different tilt goals, except for those associated with prevention and treatment of pressure ulcers. They would have liked the content of the results related to this goal to include more explanatory information such as a written summary of the graphics.

User Engagement

All the clinicians appreciated the ability to personalize the recommended tilt goals according to the users' needs such as the choice of frequency, angle, and duration of tilt and personalized text entry. Most of the participants appreciated that the system let users set their own personal tilt goal in addition to the goal recommended by the clinician for the prevention and treatment of pressure ulcers. For example, 1 user said:

> *It's good that you can set a personal goal for yourself because sometimes the occupational therapist may recommend something you are not really used to, but with your personal goal you can calmly go about reaching the recommended objective by increasing your personal goal each day.* [User-04]

Furthermore, 2 users who were less interested in adopting a personal goal mentioned that they would not set a personal goal at the start of the intervention because they preferred to rely solely on the objective recommended by the clinician.

All the participants appreciated being able to put the tilt reminder in sleep mode at any time. However, almost all of them found the indicator lights and vibration motor of the reminder irritating, too loud, or quite inappropriate in some contexts (eg, at school, work, or the movies). Consequently, they would have liked to be able to personalize the reminder settings according to their preferences (eg, deactivate the vibration motor of the reminder).

Therapeutic Persuasiveness

All users thought that the tilt reminder would encourage them to tilt more often. One clinician (Clinician-01) described the reminder as a *mini coach* in charge of motivating users to achieve their tilt goals. In addition, all the users and clinicians who were interviewed appreciated the fact that the indicator lights installed on the reminder box changed color when the user reached or exceeded the angle and duration of tilt set in their personal goal. For example, 1 clinician (Clinician-02) claimed that the synchronization of the indicator lights with the tilt parameters made the parameters much more concrete for users and consequently easier to follow. However, most users (n=4) would have liked to receive tilt reminders not only related to the goal of prevention and treatment of pressure ulcers but also concerning other tilt goals proposed by the intervention (eg, reduce pain and improve postural control when moving) because the degree of attention that these goals require varies greatly during the day. Concerning the pertinence of results regarding the daily and monthly use of tilt, most users (n=3) mentioned that feedback available on the Web interface represented an additional source of motivation to help them achieve their objectives. The 2 users who did not share this view stated that they would not be inclined to view their progress online, but they would rely instead on the tilt reminder as the single source of motivation to achieve their goals. Finally, all users said they would prefer that the feedback on the goal associated with prevention and treatment of pressure ulcers take the form of an individual analysis of each of the tilt parameters rather than a global analysis. For example, 1 user claimed:

> *In my feedback [on the goal associated with prevention and treatment of pressure ulcers], I would like to be able to isolate information regarding the frequency, angle and duration of tilt so that I could see where I need to improve more easily. This way I could know if, for example, I have to work more on tilt at a larger angle or if instead I should focus my efforts on tilting at a higher frequency.* [User-01]

Therapeutic Alliance

The vast majority of clinicians (n=4) found that the formulation of personal goals by users had a positive influence on their recommendations regarding the use of tilt. According to 1 clinician who shared this view:

> *[The personal goal] helps me better understand how I as a clinician can give better recommendations because if users find they are obtaining more benefits with their personal goals, this means that my recommendation was not totally adapted to their needs.* [Clinician-01]

Consequently, these same clinicians believed that setting personal goals favors the creation of dialog between the 2 parties and ultimately of a compromise between what the clinician recommends and what the user is willing to do. Finally, almost

all the users would have liked to see a space on their Web interface where they could share their daily and monthly experience with the use of tilt with clinicians. In fact, 4 of the 5 clinicians interviewed confirmed that they would have liked to have access to this form of user feedback because they viewed it as an opportunity to support their clients as they strive to achieve the desired behavior.

General Subjective Evaluation

All the participants confirmed that the intervention proposed would favor optimal use of tilt by users. In addition, all the users claimed that they would agree to use the system if it was available. All the clinicians also believed that this monitoring system would let them offer users more effective postprocurement follow-up of tilt use. For instance, 1 clinician mentioned:

> *I find it interesting that this type of system could offer us information on the use of tilt because when users leave the rehabilitation center, we don't know what they're doing with their tilt. When we meet them only every so often, without being in bad faith, they report what they feel is pertinent. No matter how many questions we ask, we will never get as much information as the system can provide.* [Clinician-04]

However, similar to the users, the clinicians (n=5) would have preferred that feedback on the goal associated with the prevention and treatment of pressure ulcers take the form of an individual analysis of each of the tilt parameters instead of a global analysis. Regarding the feasibility of the intervention in health care institutions, most of the clinicians (n=4) claimed that they would recommend this intervention at the beginning of care to present specific problems such as the appearance of pressure ulcers. In addition, aside from a client at risk or dealing with pressure ulcers, several clinicians (n=3) also found that such a system would be particularly beneficial for users with a degenerative neurological condition, particularly because of the many reasons obliging them to use tilt daily. Finally, 3 clinicians emphasized that the use of this system should not be limited to rehabilitation centers and that it should also be implemented in community health care centers because they too have a role to play in postprocurement follow-up of power tilt.

Discussion

Principal Findings

The objective of this study was to perform a formative evaluation of a prototype of a system to monitor tilt use in power wheelchairs. The main results suggested that the physical components and the Web interface were easy to manipulate and use daily. Participants appreciated the tilt reminder and the ability to set their own performance goals. In addition, all the participants expressed an intention to adopt the intervention, and all of them claimed that the current prototype would favor optimal use of tilt by wheelchair users. This confirmation corroborates the findings of other studies regarding the potential benefits of a tilt usage monitoring system [18,40]. The clinicians interviewed also believed that the intervention developed would make postprocurement follow-up of power tilt more effective during different stages of care (preventive or curative), with varied clients and in various practice settings.

Participants' positive evaluation of the personal goal is certainly one of the most original findings of our study for 3 main reasons. First, users' comments suggest that the personal goal could serve as an action plan and consequently mediate the gradual attainment of goals recommended by clinicians. Second, the users' opportunity to create an action plan also guarantees that they can control the use of tilt. This aspect is important because it has been established that for a power tilt usage monitoring system to be adopted by users, they must not feel forced to comply with the recommendations given [50]. Third, the personal goal helps clinicians determine whether their recommendations are truly adapted to the variability of users' daily occupations. In other words, the personal goal is the representation of what the user is willing to do regarding the use of tilt. This notion of variability of daily occupations, unique to each individual, is important for clinicians because it predicts the real use of power tilt [8,18,29]. Thus, clinicians can better judge whether they need to adjust the recommendations to correspond with the user's daily routine.

Concerning the tilt reminder, all the users mentioned that it would encourage them to tilt more often. This claim is coherent with a study of the effect of an audio reminder on repositioning behaviors in wheelchairs linked to the prevention and treatment of pressure ulcers [51]. In addition, all the participants appreciated the fact that the indicator lights installed on the reminder box changed color when their tilt reached or exceeded the angle and duration specified in their personal goal. Therefore, this function meets a common need for all participants because research has demonstrated that users and clinicians alike find it difficult to associate the value of an angle with an exact position of tilt without any cues [30].

This formative evaluation highlighted 3 main orientations for improving the future development of monitoring systems for power tilt-in-space wheelchairs. One important area of improvement will be to personalize the reminder settings (indicator lights and vibration motor) according to the context (eg, at school, work, and the movies). This is consistent with the study by Liu [52], which found that preferences in the choice of tilt reminder settings vary depending on the users' context. Another important change is to ensure that the feedback on the goal associated with prevention and treatment of pressure ulcers takes the form of an individual analysis of each of the tilt parameters rather than a global analysis. The initial prototype presented a combined result of 3 tilt parameters (frequency, angle, and duration of tilt) because this combination predicts greater effectiveness at reducing pressure on the seat [17]. The advantage of offering a global analysis of the attainment of this goal is that participants know the proportion of tilts done according to the 3 parameters of the personal and recommended goals. However, in a context of training and follow-up of the use of tilt, it is understandable that participants want to be able to obtain feedback on the frequency, angle, and duration of tilt separately because this would let them target and address any problematic parameters. Finally, we should explore the possibility of including a dedicated space in the Web interface where users could note their daily and monthly experience with

the use of tilt, similar to a logbook. The added value of this space should be evaluated carefully by considering the potential added burden on clinical follow-up and given the evidence of the proven use of this function [53-56].

Limitations

This study has some limitations. First, only occupational therapists were recruited. This choice is explained by the fact that in Quebec (Canada), it is mainly occupational therapists who evaluate clients' functional needs and who ensure training and follow-up of individuals who require mobility aids. It would be interesting to explore whether other categories of professionals would offer different insights. In addition, knowing that it could take several years before certain users consider their power wheelchair as an effective means to let them carry out significant activities [57], no attempts have been made to recruit new users of power wheelchairs, although clinicians who were interviewed identified these individuals as clients who could benefit from the intervention. In fact, the way new users of power wheelchairs experience the intervention may differ from that of more experienced users and thus influence the future development of the intervention. Finally, the conceptual framework proposed by Baumel et al [49] that underpinned the formative evaluation of our eHealth intervention puts more emphasis on users, whose targeted behavior is expected to change following the intervention, than on clinicians, who help users to attain the desired behavioral change. To fill this gap, during the analysis, we added emerging themes related to the needs identified by the clinicians. This conceptual framework could be enriched by integrating the perspectives of the staff who carry out the eHealth interventions.

Conclusions

This study aimed to conduct a formative evaluation and to identify the functionalities needed by users of power wheelchairs and clinicians relative to a monitoring system designed to be installed on all models of power tilt-in-space wheelchairs. The results will orient the development of the prototype toward a more customizable monitoring system, with a more attractive and intuitive Web interface that favors communication between users and their clinicians. A formative evaluation involving a wider range of people such as new wheelchair users, users of manual tilt-in-space wheelchairs, children, the elderly, and family caregivers should be performed before evaluating the refined prototype in a real environment (eg, at home and in their daily life). Further research will also be necessary to evaluate if the intervention actually favors optimal use of tilt among power wheelchair users and improves the postprocurement monitoring offered by clinicians.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Tilt reminder system of the use of power tilt-in-space wheelchair.
[MP4 File (MP4 Video), 85180 KB - rehab_v6i2e13560_app1.mp4]

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Abbreviations

BIT: Behavioral Intervention Technology
ehealth: electronic health

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Original Paper

Pediatric Speech-Language Pathologists' Use of Mobile Health Technology: Qualitative Questionnaire Study

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Abstract

Background: While technology use in pediatric therapies is increasing, there is so far no research available focusing on how pediatric speech-language pathologists (SLPs) in the United States use technology.

Objective: This paper sought to determine if, and to what extent, pediatric SLPs are using mobile apps, to determine what purpose they are using them for, and to identify gaps in available technology to provide guidance for future technological development.

Methods: Pediatric SLPs completed an online survey containing five sections: demographics, overall use, use in assessment, use in intervention, barriers, and future directions.

Results: Mobile app use by 485 pediatric SLPs in the clinical setting was analyzed. Most (364/438; 83.1%) pediatric SLPs reported using technology ≤50% of the time in their clinical work, with no differences evident by age group (<35 years and ≥35 years; *P*=.97). Pediatric SLPs are currently using apps for intervention (399/1105; 36.1%), clinical information (241/1105; 21.8%), parent education (151/1105; 13.7%), assessment (132/1105; 12%), client education (108/1105; 9.8%), and other uses (55/1105; 5.0%). Cost (46/135; 34.1%) and lack of an evidence base (36/135; 26.7%) were the most frequently reported barriers. Most SLPs (268/380; 70.7%) desired more technology use, with no difference evident by age group (*P*=.81).

Conclusions: A majority of pediatric SLPs are using mobile apps less than 50% of the time in a pediatric setting and they use them more during intervention compared to assessment. While pediatric SLPs are hesitant to add to their client's screen time, they would like more apps to be developed that are supported by research and are less expensive. Implications for future research and app development are also discussed.

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KEYWORDS

mHealth; speech-language pathology; surveys; assessment; pediatric; treatment; technology

Introduction

Mobile health (mHealth) is health information or medical services that are delivered or enhanced through mobile communication and information technology [1]. While its traditional purpose is to support the collection and analysis of health-related information, mHealth also encompasses a growing body of technologies that aim to support both the provider and the patient [2]. For example, applications have been created to enhance clinical decision making and diagnostics, improve treatment, increase access to services, and lower costs [2-6]. On the patient side, mHealth applications have successfully been used for education and behavior changes through direct messaging [7], and to engage patients in generating and recording their own health data [8]. Mobile apps are cost effective, accessible, and convenient, and along with the trend of greater consumer involvement, mHealth is heading in a compelling direction [9,10].

Technology use is rapidly increasing, and not just for adults. Children are interacting with technology at home: more than

half of parents have downloaded apps specifically for their children [11,12] and homes with children between 0-8 years old who had a mobile device increased from 52% in 2011 to 98% in 2017 [12]. Tablet ownership specifically increased from 8% in 2011 to 78% in 2017 [12]. Schools are also integrating technology into their classrooms. In 2010, the US Department of Education began a National Education Technology Plan to promote student-centered learning with technology, with the goal of improving student achievement [13]. This plan was updated in 2017 and reported a shift from focusing on whether technology should be used to how it can best be used with equal access [14]. They additionally reported progress in technology use for personalized and adapted learning and assessment, on increased education for teachers on how to use technology to support user outcomes, on more classrooms with high-speed connectivity, on the better design of learning spaces to accommodate technology, and on the lower costs and increased availability of high-quality educational tools [14]. In fact, in 2016, 81% of US PreK-12th grade teachers reported using computers or laptops in their classrooms, 58% reported using interactive whiteboards, and 52% reported using tablets [15].

Despite the obvious growth of mHealth in home, medical, and educational settings, research supporting the outcomes of mHealth in speech-language pathology is just emerging, and research in the United States has been limited. There is a body of research that has examined the use of game-based applications for speech and language disorder intervention [16-21], as well as emerging research on apps for speech and hearing screenings [22,23] and biofeedback [24]. Numerous studies report strong child engagement and motivation with the applications, but improvement in skills and generalization of those skills is limited by methodology (ie, no control group) or is not reported [16-21,24]. In fact, Furlong, Morris, Erickson and Serry (2018) developed a protocol for evidence-based appraisal of mobile apps for speech sound disorders [25], and in a systematic review of the Apple iTunes store and Google Play store for apps for speech disorders they found only a small proportion of applications that would be considered very high quality or therapeutically beneficial [26]. There is early evidence for creating applications that are better informed by a joint team approach that shows promise [27]. App use by speech-language pathologists (SLPs) has been examined in both Slovenia and Portugal, where SLPs have reported a positive perception of technology and personal use, but a limited use for therapy purposes [20,21,28].

However, despite the American-Speech-Language-Hearing Association (ASHA) member newsletter having published numerous articles about mHealth in clinical practice, ranging from promoting specific apps [29-33] to advising clinicians about how to incorporate apps into therapy [30,32,34,35], no evidence is available for how SLPs in the United States are, or are not, utilizing mobile applications.

It is clear that mHealth is a growing trend, with children using mobile and tablet devices at home and school. Furthermore, there is emerging evidence that suggests that how adults interact with children during tablet use plays a strong role in their effectiveness [36-39], and there is limited evidence for its efficacy in speech pathology outside of client motivation [16-21,24]. Thus, it is of utmost importance to understand how educators and clinicians are using mHealth with the children they serve to develop improved, evidence-based technologies and practices. While research on the use of mHealth and barriers to adoption exists in other professions, such as among doctors, nurses, and teachers, the usage of such technologies in the field of speech-language pathology in the United States, specifically pediatrics (birth-18 years old), has not been examined. Filling this gap in knowledge is critical for the implementation of mHealth into a field with numerous mobile application offerings without substantive research on the population utilizing them. Therefore, we aimed to understand if, and to what extent, pediatric SLPs are using mobile apps in clinical practice, barriers to use, and gaps in available technology. The following research survey addresses these main questions:

> *(1) Do pediatric SLPs use technology in clinical practice and what are the barriers to use;*

and

> *(2) Do pediatric SLPs want more technology available and in which areas?*

Methods

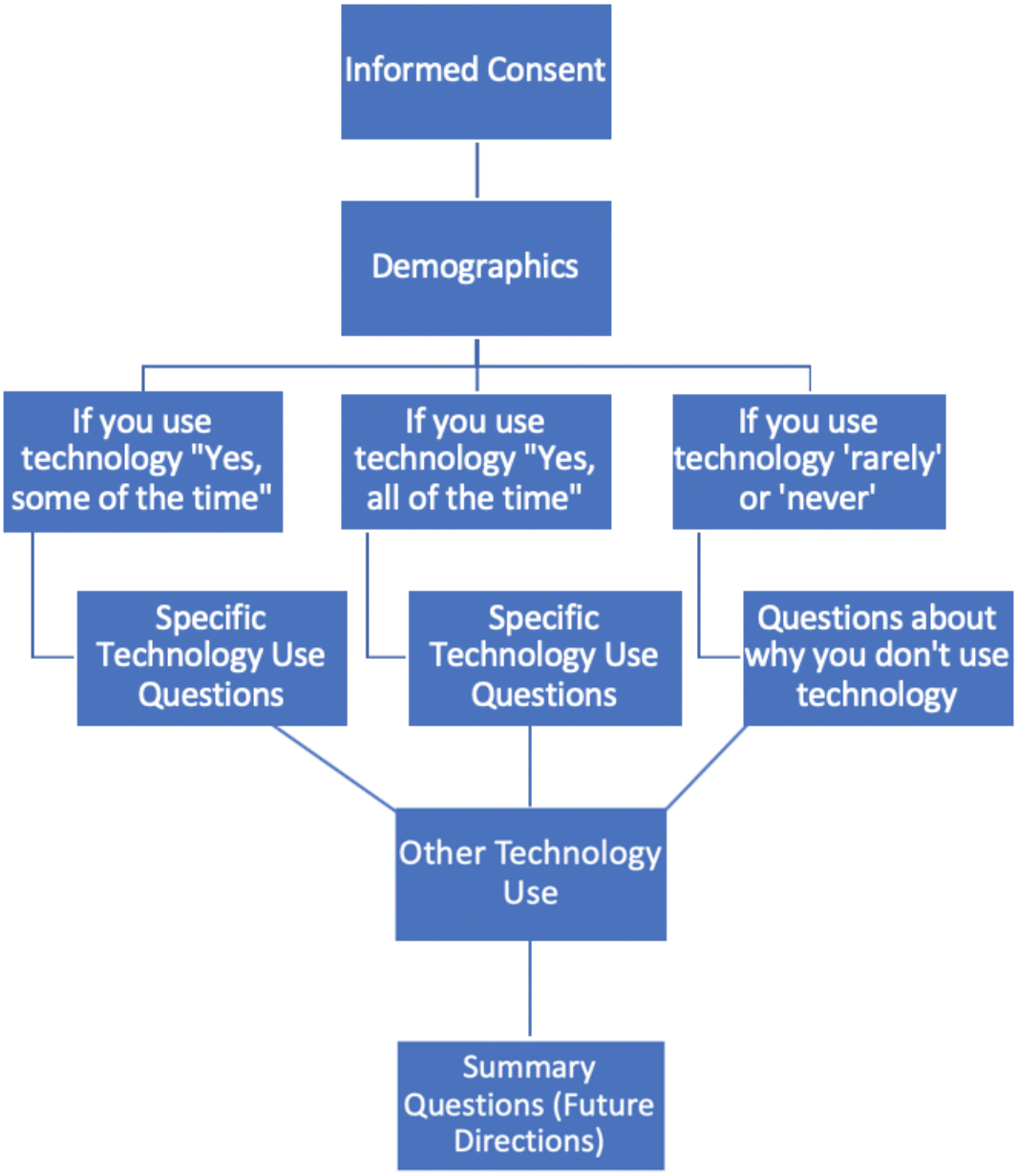
Development of the Survey

To answer the above research questions, an anonymous, open survey was developed using Qualtrics Version 2017 (Qualtrics, Provo, Utah), an online survey platform for academic, administrative, and research purposes. Questions were crafted to cover the aims of the study and allowed for forced choice, select all that apply, side-by-side, and open-ended responses. Survey questions were reviewed by two ASHA-certified SLPs and were judged to have enough face and content validity. Internal consistency was assessed for the primary technology questions, which utilized a Likert Scale, by calculating Cronbach alpha using SPSS version 25 (IBM Corp, Armonk, New York). Results showed that the Cronbach alpha was high (0.85), indicating that the primary technology questions were closely related. Then, a pilot study was deployed to further evaluate the validity and comprehensibility of the questions. SLPs who served as supervisors to graduate students in the university's SLP program were invited to participate in the initial survey. The original survey encompassed 50 questions across three sections: demographics, technology use for the clinician's three most frequently seen populations, and a summary section about if they desired more technology and the role of cost. Feedback from the pilot study led to additions to the current survey, including questions about barriers to use, factors that could overcome those barriers, if they desired more technology, and open-ended questions about specific technology they use. Additionally, the original survey was broken down by primary practice area, with different options for how they use technology based on each population. The final survey improved flow, incorporating broad options for technology use, limitations, and future directions, allowing all SLPs to provide answers for all populations and allowing for easier comparison. Incorporating the above changes, the final survey included 37 questions covering five topics: demographic information, overall

technology use, technology use in assessment, technology use in intervention, gaps or barriers to use, and future directions. The first two questions were related to inclusion criteria. Next, nine demographic questions were asked related to age, race, and work experience. The following 26 questions related to the main survey topic, technology use. Survey questions were designed by the researchers. The terms technology, mobile apps, and apps are used interchangeably in this manuscript and refer to mHealth, specifically the mobile applications that can be downloaded to a phone or tablet, not the devices themselves. The term technology was chosen in the survey as SLPs are not typically aware of the term mHealth. mHealth related to telepractice was excluded from this survey, as was computer-assisted treatment.

The final survey questions were not randomized, due to adaptive questioning. Adaptive questioning was used to reduce the number of questions asked when they were not applicable. Due to adaptive questioning, participants saw as few as two screens (if they did not meet the first inclusion criteria) or as many as 11 screens based on their responses (including informed consent). Each screen contained a range of one to six questions per page. Only inclusion criteria questions had to be answered before moving on or completing the survey. Participants were able to revise answers using a back button on the survey. See Figure 1 for survey flow.

Figure 1. Survey flow diagram.



Survey Participants

Participants were recruited using convenience sampling through advertisements on social media and direct emails to pediatric practices from all fifty states. See Multimedia Appendix 1 for the social media announcements and emails.

Investigators posted to pediatric SLP–focused Facebook groups on topics such as pediatric speech therapy, preschool SLPs, early intervention SLPs, and school-based SLPs. The announcement was also posted in research-based groups, such as "SLPs for Evidence Based Practice". SLPs visit these groups to ask clinical questions, inquire about issues in the field, provide ideas and resources to others, ask questions, present recent research, and occasionally post job openings. Thus, most survey participants were engaged in social media and continuing education in the field. Additionally, private practices were randomly selected using Google searches for "pediatric speech therapy + state name" for all 50 states. The first three listings were emailed the email script (see Multimedia Appendix 1). The survey was available online from November 14, 2017 through May 10, 2018. Inclusion criteria included being ASHA-certified and currently working with a caseload of at least 10 pediatric clients, to ensure the survey population was made up of actively practicing SLPs who would have the opportunity for experience with technology. This survey was approved by the Northeastern University Institutional Review Board before deployment. Informed consent was achieved by having participants read and agree to the Informed Consent before beginning the survey. Informed consent included information about the investigators and their contact information, the purpose of the study, the approximate length of time to complete the survey, and data storage. Participants were cautioned that, due to the nature of the online survey, it is possible they could be identified by IP address or other electronic record associated with their response but that these data were not being actively collected by the investigators. The survey was voluntary, but participants were able to enter a $100 Amazon gift card raffle in exchange for their participation. Personal data was collected in the form of demographic information, which remained anonymous, per the informed consent. Only the investigators had access to the survey portal. Participants were asked to fill out a separate survey with their name and email address in order to enter the raffle, the link to which was listed at the end of the primary survey so that their email was not associated with their response. A total of 621 responses were recorded, of which 518 were ASHA certified. Of the 518 who were ASHA certified, 485 had a caseload of at least 10 pediatric clients, resulting in a study population of 485. Per ASHA's 2018 year-end counts, 74,764 ASHA-certified SLPs worked with the birth-17 years old age range, thus this survey represents only 0.65% of the population of certified pediatric SLPs.

Participant Demographics

Participants reported demographic and practice information (see Table 1). Most participants were female (467/485; 96%), white (434/485; 89%), and between the ages of 25-34 (252/485; 52%) or 35-44 (128/485; 26%). Most reported working in a school setting, although all work sites were reported. Except for Hawaii, Nevada, North Dakota, South Dakota, and West Virginia, all remaining states were represented, including the District of Columbia. See Multimedia Appendix 2 for demographic characteristics of the sample.

Table 1. Participant demographics (n=485).

Variable	Value, n
Sex	
Female	467
Male	18
Age	
18-24	14
25-34	252
35-44	128
45-54	59
55-64	22
65-74	1
Ethnicity	
White	434
Black	8
American Indian or Alaska Native	1
Asian	17
Native Hawaiian or Pacific Islander	0
Other	15
Years since matriculation with Master's	
0-3	120
4-7	118
8-11	81
12+	154
Work site	
Hospital-NICU[a]	5
Hospital-other inpatient	5
Hospital-outpatient	40
Private practice	83
School	227
Early intervention	74
Other	41
Primary age group working with	
Birth to age 3	195
Preschool (age 3-4)	308
Early school (age 5-7)	297
Late elementary (age 8-10)	234
Middle school (11-13)	134
High school (14-18)	85

[a]NICU: neonatal intensive care unit.

Analysis

All entries were analyzed, including incomplete questionnaires. Questionnaires were not monitored for multiple entries or atypical time stamps before analysis. The survey sample was judged to be representative, as it closely aligns with ASHA membership demographics in terms of gender, ethnicity, and work site, so weighting was not utilized. One notable difference

is age, which was specifically analyzed using chi square analyses. Age was divided into two categories of near equal population size: age 18-34 years (n=254) and 35 years and older (n=201). The average time participants spent on the survey was 22 minutes. The average progress (how much of the survey they completed) was 88.2%. Of the 624 surveys opened, 482 were completed, resulting in a completion rate of 77.2%. View and participation rates could not be calculated.

For questions with discrete answers, percentages for each question were calculated automatically using Qualtrics' analysis of responses. The survey also included open-ended questions about the participants' barriers to use and desires for future use. Coding and analysis of these responses followed an inductive, iterative process inspired by grounded theory analysis, where responses were analyzed for codes and these codes were then iteratively clustered into higher-level themes [40]. For example, for question 150, participants were asked, "What areas of SLP technology would you like to see improvements?" Responses identified as encompassing codes such as: data, collection, data collection, or documentation were grouped into a theme of 'data collection', and this was continued for all codes identified. Following analysis, 26 themes were identified. For all open-response questions, only themes that included at least two respondents were reported. This analysis was completed for all open-response questions.

Results

Aim 1: Do Pediatric Speech Language Pathologists Use Technology in Clinical Practice and What are the Barriers to Use?

The first aim of the study was to understand if pediatric SLPs are using technology in clinical practice. A total of 367/457 respondents (80.3%) indicated they use technology all or some of the time. Only 73/457 (16.0%) of the pediatric SLPs reported rarely using technology, and 17/457 (3.7%) reported never using technology. There was not a significant difference between age groups in the use of technology (X^2_1=0.221; *P*=.97). See Multimedia Appendix 3 for more information.

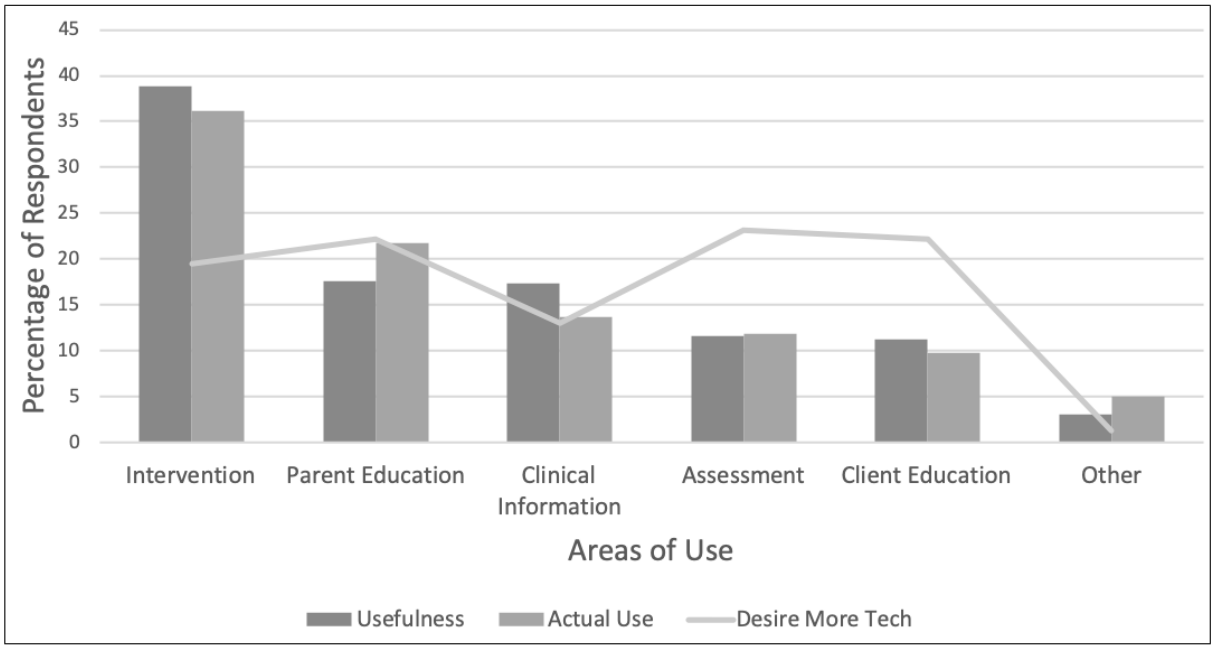
Of those who did use technology, 223/438 respondents (50.9%) used it during 0-25% of their clinical practice time, and a total of 364/438 respondents used technology during 50% or less of their clinical practice time. There was not a significant difference in percentage of time used between age groups (X^2_1=1.024; *P*=.79).

SLPs who reported using technology were asked how often they used it for assessment and intervention specifically. For assessment, 265/309 (86.0%) used it 0-25% of the time, with no difference by age group again (X^2_1=1.676; *P*=.64). For intervention, SLPs used technology more often, with 125/307 (40.7%) reporting using it 0-25% of the time, but 127/307 (41.3%) reported using it 26-50% of the time. Only 39/307 (12.7%) used it 51-75% of the time. and 16/307 (5.2%) used it 75-100% of the time. Again, no significant difference was detected in use during intervention by age (X^2_1=0.0817; *P*=.84). Overall, most SLPs did use technology but they did not use it during most of their clinical work.

Pediatric SLPs were also asked about what purposes they felt technology was most useful for in a select all that apply type of question. Intervention was most frequently cited (39.0%; 362/929 responses), followed by parent education (17.7%; 164/929), looking up clinical information (ie, developmental norms, treatment techniques) (17.3%;161/929), assessment (11.6%; 108/929), and client education (11.3%; 105/929). Of those who selected other (3.1%; 29/929), a keyword analysis revealed most pediatric SLPs found technology useful for motivation (6/929), augmentative and alternative communication (5/929), and home practice (3/929). Pediatric SLPs were also asked what they are currently using technology for in a select all that apply type of question. Results from a total of 1105 selections were like their ratings for usefulness, and are listed in order of prevalence: intervention (36.1%; 399/1105), clinical information (21.8%; 241/1105), parent education (13.7%; 151/1105), assessment (12.0%; 132/1105), client education (9.8%; 108/1105), and other (5.0%; 55/1105). It is interesting to note that SLPs are currently using apps for what they feel they are most useful for (see Figure 2).

Barriers to technology use was addressed by two questions. The first was a check all that apply type of question, with cost (34.0%; 46/135 responses) and lack of an evidence base (26.7%; 36/135) most frequently reported. Technology not being relevant to their population (13.3%; 18/135) or clinical area (9.6%; 13/135), and not being broad enough to use with a variety of clients (3.7%; 5/135) were not major barriers. Interestingly, 17 pediatric SLPs reported no barriers to using technology (see Figure 2 [SS3] [KT4]).

Figure 2. Speech-language pathologists' ratings of the most useful (dark gray), most used (medium gray) and areas where more technology is desired (light gray) across intervention, parent education, clinical information, assessment, client education and other.



An open-ended question about barriers was also presented to discover additional obstacles. Based on a keyword/theme analysis of text responses, 34/131 responses included concerns about not wanting to add to the screen time kids are already getting. Additionally, 11 responses reported anecdotal evidence of children having a tough time transitioning away from screens and 17 responses conveyed feelings that speech and language therapy should be focused on face to face interactions. Other frequently cited concerns included: recommendations for no screen time in early intervention (14/131), not having access to technology (13/131), cost (10/131), focusing on play (10/131), and lack of awareness about which apps to use (6/131).

Aim 2: Do Pediatric Speech Language Pathologists Want More Technology Available and in Which Areas?

The last section of the survey examined gaps in the availability of technology and future directions. Most pediatric SLPs, 268/380 respondents (70.5%), indicated they wished that there was more technology available "all or some of the time". This was not affected by age (X^2_1=0.974; *P*=.81).

In a select all that apply type of question with 925 total responses, pediatric SLPs desired additional or better technology for: assessment (214/925), parent education (205/925), data recording or viewing (194/925), intervention (180/925), clinical information (120/925), and other (12/925). Pediatric SLPs were also given the opportunity to expand through an open-ended question. Key words and themes extracted from text analysis indicated a strong interest in apps for data collection (11/925), less expensive apps (7/925), evidence-based apps (7/925), language apps (6/925), and customizable apps (4/925). Finally, in a select all that apply type of question, pediatric SLPs indicated they would be more likely to use apps if they were: evidence-based (51/202 responses; 25.3%), cheaper (28/202; 13.9%), targeted a specific skill (27/202; 13.4%), or were endorsed by ASHA (25/202; 12.4%). Less than 10% were interested in apps that were: customizable, broadly applicable, visually enhanced, easier to use, or games that kids were interested in.

Discussion

Primary Findings

The purpose of this study was to elucidate the practice patterns of pediatric SLPs in the United States, using mobile technology, to frame the development of future technology for this field. Specifically, we were interested in barriers and desires for future technology. We found that pediatric SLPs were using technology in practice less than half of the time and most frequently for intervention. Pediatric SLPs wanted more evidence for technology use, as they had concerns about screen time and how this may impact development, and they felt that children needed more face to face interactions. They were also concerned about cost. Pediatric SLPs were interested in more technology that focuses on aiding the clinician rather than the child, such as apps for data collection, assessment protocols, and parent education. There was no difference in technology use or desire for future technology based on age group, which is somewhat surprising as research shows younger people are more likely to use mobile technology in general [41], and some research has shown that age is a significant factor in whether teachers use technology [42-45]. However, other, more recent studies suggest that age, or years of experience (typically concurrent with age), are not a significant factor in technology use because young teachers are focused on issues of classroom management and course development, with limited resources left to integrate computers despite their personal experience [46,47].

The recurrent theme across responses was a concern about screen time and the lack of an evidence base for using technology with children. Pediatric SLPs responding to the survey cited concerns about kids getting too much screen time

or pointed to the fact that some populations they work with have difficulty transitioning from tablets back to nontablet-based activities, which can hinder the therapy session. Often pediatric SLPs cited the American Academy of Pediatrics' (AAP) recommendations that screen time should be limited for infants and toddlers, as well as feelings that speech-language pathology treatment should focus on play and face-to-face interactions. While the AAP recommends no screen time for children less than 18 months and limited screen time (1 hour/day), with a focus on educational programming and coviewing for children 18 months to 5 years, the National Association for the Education of Young Children supports the developmentally appropriate and intentional use of technology in early childhood education [48,49]. These conflicting recommendations may challenge pediatric SLPs, particularly when working with the pediatric population where most decisions are made by the parents.

Overall, data shows that how teachers and parents integrate technology with children [36-39], features of the app [36,50], and age [15,51-58] have a strong impact on how effective it is. The available evidence suggests that using technology with children over three years old can support learning and improve motivation when used appropriately and scaffolded by an adult. Given these conclusions promoting the efficacy of technology use, it is critical to understand and address the barriers to technology use for pediatric SLPs. Research on barriers for teachers can help frame the discussion for pediatric SLPs. For example, Ertmer et al [59-61] proposed two types of barriers to technology use: extrinsic (ie, lack of: access, time to learn and use, training, or support) and intrinsic (ie, beliefs, comfort, perceived value) [62]. Other studies have since corroborated these barriers. In this survey, pediatric SLPs cited intrinsic barriers most frequently (beliefs, perceived value, lack of evidence base) as well as extrinsic (cost). Teachers (and presumably pediatric SLPs) have the potential to be positive mediators of the effects of technology on student learning but may not be effectively integrating it into teaching [63,64]. For example, teachers have been found to use technology for homework, communicating with parents, or preparing class materials, but not for direct student teaching [65-67]. While pediatric SLPs in this survey cited intervention as the most used and useful purpose for technology, they cited similarly indirect usage as well, such as using and finding apps most useful for clinical information and parent education, and desiring more technology for indirect activities like data collection. This is not surprising given the limited evidence base for speech- and language-specific applications for use in a therapy setting. However, mobile app use has been shown to increase enjoyment, motivation for, and compliance with therapy in children [16,18,21,23]. Furthermore, proponents of mobile apps for pediatric SLPs suggest apps can help supplement or increase practice time and enhance a family's engagement with therapy, enhancing the efficiency of traditional therapy [25,68]. There is early evidence for an evidence-based, joint team approach to app development for speech sound disorders that may offer a solution to this problem [27]. It will be important to consider in what contexts apps may be most useful, whether at home for carryover or in the therapy room.

There are a few simple steps that should be taken to increase technology use with SLPs working in a pediatric setting. One is creating and disseminating speech-language therapy specific evidence to support or refute the appropriateness of using technology in speech language pathology assessment and intervention. This will require research into a variety of types of apps and populations, which could take a great deal of time, with limited generalizability for those in the clinical field. This is a broad area that needs to be addressed for a variety of applications, populations, age groups, and settings. Treatment applications that are specifically for use by parents as home carryover and have similarly established efficacy need to be developed.

Applications that offer easy to follow instructions and targets or prompts that the SLP can modify for the family to fit the child's needs would be beneficial. Another barrier to address is cost; reducing the cost or offering free trials of apps could encourage pediatric SLPs to try apps with their clients, as the majority of pediatric SLPs reported that they are not provided a budget for materials from their place of employment.

Finally, there is an opportunity for development of apps that are adult-facing rather than child-facing, such as apps for data collection, assessment, and parent education. Pediatric SLPs are in a critical position to use technology to enhance a child's learning and generalization and to educate parents about how to best choose and use apps for their children, as it is evident children are using technology at home regardless of evidence base [12]. Results from this study suggest that extrinsic and intrinsic barriers to adoption are impacting technology use in this clinical field.

Limitations

There are some limitations to this survey that should be acknowledged. The survey was distributed through email lists and Facebook groups, so participants were already engaged with technology. We were not able to reach pediatric SLPs from all 50 states, and although 45 states were represented, the number of respondents for each state were not proportional to the population. Our participant demographics closely matched those reported by ASHA in terms of gender, ethnicity, and work site, but one notable difference was our participants were younger than most ASHA members [69]. While research shows younger people are generally more likely to use mobile technology, our analyses revealed no difference in technology use or opinions in younger (34 years and under) and older (35 years and older) age groups, consistent with recent research on teachers' technology use [41,46]. Additionally, we had a primarily white sample (434/485; 89%), which can limit the generalizability of our findings. This is not surprising, however, as ASHA reports 79% of certified speech-language pathologists are white; there is little diversity in the field. Our sample size of 485 was reasonable, but only represents 0.65% of the population of certified pediatric SLPs. Thus, generalizability is limited. Future studies should explore key themes with larger populations and examine the impact work site, years of experience, and location on technology use. While technology was defined at the start of the survey, it is possible that respondents did not read or remember this definition while

taking the survey. As a result, some may have considered other specific technologies, like fiberoptic endoscopic evaluation of swallowing or augmentative and alternative communication devices, when answering, which could impact results. Future surveys should offer repeated statements of this definition at the start of each section. Despite these limitations, these results are judged to be representative of the target population, given our study population's demographics and additional analysis by age group, and offer an early glimpse into the thoughts of pediatric SLPs feelings toward emerging technology. Future studies should more specifically examine subsets of the pediatric SLP populations as well as attempt to reach those not already engaged in social media.

Conclusions

A majority of pediatric SLPs reported using mobile apps less than 50% of the time in a pediatric setting and used them more during intervention compared to assessment. More research is needed to elucidate the effectiveness of mobile apps for speech and language therapy, to reduce costs, and to develop apps for data collection and parent education to address the barriers to technology adoption in this population.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Social media announcement and email script for study recruitment.
[PDF File (Adobe PDF File)194 KB - rehab_v6i2e13966_app1.pdf]

Multimedia Appendix 2
Participant demographics.
[PDF File (Adobe PDF File)21 KB - rehab_v6i2e13966_app2.pdf]

Multimedia Appendix 3
Technology use by age group.
[PDF File (Adobe PDF File)81 KB - rehab_v6i2e13966_app3.pdf]

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Abbreviations

AAP: American Academy of Pediatrics
ASHA: American-Speech-Language-Hearing Association
mHealth: mobile Health
SLP: speech-language pathologist

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Original Paper

Website Redesign of a 16-Week Exercise Intervention for People With Spinal Cord Injury by Using Participatory Action Research

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Abstract

Background: People with spinal cord injury (SCI) are at higher risk for numerous preventable chronic conditions. Physical activity is a protective factor that can reduce this risk, yet those with SCI encounter barriers to activity and are significantly less likely to be active. Limited evidence supports approaches to promote increased physical activity for those with SCI.

Objective: Building upon our previous theory- and evidence-based approach to increase participation in regular physical activity for those with SCI, this study aimed to use a participatory action research approach to translate a theory-based intervention to be delivered via the Web to individuals with SCI.

Methods: A total of 10 individuals with SCI were invited to participate in consumer input meetings to provide the research team with iterative feedback on an initial website designed as a platform for delivering a theory-based exercise intervention.

Results: A total of 7 individuals with SCI whose average age was 43.6 years (SD 13.4) and lived an average age of 12.5 years (SD 14.9) with SCI met on 2 occasions to provide their feedback of the website platform, both on the initial design and subsequently on the revamped site. Their iterative feedback resulted in redesigning the website content, format, and functionality as well as delivery of the intervention program.

Conclusions: The substantially redesigned website offers an easier-to-navigate platform for people with SCI with greater functionality that delivers information using a module format with less text, short video segments, and presents more resources. Preliminary testing of the site is the next step.

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KEYWORDS

internet; exercise; intervention; spinal cord injury; community-based research

Introduction

Background

Clinical practice guidelines published by the Consortium for Spinal Cord Medicine recognize that people with spinal cord injury (SCI) face greater risk for cardiometabolic disease (CMD) than the general population. CMD refers to the presence of at least 3 of 6 chronic disease risk factors that include abdominal adiposity, dyslipidemia, hypertension, insulin resistance or glucose intolerance, proinflammatory state, and prothrombotic state [1]. The consortium posits that CMD may be more challenging to treat in those with SCI than the general population and advocates for aggressive prevention. Lifestyle intervention is recommended as the first line of treatment to reduce CMD risk, with a focus on nutrition (ie, follow a heart-healthy diet) and physical activity. Furthermore, the consortium strongly recommends that people with SCI do at least 150 min of physical

activity each week beginning as soon as possible after acute SCI [2], in line with national physical activity guidelines for all Americans [3].

Nevertheless, evidence is limited regarding effective approaches to promote regular participation in physical activity for people living with chronic SCI. Although several studies have examined barriers to physical activity that people with SCI face, people living with SCI encounter lack of access to timely and quality health information (eg, SCI-related medical issues and regarding fitness or health promotion) [4] and have fewer opportunities to engage in community-based physical activity than those without a disability [5]. Vissers et al [6] and Levins et al [7] reported that people with SCI described both environmental barriers such as inaccessible buildings, lack of available programs, and societal attitudes as well as personal factors that were barriers such as physical and mental health problems and concerns about body image [6]. Transportation continues to be a leading barrier to participation for people with SCI [8,9] across various health-related lifestyle changes, including physical activity. Given pervasive transportation difficulties facing people with SCI, the internet may offer a feasible and promising approach to help bridge the transportation barrier in delivering interventions that promote health for people with SCI.

The Potential of Internet Use for Intervention

The internet has dramatically transformed how we conduct our daily lives, and according to the Pew Research Center [10], nearly 9 in 10 adults reported accessing the internet in 2018. Nearly three-quarters (73%) of Americans have home broadband access, and 37% of Americans report using smartphones as their primary means of accessing the internet [11,12]. Although people with SCI report lower rates of internet access, 2 studies [13,14] published in the last decade indicate that 65% to 70% people have computer access, and most of these individuals (63%-92%) use the internet.

Thus, the internet offers a potentially promising platform to connect with individuals living with SCI who face transportation barriers and reside in communities with fewer accessible physical activity options. The internet is increasingly used to deliver relatively low-cost health behavior change programs to populations with chronic health problems such as diabetes [15], cancer [16], and asthma [17]. Furthermore, the internet has successfully been used to promote physical activity [18]. Despite increased use among people with SCI [14,19], there has been substantially less use of the internet to connect with people with SCI. Yet, a handful of internet-based studies have been conducted over the last 3 years that have provided participants with SCI 8 to 12 weeks of website access that included physical therapy education [20], taught self-management strategies to increase frequency of intermittent catheterization [21], reduced depressive symptoms [22,23], and reduced pain [22,24]. Another study delivered a single 60 min Web-based program to provide transfer training [25]. The others delivered educational content via the Web and provided participants with weekly phone calls [20,21,23,24] or email [23,26] by a study staff member. Several taught self-management strategies [21-24], and one used audio [22] and 2 used videos [22,24] to help participants visualize the lessons. Although not an internet-based intervention, researchers tested the effectiveness of delivering an 8-week telehealth program where participants received weekly one-on-one video conference calls with a counselor to promote leisure time physical activity that yielded significant increases in self-reported leisure time physical activity [27].

Although the internet remains an underutilized strategy for reaching and delivering health promotion programs for those with SCI, these initial results of technology use for delivering health education to people with SCI are promising [20]. This paper has described the process and outcome of using a participatory action research (PAR) approach to translate a theory-based, telephonic intervention that targeted increased participation in regular physical activity to be delivered in a group-based setting over the internet.

Methods

Design

Workout on Wheels Telephone Intervention

Our Workout on Wheels internet intervention (WOWii) program translated a theory- and evidence-based 6-month health behavior intervention, Workout on Wheels (WOW), which was originally tested with a sample of wheelchair users, in a randomized controlled trial [28]. The WOW program was delivered using the combined approach of convening a group-based, day-long educational kick-off session followed by one-on-one telephone calls by intervention staff over 12 months. The formal WOW curriculum was delivered over 6 months, with the core curriculum presented at the workshop plus over 4 months of weekly one-on-one phone calls that tapered over months 5 and 6.

WOW trial participants received a binder of written materials to review during the 6-hour educational kick-off workshop. The WOW trial yielded significant between group differences in time spent in aerobic exercise; however, the intervention group achieved only one-third (approximately 55 min) of the recommended 150 min of weekly cardiovascular activity [28]. WOW participants were observed making social connections at the educational workshop, asked when they could meet again as a group, and expressed interest to stay connected with their peers after the intervention. Thus, WOWii is a direct adaptation of the evidence-based self-management WOW program to a platform where it could be delivered in a group-based format over the internet.

Modified Workout on Wheels Internet Intervention

The prototype WOWii website comprised material from the WOW program. The site provided a menu with 8 selections: a home page (featuring images of wheel chair users, an indicator of the user's achievements in completing exercise planning tasks, and group meeting reminder and hot link), an exercise guide (eg, describes the health benefits, addresses exercise barriers exercise, exercise options for individuals with disabilities, safety issues), links to engage in exercise planning tasks (eg, goal setting, identifying exercise barriers and solutions, listing support people, describing reasons to exercise, tracking exercise, solving barriers to exercise, exercise goals,

and exercise tracking), link for tracking their exercise, resources (eg, short bios with pictures of wheelchair users and their exercise programs), achievements, a discussion forum, and leaderboard. The WOWii prototype site images are displayed in Multimedia Appendix 1. The website contained substantial text from the written materials distributed in the previous trial that addressed the health benefits and safety considerations of physical activity (accompanied by images of wheelchair users engaged in various sports and physical activities) and steps to develop and complete their individual exercise plan.

WOWii was abridged to a 16-week program that allows adequate time to teach the curriculum and members to get to know one another. The vision of WOWii was to retain the content and approach of explicitly teaching individuals with SCI self-management strategies to start and maintain an exercise program, while harnessing the power of peer support to facilitate conversation that allows individuals the opportunity and venue to share their knowledge, barriers, and successes as they initiate a new health behavior. WOWii includes 2 interactive components: (1) an internet site that allows self-directed learning via electronic modules organized with weekly content and (2) online group meetings to discuss and practice the weekly lessons facilitated by study staff.

PAR offers an approach to invite members of the community of interest to collaborate with the research team, which increases the relevance and ease of use of the research approach, procedures, and outcomes for the target group [29]. We selected to follow a PAR framework to develop a partnership with individuals living with chronic SCI to ensure that the WOWii website and its content, including the language, layout, and functionality, accurately and adequately addressed the interests and needs of people living with SCI. Focus groups and interviews represent 2 of the most common methods used in PAR to generate data. Gathering people with characteristics similar to the study population into one-on-one meetings or small groups of 7 to 12 provides ideal settings for individuals to discuss their perspectives and concerns with researchers. This approach allows researchers and members of the target community to collaborate on addressing a common goal [30].

Recruitment

Former SCI inpatients from our rehabilitation hospital who provided written consent to be contacted for future studies were emailed or handed a flier inviting them to participate in focus group meetings. Interested individuals contacted a study staff member to learn more about the study and enroll if eligible. Eligibility criteria included individuals between the ages of 18 and 65 years; had SCI for at least six months, that is, at a C6 level or below that requires wheelchair use; and have access to a computer with internet access. Injury level was included to help ensure that potential participants would have the finger function necessary to independently navigate the website. No criteria were established regarding physical activity participation to ensure those who were both active and inactive participated. Participants completed a 4-item physical activity history questionnaire that asked about their activities postinjury: (1) did any moderate or vigorous physical activities that caused an increase in their breathing or heart rate, (2) the number of days per week, (3) the number of minutes per day, and (4) the type of activities performed.

Consumer Input and Data Collection and Analysis

Input was provided by 7 people with SCI over 2 rounds of individual and group meetings. Our approach for incorporating their input was informed by qualitative approaches to identify common themes. During the first round of input, participants provided feedback on the WOWii site. The research team convened 3 sessions (each with 1 to 4 people) for individuals to share their feedback and offer input about the content and usability of the website's initial design. Participants were asked to review the website for at least 30 min on their own before the first meeting to allow adequate time to engage in brainstorming activities, generate novel ideas, and provide comments about the existing content.

Facilitators led a semistructured conversation following the Liberating Structures approach to yield generative, open discussions. Liberating Structures [31] emerged from business as an alternative approach to traditional meetings that can include inflexible power dynamics that may discourage impartial feedback. The Liberating Structures framework was first used to permit frontline workers to have more opportunities to work together to develop and offer innovative ideas with their leadership. The facilitators chose this approach to best align with the overall PAR framework centering on the participants' lived experiences and empowering them to partner with the researchers in the website redesign process. The facilitators used the 1-2-4-ALL design and the 25/10 Crowd Outsourcing approaches during the first half of the initial session to facilitate discussion. The 1-2-4-ALL design asked the group to respond to an open-ended question by spending 1 min alone, 2 min in pairs, 4 min in foursomes, and then 5 in the entire group. This time-limited approach produced several ideas and helped to keep the focus group meeting on schedule. The 25/10 Crowd Outsourcing approach asked participants to envision their boldest response to an open-ended question and write it on an index card. The cards were passed to other group members who then scored their ideas on a scale of 1 (low) to 5 (high). The cards were passed around for 5 scoring rounds, then the facilitator asked which participants were holding cards with a score of 25. The facilitators continued to ask for the highest ranked ideas in decreasing ranked order (eg, scored 24, 23, 22…) until the top 10 ideas were collected. This approach allowed the facilitators to understand what type of website design the participants envisioned and to gain a sense of which ideas were most salient. Participants responded to questions such as "If money wasn't a limitation, what would you create on this website?" During the last half of the session, participants were asked to identify their primary likes and dislikes and rate the credibility of information and ease of use of the website.

The facilitators took written notes and audio recorded each session for reference purposes to ensure that handwritten notes shared with the larger research team were complete. The team reviewed comments from the recordings and notes, and then grouped the comments into categories based on thematic content that emerged. Comments were broadly organized based on recommendations to add, revise, or delete content. The team

discussed all suggested changes and then prioritized the recommendations, giving greater weightage to modifications that were likely to have greater impact on changing behavior, given the time and budgetary constraints that prevented our implementing all recommended changes. The team worked closely with the website developer to execute suggested changes.

A second round of 90-min meetings with the original participants (2 separate meetings to accommodate the 7 individuals' schedules) were convened to obtain feedback on the new WOWii design, content, and appearance. Participants reviewed the website content while it was projected onto a screen to facilitate group discussion regarding whether the changes achieved their intended purpose and gather additional comments. Unfortunately, owing to time and funding constraints in meeting our timelines, the participants did not receive the website link to explore the revised site before the meeting. Participants provided substantially fewer recommendations during this feedback round. Their comments about the redesigned website concentrated on the flow and functionality of the site and predominantly addressed how to refine the new content.

Results

Overview

A total of 7 individuals who lived an average age of 12.5 years (SD 14.9; range 1-42 years) with SCI provided input. All individuals used a manual wheelchair, most experienced paraplegia (n=5), although 2 had tetraplegia. More than half were male (n=4), all were white, and their average age was 43.6 years (SD 13.4; range 26-60 years). Individuals in the sample were well educated, having earned a bachelor's degree (n=4) or greater (n=3) and more than two-thirds (71%, 5/7) were employed. Participants suggested an array of website enhancements that were characterized as being in 1 of 3 categories: (1) design, (2) content, and (3) functionality and program delivery, presented in Table 1 organized by which round the feedback was provided. These enhancements are described in detail in the following paragraphs.

Table 1. Consumer input participants (n=7).

Demographic Characteristics	Values
Sex, n	
Male	4
Female	3
Age (years), mean (SD)	43.57 (13.40)
Time since injury, mean (SD)	12.50 (14.94)
Spinal cord injury, n	
Quadriplegia	1
Paraplegia	6
Race, n	
White	7
Ethnicity, n	
Hispanic	1
Non-Hispanic	6
Marital status, n	
Married	4
Widowed	1
Never been married	2
Education, n	
Bachelor's degree	4
Master's degree	2
Other graduate degree	1
Employment status, n	
Not currently employed	1
Employed part-time	3
Employed full-time	2
Household income (US $), n	
20,000-24,999	1
60,000-69,999	1
100,000 or more	4
Report being physically active since injury (n=4), mean (SD)	
Days spent in moderate or vigorous activity	3.0 (2.3)
Minutes spent in moderate or vigorous activities[a]	112.50 (102.07)

[a]Activities reported: wheelchair tennis, rugby, hand cycling, swimming, wheeling, and weight training.

Design Changes

The most substantial changes made to the website design addressed participants' concerns about the organization and flow of site content. Participants strongly encouraged the team to provide users a roadmap by reorganizing the content to clearly indicate the order in which someone should review information. The website was substantially redesigned, with the focus on easy-to-navigate weekly learning modules that covered topics designed to introduce and teach self-management strategies (eg, setting goals, tracking progress, rewarding success, addressing barriers, and solving problems) that would facilitate developing a realistic exercise plan that considered changes they would make to their daily routine. Each module introduced the topic, provided examples, and included a theory-based skill building activity for participants to practice. The original WOWii included the same self-management topics, and the redesign targeted the format for presenting the content within the modules (see Table 2 and Figure 1). Topics covered in each module (module topics listed in Table 3) will be the topic discussed in that week's virtual session, which will be delivered using a commercially available communication platform that allows

videoconferencing such as Skype, Zoom, or WebEx. The participants also discussed allowing individual users to interact with each other on the site. Although budget and time constraints prevented adding this feature, the team recognized that an array of options outside the site do allow for this type of interaction. Thus, the study team opted to create a private Facebook group that participants could join and would be moderated by a WOWii researcher.

Table 2. Website changes recommended during each round of participant meetings.

Categories	Round 1		Round 2	
	Implemented	Not implemented	Implemented	Not implemented
Design	• Add roadmap for users • Present content using e-modules • Enlarge font • Add option to customize profile photo	• Allow user interaction	—[a]	—
Content	• Reduce volume of text • Add videos • Provide additional resources • Provide YouTube links	• Add calendar of events • Provide accountability partners	• Add motivational statements • Add peer intro videos • Created a downloadable pdf of resources • Delete RPE[b] scale as intensity indicator • Add more graphics	—
Functionality and program delivery	• Add federal legislation information • Include peer mentors in delivery • Add 'Ask the Expert' link • Offer text reminders for exercise • Display weekly PA[c] goals in relation to PA achieved • Optimize site for mobile access	• Assess stage of change • Add calorie burn guide	—	—
Edits	—	—	• Make wording changes in modules • Recommend formatting changes • Simplify language	—

[a]Not applicable.

[b]RPE: Rating of Perceived Exertion Scale.

[c]PA: physical activity.

Figure 1. Website screenshot of modules and resource tabs.

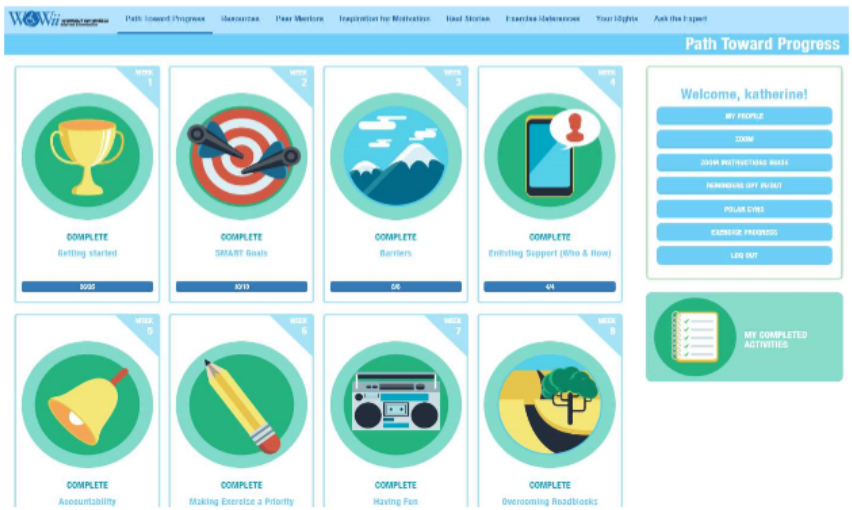


Table 3. List of module and virtual session topics.

Month and week	Topic
Month 1	
1	Getting started
2	SMART[a] goals
3	Barriers
4	Enlisting support (who and how)
Month 2	
5	Accountability
6	Making exercise a priority
7	Having fun
8	Overcoming roadblocks
Month 3	
9	Benefits of exercise
10	Staying motivated
11	Revisiting goals: are your goals realistic?
12	Managing stress
Month 4	
13	Problem solving
14	Advocating for yourself
15	Enhancing support networks
16	Planning for exercise maintenance

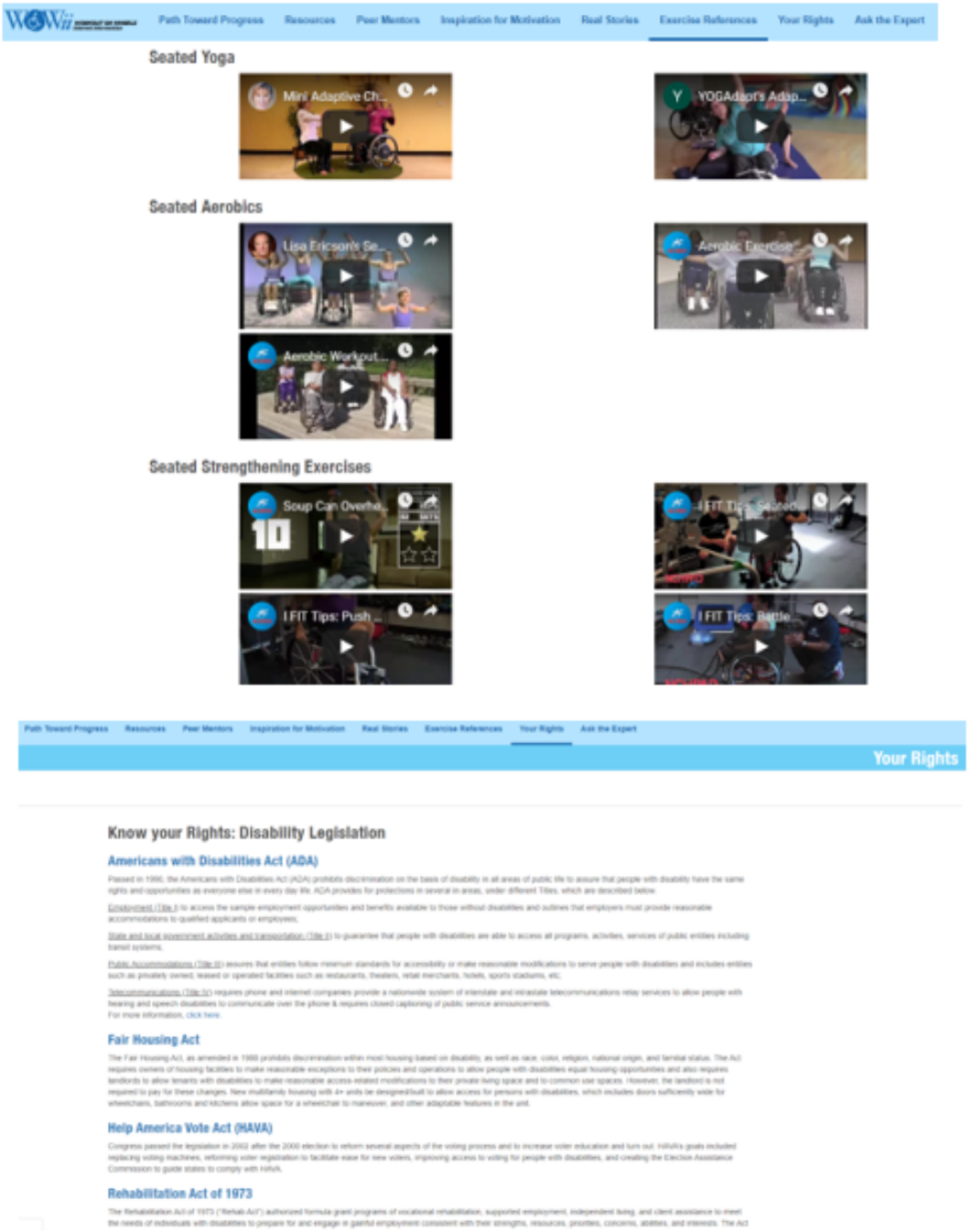
[a]SMART: Specific, Measurable, Achievable, Realistic, Timely.

Content Changes

The main content changes that participants encouraged were reducing the volume of text and using images and videos to convey that content. After the redesign, all 16 e-modules included a short video segment (eg, 1 to 3 min) that featured various people who experienced spinal cord dysfunction and who are vocal advocates or disability researchers. Each video addressed a specific aspect of the week's topic, such as ideas for helping to make or keep exercise fun. Bulleted text appeared beside the videos to highlight the main points the speaker addressed during the segment. Each person featured in a video gave a brief video introduction of themselves and were placed on the Peer Mentor tab. Changes implemented were guided by the Agency for Healthcare Research and Quality's health literacy toolkit [32] to ensure usability for consumers from varying backgrounds (eg, levels of education). Site changes used simplified language, large text, and more images to facilitate access and understanding for the average user.

The participants also recommended compiling additional resources that could be displayed on the website and to where participants could refer if they had questions about equipment, facilities, or their rights as a person with a disability. The array of ideas participants generated included adding resources to facilitate participants' access to activities and programs to support exercise adoption. To address this, the team compiled a list of local resources for physical activity that included accessible gym and recreation facilities and local durable medical equipment suppliers; added embedded links to accessible exercise videos (eg, seated yoga and wheelchair dance; see Figure 2); provided informational resources that included descriptions of disability-specific legislation (eg, Americans with Disabilities Act and Fair Housing Act); and listed contact information for governmental and social resources (eg, independent living centers and disability magazine). These were added via tabs that run across the top of the Web page.

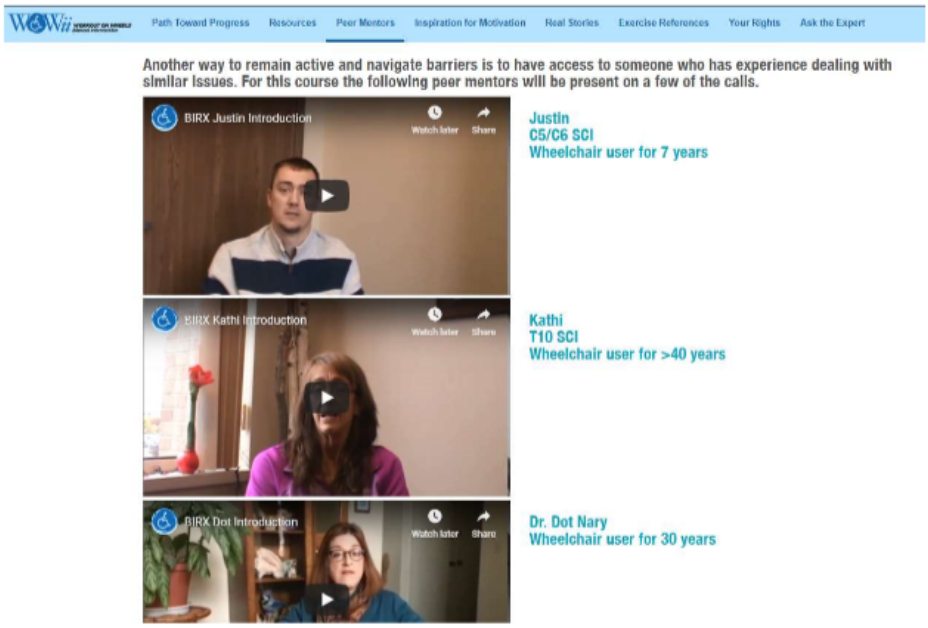
Figure 2. Resource pages.



Program Delivery and Functionality Changes

The main change related to program delivery was to include people with SCI as part of the team helping guide participants through WOWii as they begin and follow through with their exercise program. On the basis of this input, the study team invited 2 people (1 male and 1 female) with SCI who are both regularly physically active to formally serve in the role of *peer mentors* and be paid an annual stipend to serve in this consultant role (Figure 3). The mentors have several explicit roles in the project which include helping to colead several of the virtual weekly modules, facilitate online group discussions during these sessions, be available to answer questions submitted to the website's WOWii *Ask the Expert* button, and provide support by phone to WOWii participants who may be struggling with their exercise program.

Figure 3. Mentor page.



A total of 3 new features to enhance functionality of the WOWii site were added to address participants' ideas for helping users stay on track with their new exercise program. They encouraged adding (1) the ability for participants to receive text reminders for each workout, based on their individual workout schedules that users could opt *in* or *out* of to receive. They also proposed including (2) an interactive calendar feature that would allow them to view their weekly exercise progress in relation to their weekly exercise goals. Another idea that was suggested was creating (3) a tab that would display a rotating view of motivational pictures and quotes that encourage participants to stick with their exercise program. In addition, the participants discussed the potential benefits of including a calendar to show upcoming events and an individualized energy expenditure guide. Neither suggestion was implemented owing to the time required to create and maintain these tools regularly. The energy expenditure guide would also have presented exorbitant financial costs as the values are not easily available.

Discussion

Principal Findings

Using a PAR approach to formally include men and women with SCI who represented different impairment levels and exercise histories to collaborate with our team in revamping the WOWii website led to a substantial redesign of the site. The revamped site had less text, greater functionality, and more images of people with SCI throughout. The iterative process allowed our SCI partners to provide input as to whether their ideas regarding the organization, content, and functionality were accurately implemented on the redesigned site (eg, intuitive navigation, inclusion of video, reduced text, and easy access to media assets). The redesigned WOWii site contains all the material provided to participants during the educational workshop yet presented in a manner that PAR participants reported was easy to access, follow, and understand (see Multimedia Appendix 2 for the graphic that depicts changes implemented from the original into the redesigned site). The online information addresses SCI-specific exercise benefits, presents types of activities that people with various levels of SCI can perform, shows equipment, and provides links to available resources, as well as delivers step-by-step instructions about how to safely begin and continue an exercise program.

Although few published studies have investigated using Web-based platforms to improve health, SCI-specific health resources are available online, including sites that address physical activity. In their review of 30 SCI-focused websites, Jetha et al [33] reported that SCI-specific physical activity information is available, but the sites mostly present general information about the benefits of and barriers to physical activity. The authors note that few sites provide theoretically based intervention strategies to help people with SCI become more physically active and state that there is a need to improve information available on the internet about physical activity for people with SCI to enhance their access to quality information including interactive opportunities for developing behavioral skills. The collaborative relationship among those with SCI who provided iterative rounds of feedback on the WOWii site led to developing an online resource that addresses several of these shortcomings, in particular related to including theoretically based approaches to promote physical activity and adding interactive opportunities to develop these behavioral skills. Additional study is warranted to examine whether this Web resource is a feasible and effective platform for increasing physical activity among those with SCI.

Notably, a resource similar to the WOWii program is offered by the National Center on Health, Physical Activity, and Disability, which is known as 14 Weeks to a Healthier You. Both Web-based programs offer similar content in terms of informational resources and content regarding aerobic and strength training, and allow participants to schedule their workouts, track their exercise and diet, and opt in for text

reminders. However, the programs differ in terms of delivery and participant interaction. The Healthier You program guides people through starting and keeping up with a physical activity program by delivering weekly emails with links to physical activity videos and content on the Healthier You website that participants move through at their own pace, whereas the WOWii program guides participants through the 16 weeks by hosting weekly 60-min group-based virtual sessions where a group of 10 to 14 participants meet over a virtual platform (Zoom) facilitated by a WOWii staff member who introduces the skills-based topic addressed in that week's module and facilitates discussion among and sharing by the group members. These weekly virtual sessions are designed to facilitate group cohesion and have members serve as a support network and accountability, allowing enrollees to connect with other program users by adding them as a friend on the Healthier You site.

Limitations

Feedback for adapting the website came from a small convenience sample of individuals with SCI who were not representative of the broader population living with SCI. The sample had more education, higher employment, and was less racially diverse than observed among the broader SCI population. Thus, including individuals with more diverse racial, educational, and employment backgrounds may have allowed those with different internet experiences to have potentially provided other recommendations for changing the content and function of the website.

Conclusions

Using an iterative PAR approach to collaborate with individuals who represent the target audience for this intervention allowed for receiving substantial input and guidance that transformed the layout and functionality of the WOWii internet site. Participants shared their insights about what they would like to see and have available on the site. Feasibility of using the redesigned website by individuals with SCI will be tested in a 4-week trial, and effectiveness of the 16-week WOWii program will be investigated in a subsequent randomized controlled trial.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
WOWii redesign.
[PNG File , 260 KB - rehab_v6i2e13441_app1.png]

Multimedia Appendix 2
Diagram of website changes.
[PNG File , 169 KB - rehab_v6i2e13441_app2.png]

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Abbreviations

ACL: Administration for Community Living
CMD: cardiometabolic disease
HHS: Health and Human Services
NIDILRR: National Institute on Disability, Independent Living, and Rehabilitation Research
PAR: Participatory action research
SCI: spinal cord injury
WOW: Workout on Wheels
WOWii: Workout on Wheels internet intervention

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Original Paper

The Effectiveness of Telerehabilitation as a Supplement to Rehabilitation in Patients After Total Knee or Hip Replacement: Randomized Controlled Trial

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Abstract

Background: Telerehabilitation can contribute to the maintenance of successful rehabilitation regardless of location and time. The aim of this study was to investigate a specific three-month interactive telerehabilitation routine regarding its effectiveness in assisting patients with physical functionality and with returning to work compared to typical aftercare.

Objective: The aim of the study was to investigate a specific three-month interactive telerehabilitation with regard to effectiveness in functioning and return to work compared to usual aftercare.

Methods: From August 2016 to December 2017, 111 patients (mean 54.9 years old; SD 6.8; 54.3% female) with hip or knee replacement were enrolled in the randomized controlled trial. At discharge from inpatient rehabilitation and after three months, their distance in the 6-minute walk test was assessed as the primary endpoint. Other functional parameters, including health related quality of life, pain, and time to return to work, were secondary endpoints.

Results: Patients in the intervention group performed telerehabilitation for an average of 55.0 minutes (SD 9.2) per week. Adherence was high, at over 75%, until the 7th week of the three-month intervention phase. Almost all the patients and therapists used the communication options. Both the intervention group (average difference 88.3 m; SD 57.7; *P*=.95) and the control group (average difference 79.6 m; SD 48.7; *P*=.95) increased their distance in the 6-minute-walk-test. Improvements in other functional parameters, as well as in quality of life and pain, were achieved in both groups. The higher proportion of working patients in the intervention group (64.6%; *P*=.01) versus the control group (46.2%) is of note.

Conclusions: The effect of the investigated telerehabilitation therapy in patients following knee or hip replacement was equivalent to the usual aftercare in terms of functional testing, quality of life, and pain. Since a significantly higher return-to-work rate could be achieved, this therapy might be a promising supplement to established aftercare.

Trial Registration: German Clinical Trials Register DRKS00010009; https://www.drks.de/drks_web/navigate.do?navigationId=trial.HTML&TRIAL_ID=DRKS00010009

(JMIR Rehabil Assist Technol 2019;6(2):e14236) doi:10.2196/14236

KEYWORDS

telerehabilitation; home-based; total hip replacement; total knee replacement; exercise therapy; aftercare; rehabilitation

Introduction

Background

According to data from the Organization for Economic Cooperation and Development (OECD), 299 total hip and 206 total knee replacements were performed per 100,000 people in Germany in 2015. With these numbers, Germany ranks second (hip) and fourth (knee) in the world [1]. A further increase in endoprosthetic interventions on the knee and hip joint is to be expected due to an aging society and an increasing rate of obesity [2-4].

After an orthopedic procedure, rehabilitation as a multidisciplinary approach can improve the function of the joints and the ability to maintain a normal daily life, as well as relieve a patient's pain [5-7]. The effectiveness of rehabilitation after a knee or hip replacement has already been documented with substantial evidence [8-12]; however, maintaining the achieved therapeutic outcome remains a challenge. Prior studies have reported various barriers to using rehabilitation services, such as miscellaneous financial, structural, personal, and attitudinal determinants of access to rehabilitation [13]. Currently, there is an ongoing study, whose results will soon be published, [14] that seeks to determine barriers to using rehabilitation services.

In Germany, patients are offered numerous aftercare options, such as the multimodal intensified program (IRENA) or training rehabilitation aftercare (T-RENA), but only about half of eligible patients take advantage of them [15]. Therefore, to improve the sustainability of postoperative therapies, more flexible and individualized offers need to be developed.

In this regard, telerehabilitation seems to be the obvious choice since it can be performed irrespective of location and time, and it has the potential to increase both utilization and therapy adherence. The current telerehabilitation offerings should be adapted to the individual and indication-specific needs of the patients and should enable contact with the supervising therapists. However, this could not be investigated with the currently available systems, as they are either not specific enough for the indications of a patient or do not offer a tool to communicate with a therapist [16-22]. The telerehabilitation systems studied until now often differ in terms of their communication structures and their feedback options. Thus, Moffet et al [17] and Tousignant et al [19] investigated synchronous telerehabilitation applications where the physiotherapist and the patient communicated in real-time via videoconferencing, while Bini et al [16] and Piqueras et al [18] studied systems in which the communication between therapist and patient took place with a time delay. Additionally, the latter group of papers used a system with sensor-based kinematic feedback on motion execution. It is well known that the addition of external feedback can contribute to improved movement performance [23]. Regarding kinematic feedback systems, prior investigations on motion detection using a Kinect sensor already exist. In two studies, the acceptable reliability and validity of a Kinect-based motion analysis was demonstrated when compared to other marker-based kinematic measurement systems [24,25]. Both authors concluded that the Kinect may be a suitable tool for analyzing movement in the clinical field.

Hence, the MeineReha system [26,27] combines many components that were thus far investigated individually and additionally provides real-time visual feedback using a Kinect camera. Following development and validation [28], the MeineReha system was supplemented with an individualized and therapist-controlled telerehabilitation program consisting of 38 training exercises available for patients after their knee and hip replacements.

Aim of the study

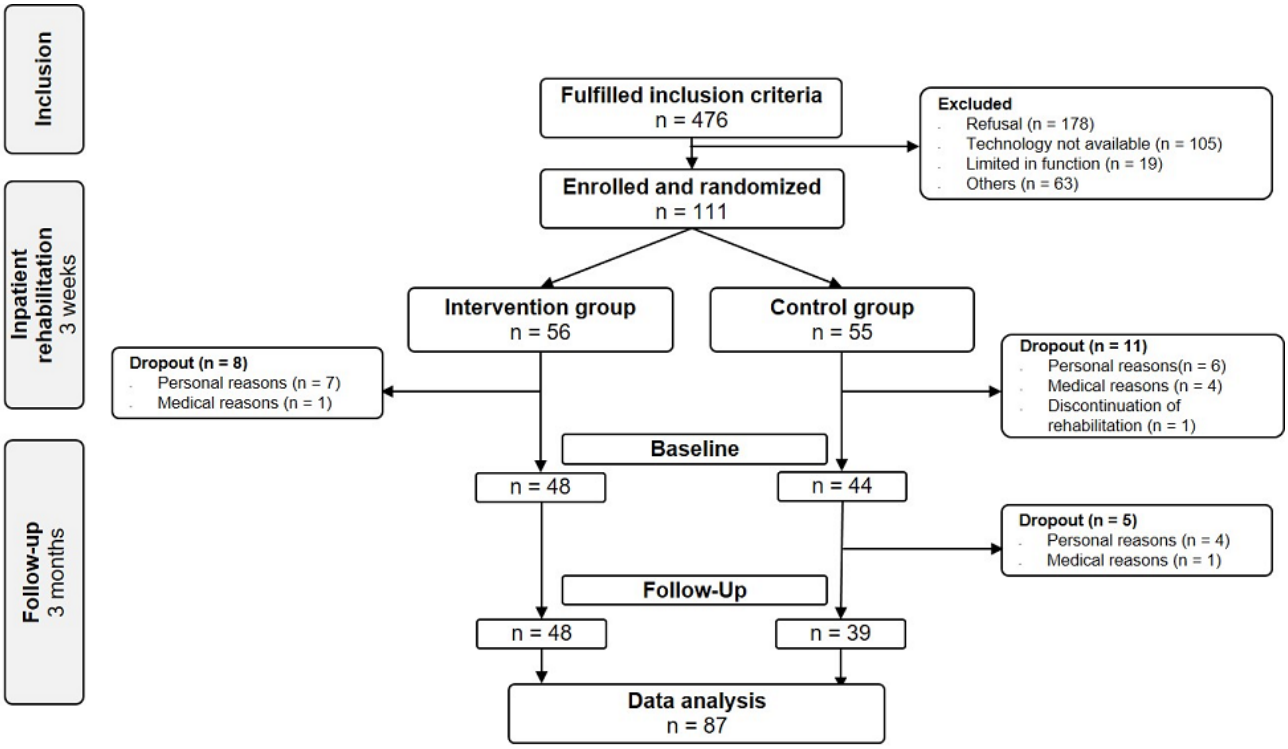
The aim of this randomized controlled trial was to examine previously developed telerehabilitation therapy in terms of its functional parameters, quality of life, and pain relief, as well as time to return to work, compared to usual aftercare programs.

Methods

Patients

From August 2016 to December 2017, after a screening of 476 patients in three inpatient rehabilitation centers, 111 patients were included in the randomized controlled trial (Figure 1). Patients were eligible for inclusion if a total hip or knee replacement was performed following idiopathic, posttraumatic, or congenital osteoarthritis, if they were aged between 18-65 years, and if they were insured by the national or regional German Pension Insurance. Patients not expected to achieve functional safety in walking with full load by the end of the rehabilitation were excluded. For those patients, it was assumed that they would not be able to perform exercises with adequate load or the assessments at the study site. Insufficient verbal and written German-language skills also led to exclusion. For the use of the telerehabilitation system at home, some additional criteria (eg, High Definition Multimedia Interface [HDMI]-compatible screen, minimum 2.5-meter space in front of the screen, and internet access) were required for the patients at home. After enrollment, patients were assigned to either the intervention group (IG) or the control group (CG) using block randomization in a 1:1 ratio and based on randomization lists drawn up in advance by the biometric institute. Written consent was obtained from all patients.

Figure 1. Consolidated Standards of Reporting Trials flow chart for the inclusion process.



Intervention

Following three weeks of inpatient rehabilitation, the patients assigned to the IG performed a three-month, home-based telerehabilitation program based on the MeineReha system, which consisted of a home component as well as a working portal for the therapist in the clinic. The main component, from the patient's perspective, was the MeineReha application that was installed on the rehab box at home. The rehab box (minicomputer with internet access) was connected to the usual peripherals (mouse and keyboard) as well as to a screen and Kinect sensor (camera) (Figure 2).

Figure 2. Hardware of the telerehabilitation system and an example exercise demonstrated by a virtual avatar.

The exercises to build up strength and improve postural control were chosen by the supervising therapist from a previously developed exercise catalog. The training intensity was individualized in terms of the choice of exercises, the number of sets and repetitions, and the duration of the breaks, which could all be adjusted by the therapist. Patients were asked to perform the training three times a week. There were different options for the patient and the therapist to communicate with each other: (1) the patient could record and send audio messages to their therapist whenever they wanted and the therapist was able to listen to it whenever their schedule gave them time to do it; (2) the therapist could respond or start a conversation with their patient at any time with individualized text messages, which the patient was shown whenever they started the system (eg, therapists could either remind the patient to do their exercises more often or just ask them about their condition); and (3) the patient and the therapist were able to make appointments for live video conferences, which they were supposed to conduct on a weekly basis to perform individual training consultation or to allow for the patient to ask questions about their training.

During the training, the exercises were demonstrated on screen by an avatar (Figure 3). The patient performed the exercises simultaneously and was detected by means of a Kinect sensor (camera). The system compensated for a patient's movement patterns with a predetermined target movement and sent them real-time visual feedback in which their relevant body segments were colored green for correct movements and red in the case of incorrect movements (Figure 3). The quality of each exercise was demonstrated to the patient following the performance of the exercise by using a school grade and the percentage of red and green values. The grading algorithm considered the synchronicity of the movements, the compliance with the target movement, and the number of repetitions. For training supervision, the therapist was given access to the frequency of the training as well as the exercise evaluations.

Figure 3. Real-time feedback during an exercise.

Control Group

Patients in the control group did not receive any study-specific therapy after their inpatient rehabilitation. The follow-up was carried out identically to the IG three months after randomization. The patients of both groups were also offered the usual aftercare, that is IRENA and physiotherapy.

Data Collection

To verify the patients' adherence, the process data for the IG (ie, frequency and duration of training, use of communication options) were read from the system. In addition, the frequency and duration of training and the use of other aftercare therapies were recorded by all patients in their training diaries. Further, all patients were investigated for functional parameters (eg, the 6-minute walk test, the Stair Ascend test, the Five-Times-Chair-Rise test, and the Timed-Up-and-Go test) at the study site (University of Potsdam) after the inpatient rehabilitation. Further, subjective parameters such as the Short Form Health Survey-36 (SF-36) on health-related quality of life, pain on the operated joint, stiffness, and function were assessed using the Western Ontario and McMaster Universities Arthritis Index (WOMAC), with a patient's ability to return to work also being assessed. In addition, patient characteristics, comorbidities, and medications were documented. The investigations were repeated after three-months follow-up. In terms of acceptance, we collected data from the IG using the Telehealth Usability Questionnaire (TUQ), including the concepts ease of use, learnability, satisfaction, future use, and reliability, on a 7-point Likert scale, with a 1 meaning disagree and a 7 meaning agree. To achieve comparability of the scales, we normalized the results as a quotient of the sum of the raw

values and the total number of items, multiplied by a factor of 100.

Statistical Analyses

The statistical analyses were conducted according to the description in the previously published study protocol [29]. All analyses were performed with the full analysis set of randomized patients (modified intention-to-treat). Patient characteristics and follow-up values were described with mean and standard deviation (metric variables), and absolute and relative frequencies (categorical variables). Group-specific changes in metric variables (trends) were tested for significance versus no change with one-factorial variance analyses. The calculation of the number of cases (n=84) was based on the comparison of the primary endpoint (improvement in the 6-minute walk test) between the groups. This comparison was carried out with an analysis of covariance (ANCOVA) with 22 baseline covariates at the 5% level (two-sided). All metric secondary endpoints were tested analogously without multiple adjustment. The ANCOVA estimates of the group differences in the continuous endpoints are presented in a forest plot. The group difference in the return-to-work rates was tested with the Chi-squared test. At the end, an analysis was performed within the IG on whether the improvement in the 6-minute walk test was dependent of the number of training units, the number of text messages sent by the therapist, or the number of audio messages sent by the patient.

Results

Patient Characteristics

At baseline, data from 87 patients from the IG (n=48) and the CG (n=37) (Figure 1) could be analyzed. The patients were an average of 54.9 (SD 6.7) years old, with an average of 56.8 (SD 5.7) for the CG and an average of 53.3 (SD 7.0) years (P=.012) for the IG. Overall, 51.7% (45/87) were female and had an above-average level of education (43.7% with a polytechnic or university degree). About two-thirds (69.0%; 60/87) of the patients received hip replacements, 31.0% (27/87) knee replacements, almost half of the patients (43.7%; 38/87) were obese (body mass index [BMI]≥30 Kg/m²), a third (36.8%; 32/87) of the patients had a cardiac comorbidity, and about a quarter (24.1%; 21/87) of the patients had an orthopedic comorbidity. At baseline, 48.4 days (SD 13.1) after surgery, one in ten patients (9.2%; 8/87) was treated with opioids and half of the patients (49.4%; 43/87) with nonopioid analgesics. Before elective surgery, 87.4% (76/87) of patients were gainfully employed. Table 1 shows the corresponding baseline figures of 87 patients with functional parameters at follow-up, which were eligible for the multivariate analysis. Categorical variables are expressed as absolute and relative frequencies with n (%), and metric variables as mean (SD).

According to the self-reported exercise diary, the patients in the IG performed their telerehabilitation an average of 55.0 minutes (SD 9.2) per week. The data read from the system showed a training duration of 39.0 minutes (SD 8.0). The participation rate was over 75% until the 7th week of the three-month intervention phase, but afterwards it decreased in parallel to the return to work (Figure 4). More than half of the patients continued their telerehabilitation after the 7th week until the end of the 12-week intervention. The communication via text and voice messages between the patients and therapists was used during the first few weeks. At the beginning of the intervention phase, almost all of the patients and therapists contacted each other (98% of the therapists sent text messages and 88% of the patients sent voice messages), but after the 4th week there was only a little communication (<50% sent messages). Overall, the patients sent an average of 6.0 audio messages (SD 5.9), while the therapists sent a mean of 7.0 text messages (SD 4.5) during the 12-week intervention. Furthermore, patients in both the IG and CG used regular rehabilitation aftercare. A total of 51.3% (20/39) of the CG and 33.3% (16/48) of the IG used IRENA aftercare, and physiotherapy was conducted by 81.3% (39/48) of the IG and 71.8% (28/39) of the CG.

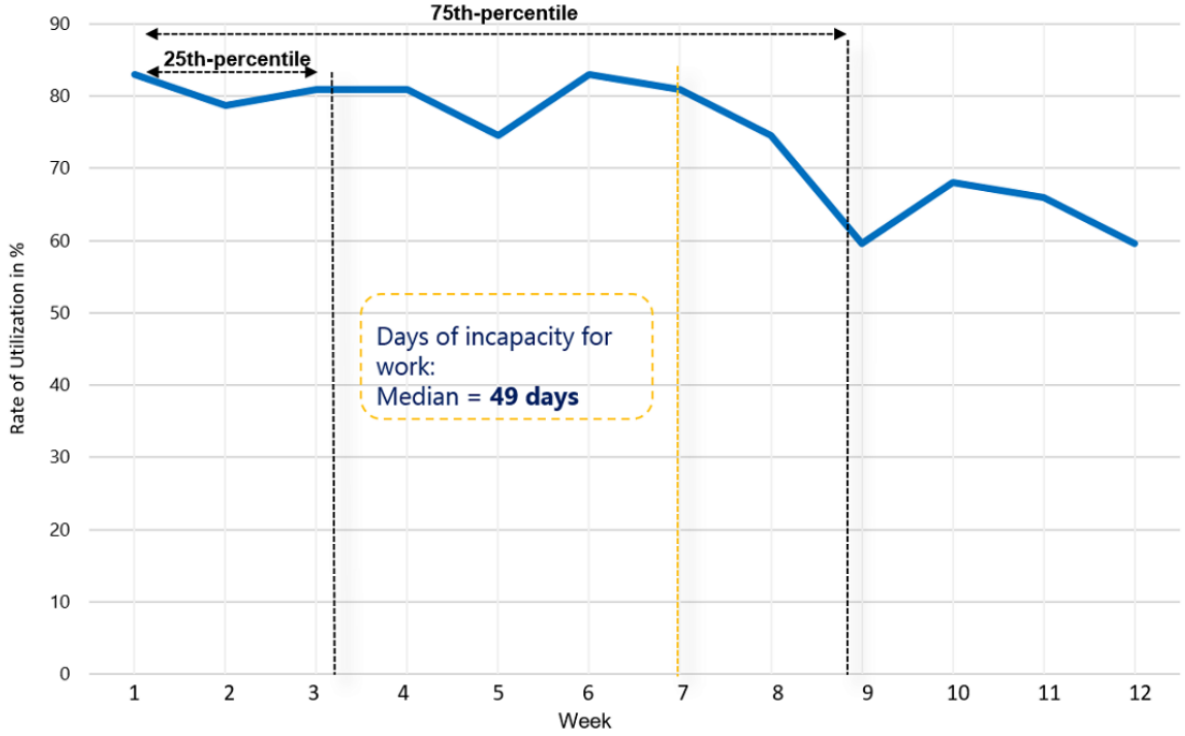
Table 1. Patient characteristics (n=87).

Characteristics	Control group (n=39)	Intervention group (n=48)	Total cohort (n=87)	*P* value
Socio-demographic data, lifestyle, and postoperative period				
Age (years), mean (SD)	56.8 (5.7)	53.3 (7.0)	54.9 (6.7)	.012
Sex (female), n (%)	19 (48.7)	26 (54.2)	45 (51.7)	.61
BMI[a] (kg/m²), mean (SD)	**30.3 (4.9)**	**29.8 (5.9)**	**30.0 (5.5)**	**.52**
Normal weight: 18.5–<25, n (%)	5 (12.8)	8 (16.7)	13 (14.9)	.86
Overweight: 25–<30, n (%)	17 (43.6)	19 (39.6)	36 (41.4)	—[b]
Obesity: ≥30, n (%)	17 (43.6)	21 (43.8)	38 (43.7)	—
Smoking behavior (smoker), n (%)	10 (25.6)	13 (27.1)	23 (26.4)	.88
Time from surgery to admission of inpatient rehabilitation (days), mean (SD)	18.4 (8.8)	18.8 (12.9)	18.6 (11.3)	.61
Time of inpatient rehabilitation (days), mean (SD)	23.3 (3.7)	23.3 (3.5)	23.3 (3.5)	.77
Time from surgery to baseline investigation (days), mean (SD)	50.4 (11.6)	46.9 (14.1)	48.4 (13.1)	.11
Education and occupation				
Graduation, n (%)				**.82**
Less than general or subject-linked higher education entrance qualification	21 (53.8)	27 (56.3)	48 (55.2)	
General or subject-linked higher education entrance qualification	18 (46.2)	21 (43.8)	39 (44.8)	
Vocational education, n (%)				**.20**
Less than polytechnic or university degree	19 (48.7)	30 (62.5)	49 (56.3)	
Polytechnic or university degree	20 (51.3)	18 (37.5)	38 (43.7)	
Gainfully employed, n (%)	34 (87.2)	42 (87.5)	76 (87.4)	.96
Unemployed, n (%)	2 (5.1)	2 (4.2)	4 (4.6)	.83
Incapacity for work before surgery (days), mean (SD)	16.6 (49.9)	21.3 (47.3)	19.2 (48.2)	.27
Work intensity (moderate/severe), n (%)	8 (20.5)	9 (18.8)	17 (19.5)	.84

[a]BMI: body mass index

[b]Not applicable

Figure 4. Utilization of telemedical assisted exercise therapy.



Functional Parameters

The patients in the IG could increase their 6-minute walking distance from an average of 440.6 (SD 78.2) to 530.4 meters (SD 79.0) (Difference [Delta]=88.3 m; SD 57.7 m; *P*<.001), and the patients in the CG from 433.3 (SD 80.2) to 513.0 meters (SD 70.6) (Delta=79.6 m; SD 48.7; *P*<.001) (Table 2). In the multivariate analysis, no group difference could be detected (*P*=.95) (Figure 5). The improvement within the intervention group was associated with the number of audio messages sent by the patient (*P*=.02), but not with the number of text messages sent by the therapist (*P*=.49) or with the number of training units (*P*=.07).

Other functional parameters (eg, the Timed Up and Go Test, the Stair Ascend Test, and the Five Times Chair Rise Test) also showed similar improvements in both groups (Table 2). The only multivariate significant group difference could be shown in the Five Times Chair Rise Test (*P*=.004) (Figure 3).

Table 2. Functional und subjective parameters (n=87). All values presented as mean (SD).

Parameter	Baseline			Follow-up			Differences (Delta)	
	IG[a]	CG[b]	*P* value	IG	CG	*P* value	IG	CG
6-minute walk test (m)	440.6 (78.2)	433.3 (80.2)	.90	530.4 (79.0)	513.0 (70.6)	.43	88.3 (57.7)	79.6 (48.7)
Stair Ascend Test (s)	8.7 (2.7)	8.6 (4.0)	.33	6.2 (1.2)	6.1 (1.5)	.44	–2.5 (2.4)	–2.5 (3.0)
Timed Up and Go Test (s)	9.3 (1.8)	9.0 (2.4)	.16	7.5 (1.2)	7.5 (1.6)	.93	–1.9 (1.5)	–1.5 (2.2)
Five Times Chair Rise Test (s)	16.9 (3.7)	17.1 (6.2)	.38	14.2 (2.7)	13.2 (2.3)	.06	–2.7 (3.5)	–3.8 (5.1)
SF-36[c] PCS[d]	33.8 (7.6)	33.3 (7.9)	.82	44.6 (9.9)	44.4 (8.3)	.80	10.7 (10.4)	11.1 (7.2)
SF-36 MCS[e]	54.8 (10.6)	53.9 (11.8)	.98	52.4 (10.6)	54.1 (9.8)	.28	–2.5 (12.4)	0.1 (8.5)
WOMAC[f] Index	26.4 (18.5)	24.8 (16.4)	.78	11.5 (12.7)	13.9 (14.3)	.51	–14.9 (13.6)	–10.9 (13.5)

[a]IG: intervention group

[b]CG: control group

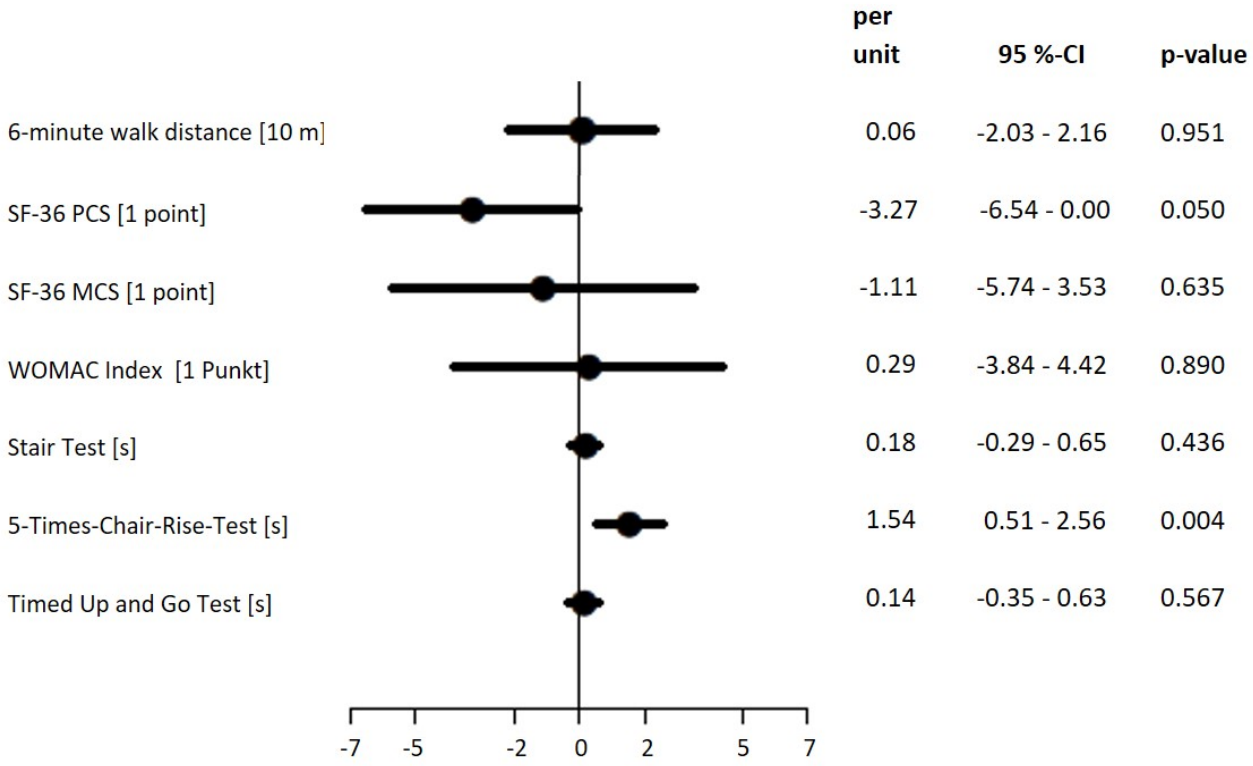
[c]SF-36: Short Form Health Survey-36

[d]PCS: physical component scale

[e]MCS: mental component scale

[f]WOMAC: Western Ontario and McMaster Universities Osteoarthritis Index

Figure 5. Differences in endpoints between intervention and control group, multiple adjusted. SF: Short Form Health Survey; PCS: physical component scale; MCS: mental component scale; WOMAC: Western Ontario and McMaster Universities Osteoarthritis Index.



Health-Related Quality of Life, Pain, and Return to Work

Regarding the health-related quality of life on the SF-36, an improvement in the physical component scale (PCS) was achieved in both groups. Furthermore, the WOMAC Index showed a significant reduction in both groups (Table 2). At the end of the intervention, 31 patients (64.6%) from the IG and 18 patients (46.2%) from the CG were gainfully employed (*P*=.01).

Acceptance of the Telerehabilitation System

In terms of acceptance of the TUQ, the patients of the IG showed high consent in the normalized values of the scales of ease of use and learnability (mean 85.2; SD 2.9) as well as in satisfaction and future use (mean 79.8; SD 3.2), whereas the values of the reliability scale were lower (mean 51.8; SD 3.7).

Discussion

Summary

In short, the use of telerehabilitation with patients having just undergone knee or hip replacements was equivalent to the usual aftercare in terms of the difference achieved in the 6-minute walk test. In addition, equivalent increases in both groups were demonstrated as secondary endpoints for functional mobility, health-related quality of life, and joint-related complaints. However, the patients in the intervention group were employed at a significantly higher rate at the end of the intervention.

The patients in the intervention group intensively used the telerehabilitation as a complementary aftercare option for a prolonged period of the study. The difference between the training durations given by the patient and those read out of the system can be explained by the preparation and cool-down times of the exercises, since only the exact execution time of the exercises was measured in the system. Likewise, the communication possibilities of the system, in terms of using text and voice messages, were exhausted. It is self-evident that the need for close contact with the therapist diminishes over a longer period, because the patients eventually either returned to work or all their questions about the system and training had already been answered.

The usual aftercare treatment was also used extensively by the patients in both groups. The participation rate of the control group (51%) in the IRENA aftercare program was comparable to the participation rate (50%) for the medical rehabilitation aftercare (MERENA) program in patients with chronic back pain [15]. More than 30% of the IG patients also used IRENA. About 80% of the IG performed their telerehabilitation until the 7th week of the three-month intervention phase, and even in the following weeks participation rates of more than 60% could be achieved. The high rate of use of the telerehabilitation may be due to its being time- and place-independent, as occupational obligations are a major obstacle to participation in aftercare [15]. Our study results further show that even after a sizeable proportion of the patients returned to work there was still good adherence to the telerehabilitation. This indicates the practicability of this program for patients of working age following a knee and hip replacement. Thus, in another study, good adherence to telerehabilitation for patients having undergone knee replacements could also be researched [17].

During the three-month investigation phase, a significant increase in the 6-minute walking distance was recorded in both

groups. For the population of knee and hip replacement patients, an improvement of 50-60 meters in the 6-minute walk test is considered clinically relevant [30]. The values at follow-up showed only small deviations from the normal values for healthy individuals, with 578 meters for men and 534 meters for women in the 50-60 years old age group [31], which shows that patients' functionality seemed to be largely restored four to five months post operation. Furthermore, the baseline values of the patients had already exceeded those of comparable clinical populations [30,32,33] and thus indicated a high initial level of physical performance. It is possible that patients had already improved their functionality in the inpatient rehabilitation to such a high extent that there was little potential for further improvement.

Consistent with the results of the 6-minute walking test, further functional mobility tests with significant improvements in both groups demonstrated the equivalence of the telerehabilitation. In the Five Times Chair Rise Test, the control group had a statistically significant and higher improvement, however, the difference between the groups was significantly below the clinically relevant value of 2.5 seconds [34], which relativizes the group difference despite its significance.

As for the WOMAC Index, values below 29.5 points are considered a treatment success for patients after a knee replacement [35]. The score achieved by the patients at baseline was already below this cut-off value. Furthermore, this value decreased significantly during the intervention phase in both groups and was below the postoperative WOMAC scores of comparable clinical populations [36-39].

For health-related quality of life, both groups achieved a significant increase on the physical component scale during the study phase. Against the background of the mainly physically oriented aftercare programs, this enhancement seems reasonable. However, despite the improvement, at the end of the intervention patients were slightly below the age-related normative values of 47-49 points, with an average of 44 points [40]. For the intervention period of three months, similar values can be found for patient populations after knee and hip replacement [32,33]. The results of the mental component scale did not change significantly for either group but were slightly above the norm of 48-50 points at the end of the intervention [40].

Although most of the investigated endpoints did not show the superiority of the telerehabilitation, a significantly higher proportion of the IG returned to work at the end of the three-month study period. However, this fact cannot be explained by improved physical performance, quality of life, or reduced joint-related complaints of the intervention group. It remains to be discussed whether the possibility of performing telerehabilitation regardless of time and place could have led to an earlier return to work by the IG. In addition, the high dropout rate of the control group (29.1%; 11/39) compared to the intervention group (14.1%; 7/48) should also be considered. Given the route to the study site, as well as the time of about two hours required for each baseline and follow-up investigation, there exists the possibility that the CG patients who returned to work were no longer willing to participate in the study.

Limitations

In the investigated sample, an above-average education level can be ascertained (43.5% with a polytechnic or university degree). Data from the Employment Agency in Germany shows that, in the total population, only 20% of gainfully employed individuals have a polytechnic or university degree [41]. Furthermore, the 5.4% unemployment rate of the sample should be classified as low compared to the 8.4% Berlin average [42]. In addition, a substantial proportion of patients came from Berlin and the surrounding countryside. Therefore, in this study, the access route to the study site that the patients had to traverse twice independently may have been an obstacle to the participation of patients from more distant, infrastructurally weak areas. Only a quarter of the screened patients participated in the study. Thus, the low participation rate and the discussed patient characteristics suggest a selection bias.

Another limitation of the study design is the lack of blinding of study participants and investigators. As a result, this is a possible influence on the participants during the investigations that cannot be excluded. It is known that nonblinded studies can demonstrate greater intervention effects than blinded ones [43].

All patients underwent inpatient rehabilitation and aftercare treatment. It is not possible to determine which improvements can be directly traced back to the effect of telerehabilitation, as due to ethical reasons the usual aftercare programs in this study were not replaced but instead complemented by the new approach.

Conclusion

The investigated telerehabilitation for patients having undergone knee or hip replacement was equivalent to the usual aftercare treatments in terms of improvements in the 6-minute walk test and in other functional parameters. However, at the end of the intervention, patients in the intervention group returned to work at a significantly higher rate. These results suggest that the system is complementary to the established aftercare programs in Germany (eg, IRENA or T-RENA), especially in infrastructurally weak areas.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1
CONSORT-EHEALTH checklist (V 1.6.2).
[PDF File (Adobe PDF File), 127 KB - rehab_v6i2e14236_app1.pdf]

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Abbreviations

ANCOVA: analysis of covariance
BMI: body mass index
CG: control group
HDMI: High Definition Multimedia Interface
IG: intervention group
IRENA: multimodal intensified aftercare
MERENA: medical rehabilitation aftercare
OECD: Organization for Economic Cooperation and Development
PCS: physical component scale
SF-36: Short Form Health Survey-36
T-RENA: training rehabilitation aftercare
TUQ: Telehealth Usability Questionnaire
WOMAC: Western Ontario and McMaster Universities Arthritis Index

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Original Paper

Analyzing the Communication Interchange of Individuals With Disabilities Utilizing Facebook, Discussion Forums, and Chat Rooms: Qualitative Content Analysis of Online Disabilities Support Groups

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Abstract

Background: Approximately 1 in 5 adults in the United States are currently living with a form of disability. Although the Americans with Disabilities Act has published guidelines to help make developing technology and social networking sites (SNS) more accessible and user-friendly to people with a range of disabilities, persons with disabilities, on average, have less access to the internet than the general population. The quality, content, and medium vary from site to site and have been greatly understudied. Due to this, it is still unclear how persons with disabilities utilize various platforms of online communication for support.

Objective: The objective of this study was to qualitatively explore and compare the interactions and connections among online support groups across Facebook, discussion forums, and chat rooms to better understand how persons with disabilities were utilizing different SNS to facilitate communication interchange, disseminate information, and foster community support.

Methods: Facebook groups, discussion forums, and chat rooms were chosen based on predetermined inclusion criteria. Data collected included content posted on Facebook groups, forums, and chat rooms as well as the interactions among group members. Data were analyzed qualitatively using the constant comparative method.

Results: A total of 133 Facebook posts, 116 forum posts, and 60 hours of chat room discussions were collected and analyzed. In addition, 4 themes were identified for Facebook posts, 3 for discussion forums, and 3 for chat rooms. Persons with disabilities utilized discussion forums and chat rooms in similar ways, but their interactions on Facebook differed in comparison. They seem to interact on a platform based on the specific functions it offers.

Conclusions: Interactions on each of the platforms displayed elements of the 4 types of social support, indicating the ability for social support to be facilitated among SNS; however, the type of social support varied by platform. Findings demonstrate that online support platforms serve specific purposes that may not be interchangeable. Through participation on different platforms, persons with disabilities are able to provide and receive social support in various ways, without the barriers and constraints often experienced by this population.

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KEYWORDS

persons with disabilities; social media; social support; online social networking; internet; psychosocial support systems; qualitative research

Introduction

Overview

Currently within the United States, more than 20% of adults are living with some form of disability [1]. As defined by the Centers for Disease Control and Prevention, a disability is "any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions)" [1]. Although living with a disability can impact participation in many parts of your life, it does not prevent most persons with disabilities from participating in information sharing, participating in community engagement, and providing support on social networking sites (SNS). In fact, research suggests the use of SNS is generally high among persons with disabilities [2], which includes SNS such as online discussion forums, chat rooms, and Facebook.

With developing technology and SNS, the ease of communication has drastically increased over the last few years, and the internet has become an increasingly common platform for the formation of electronic peer-to-peer, or online, communities [3,4]. Online communities are social networks formed or facilitated by means of a technical platform (eg, Facebook, discussion forums, and chat rooms) through which groups of people with similar interests can establish social relationships and connect and interact with one another [3,5]. Through the development and utilization of online communities, we have seen a shift in the way social support is sought, organized, and communicated, resulting in online communities that function similarly to physical, or in-person, communities [6,7].

Social Support and Online Communities

Social support is a theoretically complex and multidimensional construct that is often defined as the "aid and assistance exchanged through social relationships and interpersonal transactions" [8-10]. Although in-person social support has been of interest to researchers for several decades, a shift toward investigating and understanding social support in an online context has begun to occur. Online social support has been defined as the internet-facilitated receipt of both tangible and intangible assistance from people in one's social network [6,11]. Numerous studies have found that online communities provide a platform for social support to be communicated [4,5,12-14] and that similar types of social support found in offline settings also exist in online contexts [4,6,13,14].

Social support, whether in-person or online, can generally be divided into structural and functional aspects [6,15,16]. Structural aspects include the extent to which individuals are situated within or integrated into social networks. This can be the size and structure of a social network, such as density and composition, social integration, or embeddedness [15,17-19]. Functional aspects include the psychological and material resources available from an individual's interpersonal relationships. Functional aspects refer to the types of social support, such as esteem and emotional, informational, instrumental support, and belonging [4,6,9-11,15,17-19]. Definitions for each type of social support can be found in Table 1. The provision of social support is considered one of the important functions of social relationships [9,10], which can be measured by structural support, functional support, or a combination of both.

Table 1. Social support types and their accompanying definitions.

Type of social support	Definition
Esteem and emotional support	Communications from others that convey being held in high esteem, offering help with one's emotional state, or expressing acceptance, caring, liking, respect, concern, empathy, or sympathy [6,9,10,19,20]
Informational support	Offering help in the form of advice, constructive feedback or affirmation, new information or perspectives, or references to new resources [6,9,10,19,20]
Instrumental support	Provision of tangible aid and services, such as offering financial aid, providing material resources, or taking on a responsibility [6,9,10,19]
Belonging support	Conveys a sense of social belonging and having others to engage with in shared social activities [6,9]

The benefits of social support have been repeatedly affirmed in the literature [13]. Social support has been associated with predicting and promoting good physical and mental health, reducing and preventing illness, moderating life stress, and improving quality of life [8,15,17,18,21]. In general, however, persons with disabilities are more likely to have limited access to social support and its benefits. They may experience a lack of access to social support because of misconceptions about disabilities, stigma surrounding disability, feelings of embarrassment or social isolation, and physical barriers [16,22]. The internet could circumvent these barriers by providing a useful alternative for persons with disabilities to access social support and interact in a way that may not be possible offline [13,14,22]. Due to the availability and proliferation of online communities, a new outlet for social support can be accessed. Persons with disabilities can utilize the internet's extensive communication capabilities to access information and develop online support groups with other persons with disabilities through online platforms [13,22]. The formation of these groups may not only offer support and community-building but also link users to an increasing amount of resources, knowledge,

services, shared experiences, and social exchanges [3-5]. In addition, computer-mediated environments afford them the ability to break down physical and geographic barriers to participation, including the constraints of time and distance, which might otherwise exist [16,23].

Objective

Although it is known that persons with disabilities utilize SNS [2], it is still unclear how they utilize the various forms of online communication for support. There is a lack of research qualitatively assessing the interactions occurring among individuals within these online communities as well as the variation of quality and content from site to site [13]. With the rise in popularity of online support groups and the ever-changing nature of the internet, there is a need to explore the experiences of persons with disabilities in various supportive communication settings. The objective of this study was to explore and compare the interactions and connections among online support groups to understand how persons with disabilities are utilizing different SNS to gather and disseminate information and foster community support. Specifically, 3 SNS were selected for comparison: (1) Facebook groups, (2) online discussion forums, and (3) online chat rooms. These platforms were selected because of their popularity as platforms for the formation of online support group communities [3,5,14,20]. All 3 platforms offer users distinct environments for various types of social support to be exchanged. In addition, social support has been shown to exist among each of these online platforms to some degree [4,5,18,20].

Methods

Description of Social Networking Sites

Due to its popularity and accessibility, Facebook has become a common platform for the organization of online support groups [24]. Facebook offers both synchronous and asynchronous features to its users, such as the ability to react to, comment on, or share a post. Compared with online discussion forums and online chat rooms, Facebook is a less anonymous platform. Although the use of Facebook as a means for Web-based interaction has increased in popularity over the past decade, online discussion forums are still regularly used by approximately 20% of online users in the United States [25]. Discussion forums are an asynchronous communication platform whereby one person writes a post which is then answered by other members, thus creating a thread of posts related to one subject [14]. Discussion forums are a common platform for online support groups. They have been shown to be a useful source of support [14,25] and to be helpful to users because they can provide connections to others with similar experiences [26]. Online chat rooms that cater specifically to persons with disabilities also exist [22]. Chat rooms are a synchronous form of communication, that is, communication occurs in real time, and simultaneously, between users. Both discussion forums and chat rooms afford their users anonymity [25].

Data Collection

The study was approved by the Institutional Review Board of the University of Florida. During the approval process, the information being obtained for this study was deemed *public record* and, therefore, exempt from informed consent. All data were deidentified before being analyzed by the researchers.

Facebook Groups

General disability support groups were targeted for the study to increase the generalizability of the information posted. These were groups that did not identify themselves for a specific disability (ie, epilepsy and multiple sclerosis). The term *disability support group* was searched using the Facebook search bar function. The Facebook groups had to have at least 6 months' worth of data to collect to be included in this study.

In total, 3 disability support groups on Facebook were initially identified according to group type (general disability support group) and group size. Names of the specific groups have not been included to protect all individuals' identities. Upon review of the identified support groups, only 1 group fully met our inclusion criteria of having at least 6 months' worth of data to collect. Therefore, the other 2 groups were excluded from this study. The included Facebook group had 11,765 followers at the time of the study and was an online support community for anyone who had a disability or supported someone with a disability. Screenshots of posts, comments to posts, and reactions on posts were captured to assist with analyses. After 6 months' worth of data were collected retrospectively, there were a total of 133 Facebook posts, all of which were analyzed. All postings were deidentified to protect participants' identities.

Discussion Forums

The discussion forums were selected through the Google search engine using the keywords *disability* and *disability support group*. The discussion forums had to be publicly available and have active discussion to be included in the study. Out of the 4 discussion forums initially identified, only 2 met the inclusion criteria. There was no set time period for data collection from the forums. Discussions from the designated forums were chosen based on high activity levels. Discussions from the forums were copied and pasted verbatim for analysis. A total of 116 discussion forum posts were collected and analyzed. All postings were deidentified to protect participants' identities.

Chat Rooms

Similar to the discussion forums' selection, online chat rooms were chosen through the Google search engine using the keywords *disability* and *disability support group*. Chat rooms had to be publicly available and have active participation to be included in the study. A total of 2 chat rooms were selected, both meeting the inclusion criteria. It was predetermined by the researchers that a minimum of 60 hours of live session chat room data should be collected. Chat room data were collected during live sessions at various times on weekdays (Monday through Friday) and weekends (Saturday and Sunday) to ensure that all forms of conversations and all active participants were captured in the data collection process. To capture an accurate representation of communications occurring among chat room users, the researchers collected live session chat room data at different times of the day: 20 hours of data were collected in the morning (8:00 am-11:00 am) and early afternoon (11:00 am-1:00 pm); 20 hours of data were collected in the midday

(1:00 pm-4:00 pm) and evening (4:00 pm-9:00 pm); and 20 hours of data were collected at night (9:00 pm-12:00 am). Each of these time points were collected on each day of the week. Discussions from the online chat rooms were copied and pasted verbatim for analysis. All postings were deidentified to protect participants' identities.

Data Analysis

The constant comparative method was used to analyze the content from the Facebook support group, discussion forums, and chat rooms to reduce the data into manageable units and coded information [27-29]. To begin this process, trained researchers independently open-coded the Facebook posts (AJ and JQ) and the discussion forum and chat room posts (AV and MA). Open coding has been defined as "the process of breaking down, examining, comparing, conceptualizing, and categorizing data" [27-29]. Upon completion of open coding, major themes and subthemes were carefully and purposefully developed from these codes for the Facebook, discussion forum, and chat room posts. Coding was continued until saturation of the data was met and no new themes emerged [27-29]. To accurately represent the discussions persons with disabilities had on each platform, the information users posted was not fact-checked by the researchers. This was decided as acceptable by the researchers because of the focus of this study being on the content of what was being posted and shared and the ways persons with disabilities utilized platforms, not on the accuracy of what was being posted.

Results

Facebook Support Group

All Facebook support group posts were deidentified, and no user names were included. Instead, quotes are presented as blockquotes with the participant identifier as [User post] after the quoted text to indicate an original comment. Quotes taken from the Facebook support group underwent minor modifications, such as corrections to spelling or grammatical errors and removal of explicit language. The researchers decided to modify posts in this way to enhance readability of the posts, alleviate any confusion to the reader, and protect the privacy of all users. Quotes were only modified as long as the context of the post did not change.

Among the 133 posts analyzed, the constant comparative method revealed 4 major themes, as displayed in Textbox 1. The 4 themes that emerged through analysis of the Facebook support group included mutual and shared experiences, societal concerns, awareness, and health care policy (Textbox 1).

Textbox 1. Disability support group themes from Facebook, discussion forums, and chat rooms.

Themes:

Online platform: Facebook

- Mutual and shared experiences
- Societal concerns
- Awareness
- Health care policy

Online platform: discussion forums

- Emotional outlet and support
- Health
- Quality of life

Online platform: chat rooms

- Emotional outlet and support
- Health
- Quality of life

Mutual and Shared Experiences

Mutual and shared experiences' posts centered on participants sharing details regarding their own disabilities and personal stories. This was often as a way to inspire, motivate, and relate to others. The following is an example of 1 of these posts by a Facebook group member:

> *Just wonder of those disabled out there, are there others like me that only a few select family members support you? I have a spouse that has no compassion for me. Expects me to do everything, feels I am lazy, not in any pain! He resents the fact I receive benefits and don't work. I'd give just about anything if I wasn't ill and had no pain. I am looking for friends that know how I feel.* [User post]

People often responded with comments about how they are experiencing or have overcome a similar situation. Although not as frequent, some members posted on the Facebook group asking for support through sharing GoFundMe pages or similar financial support pages.

Societal Concerns

Posts classified under societal concerns included participants expressing their concerns regarding society's interactions with their disability. Group members posted about concerns or excitement they had regarding inclusivity and accessibility in society:

> *I agree with you 100%. It's the barriers we encounter through life. I never had trouble with kids as a child. But was segregated from things due to lack of access. Today it's better as far as schools and public buildings. It has a long way to go. I encounter many places that I STILL cannot get in the bathroom or even the building. The American Disability Act exists here for that. But it is not enforced.* [User post]

Awareness

Awareness posts focused on events, helpful tools, and current research that could increase participants' awareness about happenings in the disability community. The Facebook group allowed for the dissemination of content to raise awareness about several topics. For example, information about various types of disabilities was shared to inform people of technology they might not have heard about otherwise, often in the form of Web-based articles or news articles. Some of the posts and articles about technology included *No tie shoelaces for people with Autism or special needs*, *First paralyzed human treated with stem cells has now regained upper body movement*, and *The benefits of online therapy if you have a disability*. Relevant information about current research studies, prosthetics, and articles and videos about new types of treatments for persons with disabilities was also shared to increase awareness and knowledge of group members.

Health Care Policy

Health care policy posts in the Facebook support group voiced concerns regarding the impact of health care policy changes for persons with disabilities and current policy implementation in the United States. Many posts discussed implications for proposed policy changes to health insurance and other health care–related policies. In response to their concerns, members of the support group offered information and resources about Medicare and Medicaid to members in need. For example, 1 user posted a short explanation about how to lower the amount you are paying for Medicare:

> *To date, between 300 and 500 folks who were members and/or recently joined the Disability Digest have requested help with their Medicare Plans. It is estimated that their savings will be between $144,000 and $244,000 over the next year because they took advantage of our free health care consultation, with our health care experts. Now isn't that a nice piece of change. The average savings per person is $40.00 a month, simply by getting into the correct Medicare Plan.* [User post]

Other common concerns that were shared and posted by group members involved government funding cuts and the current political administration.

Online Discussion Forums

All posts from the online discussion forums were deidentified, and no user names were included in this paper. Quotes are presented as blockquotes with the participant identifier as [User post] after the quoted text to indicate an original post by a forum user. The same steps taken for the modification of Facebook posts were also taken for the modification of discussion forum posts. From the 116 discussion forums posts analyzed, 3 major themes were revealed: emotional outlet and support, health, and quality of life (Textbox 1).

Emotional Outlet and Support

The theme of emotional outlet and support was characterized by participants using connections provided through the forums for social support, advice seeking, and expressing emotions. Forum members posted about psychological stress and emotions and often received feedback and advice from others. For example, 1 member used a discussion forum as a space to express their process of self-realization to other members:

> *People that have dealt with difficulties are thought to be more compassionate and have empathy for those difficulties. I'm finding myself that in many ways this isn't really true. I'm learning that I can share my experiences and listen. It's not my job to fix their problems.* [User post]

This theme was also characterized by participants seeking everyday support through small talk with other forum members:

> *One thing I've found about [this forum] is that I can have a disagreement with another member and yet still remain friends. We can still give support to each other joke around together. This a very special place I'm thankful for it.* [User post]

Health

The theme of health can be described as participants utilizing the online discussion forum to share any physical, mental, or health care–related stories. It was common for forum users to post about their specific disability and the symptoms they experience. Many users were shown discussing health by describing their medical interactions. Medical interactions ranged anywhere from their disability diagnosis by a professional to symptom management. In the forums, participants also shared their personal medical diagnosis stories. For example, 1 user described their injury and disability sustained from a drunk driving incident:

> *I have four TBI [Traumatic brain injury] PTSD, herniated disks throughout my back and most of my neck. Alone with a variety of knee & hip injury. The joys of being hit by a drunk driver.* [User post]

In addition, many users mentioned mental health and mental illness in their posts. These posts comprised mental diagnosis disclosure, the emotions associated with such diagnoses, and seeking support from others with similar mental health experiences:

> *Well I have a learning disability (idk which one) along with depression, self-harm, and suicidal thoughts,*

> *and I been to a mental hospital twice…so that's my junk I got to deal with…may I ask what disabilities you guys have? I'd like to know if anyone on this site is going through similar things. you don't have to answer of course.* [User post]

Quality of Life

Discussion forum members posted on discussion boards about their perceived quality of life and how their disabilities affected their day-to-day lives in both positive and negative ways. Quality of life was shown to be influenced by perceptions about discrimination, accessibility and technology, family and relationships, and participation. One of the most common areas discussed was on discrimination. Participants posted about how acts of discrimination (ie, harassment or injustices done to persons with disabilities) and discrimination in community spaces (ie, neighborhoods, churches, and governmental agencies) could negatively impact an individual's quality of life:

> *One day a female carrier and myself was in a discussion about school. She asked me about my income. I told her I don't talk about with people because it's no one's business. She said it was her business because she works for the USPS. I told her in very unclean language how I see that, and left. She started mishandling my mail, so I filed for grievance.* [User post]

Forum members also shared about how accessibility could be positive or negative. Structural and environmental changes to make places more accessible for persons with disabilities were perceived as positive, but the lack of accessibility in most places was perceived as negative:

> *I am lucky enough to have moved in when the big adaptations were in place. I am extremely grateful for a fabulous wet room that I can access even on a wheelchair. The only addition made to this after I moved in was a "BIO BIDET", this is a godsend for me with the personal problems I have, the simple act of being able to attend to your own toilet needs is a great boost to one's self esteem.* [User post]

In addition, discussions forums were used as a way to share information with persons with disabilities about opportunities to participate in various activities and hobbies, such as jobs, sports, or entertainment, illustrating a willingness to help one another.

Online Chat Rooms

The same steps taken for the modification of Facebook posts were also taken for the modification of chat room posts. In addition, for chat rooms specifically, it was common for multiple conversations to be going on at once. To eliminate confusion, the researchers deleted any comments not relevant to the ongoing conversations. Quotes from the online chat room data presented in this section are accompanied by anonymized identifiers. These were created to protect the identities of users.

From the 60 hours of data collected from the 2 online chat rooms, 3 major themes emerged: chat room interactions for emotional outlet and support, health, and quality of life (Textbox 1).

Emotional Outlet and Support

The theme of emotional outlet and support was characterized by chat room conversations where participants sought social support and interactions for physical, mental, and environmental struggles from other participants. The chat rooms served as spaces for participants to vent to one another, share feelings of distress and coping mechanisms, and receive feedback and advice from others when solicited. Moreover, they offered spaces for support through small talk and member interactions. Participants engaged in exchanges with other members by sharing information regarding everyday life, such as this interaction in one of the chat rooms seeking experiential advice about finding a job as a persons with disabilities:

> *Did you have a bad experience trying to find a job?* [User A]
>
> *I was being thrown many curved balls* [User B]
>
> *That with determination* [User B]
>
> *Sometimes people take my kindness as a weakness and they get surprised* [User A]
>
> *It can be done* [User B]
>
> *Some people do use people's kindness to gain from* [User B]
>
> *Especially the people around my neck of the woods, give them an inch and they take a lightyear* [User C]
>
> *Yeah I admit I lost a lot of my confidence when I became disabled, but just running this household I am getting it back* [User A]

Health

The theme of health in online chat rooms was characterized by participants posting their daily physical, medical, and mental signs and symptoms of disabilities as a way of sharing their health experience with other users. Participants engaged in the online chat rooms by describing their specific disability, the symptoms associated with it, the way they managed their symptoms, and their interactions with medical professionals. The discussion below demonstrates the back-and-forth between users about their disability stories:

> *Are you disabled User E?* [User D]
>
> *Yup, multiple spinal diseases* [User E]
>
> *Sorry to hear* [User D]
>
> *I have crushed spinal cord* [User D]
>
> *No problem had quite a while to get used to it, its degenerative and very painful* [User E]
>
> *Try and stay happy lol* [User E]
>
> *You will get comfortable here…I have degenerative bone disease as well, in feet and moving up* [User F]
>
> *Accentuate the positive…* [User G]
>
> *Mine was lower back to start with affecting my legs & feet but now it's in my neck causing problems with my arms & hands* [User E]

Mental health was another popular discussion topic among persons utilizing chat rooms, especially participants' personal experiences with diagnosis, how their illness affected them, and coping mechanisms they use. This excerpt from a chat room exemplifies how users discussed mental health with one another:

> *I will admit I planned my funeral* [User B]
>
> *Some things that went through my head omg* [User B]
>
> *Still gets scary when legs you count on don't respond to input* [User D]
>
> *Then you try hard to find comfort in routine and become dependent on what you expect to go smoothly as every other day but get hit with a sudden jolt and it wrecks your nerves and throws off your balance* [User C]
>
> *I call them curved balls* [User B]
>
> *But I think, why was that thrown at me* [User B]
>
> *Was having a good month so far then WHAM my bank account got hijacked* [User C]

Quality of Life

Quality of life chat room discussions centered around the individual's perception on how disabilities positively or negatively affected their day-to-day life. Factors contributing to quality of life included jobs, finances, medical coverage, social support (eg, family and relationships), daily struggles, and issues regarding environment and accessibility. For instance, 1 chat room conversation was centered around an individual's struggles with Medicare, prescriptions, and lack of information:

> *My Medicare keeps getting hacked for prescriptions, I have no idea how they get it but I have had several scripts filled in my name in Charlotte for different types of pain medication and Adderall* [User A]
>
> *It's odd they are hitting small amounts* [User C]
>
> *They do that* [User B]
>
> *Damn that's horrible* [User C]
>
> *Hoping you don't notice* [User B]
>
> *Scammers everywhere, but I still see the good in mankind* [User B]
>
> *Well no one is doing anything about it, you need valid ID in NC to pick them up, but maybe they are fake, they tell me nothing. I just have to deal with it every time my doctor checks my records so he can fill mine* [User A]

Relationships were another aspect of quality of life that users were willing to disclose and discuss, often seeking counsel or solace:

> *Hey all, needing some help processing something at the moment. Not sure if this is the best place for this but here it goes. I found out today that my husband has been cheating. Any married gays out there with words of support?* [User H]
>
> *Chop his *explicative* off* [User I]
>
> *I don't really know what there is to say. But sitting thinking about it hasn't been productive for me* [User H]
>
> *Collect proof first, without letting on that you know* [User K]

Especially among participants in the chat rooms, personal information regarding family, relationships, and significant others was shared. Chat room members expressed how certain factors relating to family, relationships, and significant others influenced their quality of life.

Discussion

Principal Findings

In this study, we explored the ways in which online communities were utilized by persons with disabilities to facilitate communication interchange, disseminate information, and foster community support. The results indicate that persons with disabilities are utilizing the 3 platforms for various interactions (Table 2 and Textbox 2). On the basis of the findings of this study, the medium with which the individual is interacting (eg, Facebook, discussion forums, or chat rooms) influences the individual's interactions. They are likely intentionally choosing to interact on a platform based on the functions it offers. It is possible that specific platforms serve specific purposes that may not be interchangeable [25].

Table 2. Differences between how persons with disabilities used the 3 social networking sites.

Differences across platforms	Social networking site		
	Facebook	Discussion forums	Chat rooms
Type of social support	Informational, esteem and emotional, and instrumental	Informational, esteem and emotional, and belonging	Informational, esteem and emotional, and belonging
Format	Structured	Less structured and informal	Less structured and informal
Topics of discussion	News stories, raising awareness, and advocating for persons with disabilities; very little mention of mental health	Advice seeking, emotional processing and stress relief, and day-to-day experience of living with a disability; almost daily discussions of mental health	Small talk, emotional processing and stress relief, disability disclosure, and day-to-day experience of living with a disability; almost daily discussions of mental health
Familiarity with group members	Little sense of familiarity among members	Some sense of familiarity among members	Greatest sense of familiarity among members
Depth of content	Surface level sharing	Surface level to medium-depth sharing	In-depth sharing
Type of interactions	Mostly positive responses	Mostly positive responses with some negative responses	Positive and negative responses
Personal identifiers	Information shared and discussed was linked to personal Facebook accounts	Anonymous	Anonymous

Textbox 2. Similarities between how persons with disabilities used the 3 social networking sites.

Similarities across all platforms:

- Members both request and provide information
- Members sympathize with one another
- Support through shared experiences
- Platforms serve as safe spaces for sharing among members
- Functional social support present among each type of social networking site

The Facebook support group for persons with disabilities emphasized mutual and shared experiences, societal concerns, raising awareness, and concerns about health care policy in the United States. People in the Facebook group seemed willing to be somewhat vulnerable within this online community setting, sharing stories of personal distress, independence, and support (or lack thereof); however, interactions within the Facebook group appeared much more structured and superficial than discussion forums or chat rooms (Table 2). The perceived injunctive norms might contribute to the structure and superficiality among Facebook support groups [30,31]. In addition, the Facebook group provided a safe space for users to respond to news stories and articles about abuse, violence, and discrimination against persons with disabilities as well as share their concerns or excitement regarding inclusivity and accessibility in society (Table 2 and Textbox 2). It is possible that this platform allows people to share about certain topics without fear of criticism, negativity, or backlash from others. This may not be the case if one of them were to post similar content on their personal Facebook timeline.

The most common forms of interaction between members of the Facebook group included requesting and providing information, sympathizing with other users, raising awareness and advocating for persons with disabilities, and generating support through shared experiences and concerns (Table 2). The interactions between members correspond to both informational and esteem and emotional social support (Table 2). These findings align with research conducted by Mustafa et al [24] who found that Facebook support groups for parents with Autism Spectrum Disorder were commonly used for informational support, emotional support, and sharing of personal experiences. The findings are also in line with a different study, which found that Facebook, as an SNS, was an online environment well suited for the exchange of informational support [20]. Although not as common, instrumental support was sought by some Facebook group members. This was exemplified by members sharing their financial support pages, most likely as a request to receive instrumental support from the online community (Table 2).

In comparison, the interactions within online discussion forums and chat rooms were less structured than the Facebook support group and more similar in the way persons with disabilities utilized them (Table 2). The same 3 themes emerged in both the platforms: emotional outlet and support, health, and quality of life. Both platforms were most commonly used as venues for persons with disabilities to relieve psychological stress, express themselves emotionally, and share and vent about their experiences in hopes of receiving positive support, feedback, and relief from others (Table 2). Members seemed especially grateful for the existence of a safe space where mundane,

everyday interactions could take place, and yet, the individuals still felt a sense of belonging and support by their community (Table 2 and Textbox 2). Although both platforms exhibited interactions characterized by members responding both positively and negatively to others, these types of interactions were most common among online chat room users (Table 2). These interactions seemed accepted, and expected, by members of the chat room, exemplifying a comfort among chat room users to offer support in the most candid ways possible. This familiarity seemed to encourage real and honest connections between users, similar to a group of tight-knit friends (Table 2). These findings demonstrate the existence of esteem and emotional, belonging, and informational social support among discussion forums and chat rooms (Table 2).

Interactions in discussion forum and chat room settings are anonymous, a feature that has been found to be valuable to persons with disabilities on these platforms [14,23,25,32] (Table 2). Anonymity is not a feature of Facebook, as your profile is linked to your name and usually includes a picture of yourself (Table 2). It is possible that interactions are more candid and unstructured among forums and chat rooms because of the comfort and protection anonymity can provide for users [14,16,25,32]. This could also explain the prevalence of discussions surrounding mental health issues on both forums and chat rooms and the lack of such discussion on the Facebook group (Table 2). Members of the forums and chat rooms mentioned their experiences with mental health almost daily, whereas members of the Facebook group seldom posted about mental health and mental illness (Table 2). Mental health and mental illness discussions were most prevalent among chat room users compared with any of the other support groups.

In general, chat room discussions of mental health and mental illness were more in-depth and descriptive, with participants offering more personal details (Table 2). Participants logged into the chat room would respond to others in supportive, consoling ways and attempt to offer helpful advice to disclosing users. Discussion forum posts were more surface-level in their discussion of mental health and mental illness, with participants offering little insight into their own personal experiences (Table 2). Facebook group posts were mostly aimed at spreading awareness as opposed to disclosing one's own personal experience with mental illness (Table 2). These findings suggest that a safe and anonymous online environment might help facilitate engagement in discussions about commonly stigmatizing and taboo topics.

Limitations

This study is not without limitations. First, the data are subjective based on the researchers' interpretations, as is the nature of qualitative research. The importance of using qualitative methods for this study, however, should not be understated. The content gained from a qualitative process provides a more in-depth and nuanced understanding of how Facebook support groups, discussion forums, and chat rooms are used by persons with disabilities. Although qualitative studies are relevant and important in their own right, quantitative research is also necessary as a next step. Future research could investigate how the effectiveness of online social support can be maximized for persons with disabilities. Second, as only 1 Facebook online support group was analyzed in this study, we cannot generalize these findings to all support groups on Facebook. Discussion within this Facebook group was not necessarily encouraged between members, which might indicate a more passive approach to participation among Facebook support group users. This could potentially limit the usefulness of support offered through this domain or influence the type of support that is perceived or received. It is possible that users seek out support groups on Facebook because of this type of participation; however, further research is required to understand how and why users seek out certain forms of online support and the roles active and passive participation play in the overall perception and reception of social support. Third, because of the predetermined date constraints and the difficulty collecting data from live chat rooms, only a few groups for each type of SNS were analyzed and compared. As this was a pilot study, the number of groups per SNS needed for the researchers to capture a snapshot of what was occurring in online disability support groups was small. In the future, more groups should be analyzed and compared to enhance the explanatory power and generalizability of the study. It might also be important to investigate online social support among SNS groups as it relates to specific disabilities. Future studies could compare online support groups among these 3 SNS by type of disability to understand the similarities and differences of how individuals with varying disabilities interact. This could provide an even more nuanced understanding into the ways SNS are used for social support by persons with disabilities.

Implications of Findings

This study allows us to focus on and determine beneficial ways to incorporate SNS into treatment, foster social support, and develop awareness among the community of persons with disabilities. Future directions highlight the potential to intervene with this population through social network mediums. Future interventions can be developed utilizing Facebook, discussion forums, and chat rooms as mediums, depending on the desires and needs of the population of persons with disabilities. Moreover, the reach of these Web-based interventions and groups can be easily assessed because of increasing ease of access to the internet.

Online support groups are not bounded by space constraints. They are a medium where perspectives, experiences, and viewpoints are welcomed, and diversity is encouraged, while also promoting a feeling of universality among members [32]. Online support groups offer the ability to increase support for persons with disabilities while simultaneously breaking down the geographic, transportation, and stigmatizing barriers this population faces. Facebook support groups, discussion forums, and chat rooms represent 3 unique platforms where social support can be facilitated via social networks. Interactions on each of the platforms displayed elements of each of the 4 types of social support (esteem and emotional, informational, instrumental, and belonging; Textbox 2) [6,9], indicating the ability for social support to be facilitated among SNS.

As social support is being provided (in varying ways) on each of the online platforms studied (Table 2 and Textbox 2), it is

important to understand how online social support might influence the health and well-being of persons with disabilities. Online social support has been suggested to have similar benefits to those of in-person social support, including benefits to health and well-being [6,16,18,25,33]. Disability research has shown that social support has the ability to either alleviate or exaggerate disability symptoms depending on several factors [34]. According to the 3 theoretical models of social support [9,10], social support can influence health in many ways. As the nature of the study was qualitative, we could only speculate how the interactions of persons with disabilities via these platforms might have positively influenced their health.

The stress prevention model posits that social support may provide an individual with resources to avoid or reduce exposure to certain stressors. Reduced exposure to stressors, in turn, is associated with enhanced health [9,10]. Through the facilitation of social support among online communities, group members may be able to provide other persons with disabilities with the resources they need to avoid or reduce their exposure to some types of stressors. This could be by influencing cognitive processes, encouraging proactive coping, or decreasing exposure to secondary stressors [9]. There is also the stress buffering model, which proposes that social support can act as a stress-buffering agent. In this model, social support provides resources that help an individual appropriately cope with stress, which buffers the association between stress and health-related outcomes [9,10,15]. The provision of social support from online support group members could enhance one's coping resources and interpretation of their stressful situation, thus weakening the harmful effects of stress on health and well-being [9,15]. Finally, the direct effect model suggests that social support is effective in a more general sense, regardless of stress. This model is concerned with the ways in which membership in a social network and an individual's sense of connection has an overall beneficial effect on their well-being, health, and health-related outcomes [9,10,15]. By being a member of an online support group, persons with disabilities might have, overall, a greater sense of connection and feel cared for and supported by others [9].

SNS allow persons with disabilities to mobilize social support in ways similar to traditional offline settings and in ways that are unique to online contexts. As social platforms continue to develop, grow, and evolve, they have the potential to help reduce, and possibly eliminate, many of the barriers to social support experienced by persons with disabilities. In doing so, these platforms could have lasting impacts on both their health and well-being.

Conflicts of Interest

None declared.

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Abbreviations

SNS: social networking sites

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Original Paper

A Collaboration Between Game Developers and Rehabilitation Researchers to Develop a Web-Based App for Persons With Physical Disabilities: Case Study

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Abstract

Background: Individuals with a disability and their partners, who often provide care, are both at risk for depression and lower quality of life. Mobile health (mHealth) interventions are promising to address barriers to mental health care. Rehabilitation researchers and software development researchers must collaborate effectively with each other and with clinical and patient stakeholders to ensure successful mHealth development.

Objective: This study aimed to aid researchers interested in mHealth software development by describing the collaborative process between a team of rehabilitation researchers, software development researchers, and stakeholders. Thus, we provide a framework (conceptual model) for other teams to replicate to build a Web-based mHealth app for individuals with physical disability.

Methods: Rehabilitation researchers, software development researchers, and stakeholders (people with physical disabilities and clinicians) are involved in an iterative software development process. The overall process of developing an mHealth intervention includes initial development meetings and a co-design method called design box, in which the needs and key elements of the app are discussed. On the basis of the objectives outlined, a prototype is developed and goes through scoping iterations with feedback from stakeholders and end users. The prototype is then tested by users to identify technical errors and gather feedback on usability and accessibility.

Results: Illustrating the overall development process, we present a case study based on our experience developing an app (SupportGroove) for couples coping with spinal cord injury. Examples of how we addressed specific challenges are also included. For example, feedback from stakeholders resulted in development of app features for individuals with limited functional ability. Initial designs lacked accessibility design principles made visible by end users. Solutions included large text, single click, and minimal scrolling to facilitate menu navigation for individuals using eye gaze technology. Prototype testing allowed further refinement and demonstrated high usability and engagement with activities in the app. Qualitative feedback indicated high levels of satisfaction, accessibility, and confidence in potential utility. We also present key lessons learned about working in a collaborative interdisciplinary team.

Conclusions: mHealth promises to help overcome barriers to mental health intervention access. However, the development of these interventions can be challenging because of the disparate and often siloed expertise required. By describing the mHealth software development process and illustrating it with a successful case study of rehabilitation researchers, software development researchers, and stakeholders collaborating effectively, our goal is to help other teams avoid challenges we faced and benefit

from our lessons learned. Ultimately, good interdisciplinary collaboration will benefit individuals with disabilities and their families.

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KEYWORDS

spinal cord injury; software design; interdisciplinary health team; rehabilitation; internet

Introduction

Background

Individuals with disability, including spinal cord injury (SCI), traumatic brain injury, and stroke, are at greater risk for mental health issues such as anxiety and depression compared with the general population [1-3]. Yet, findings across the literature consistently document low rates of mental health treatment in these groups. Major barriers exist in accessing effective treatments, including the availability of cost-effective, accessible, and affordable interventions, particularly in more rural areas where transportation barriers may exist [4]. As such, there is a call for improving access, cost, and effectiveness of treatment for individuals with physical disability [5,6].

Mobile health (mHealth) interventions, defined by the World Health Organization as "medical and public health practice[s] supported by mobile phones, patient monitoring devices, personal digital assistants, and other wireless devices," offer a promising means to overcome many barriers to treatment, including affordability, access, and convenience [7,8]. For example, several mHealth interventions have been developed to provide support for self-management and address physical and psychological needs for individuals with a variety of chronic conditions, including diabetes, depression, and chronic pain [9-14].

Despite the promise and proliferation of mHealth interventions, there is often little attention paid to the design of mHealth tools and apps; the design can be critical to the usability and success of interventions [15]. Research teams interested in pursuing development of mHealth apps may lack critical knowledge of the software development landscape and have limited understanding of how to promote optimal app design [16]. In addition, they may struggle with accessing software developers familiar with the complexities of mHealth, engaging the research population, identifying underlying clinical or research goals, and addressing ethical and legal considerations. Although researchers are well trained in the development of high-quality evidence-based interventions, mHealth apps that fail to address issues of usability and the needs of the target audience will have limited applicability [17].

Although mHealth design can be challenging for the general population, more specialized mHealth solutions may be required to address the unique usability needs of persons with physical limitations, compounding the difficulties. For example, mHealth apps should be compatible with consumer off-the-shelf technologies that support communication limitations, such as eye gaze devices, which is not a standard integration. *Universal design* guidelines and *accessibility-based* approaches have drawn much-needed focus on providing access to technology for individuals with disabilities. However, these frameworks are not sufficient and could even be counterproductive; the inherent variability in needs makes it difficult and unrealistic to develop products for every user. Instead, developers may create products for *average* user accessibility needs, which may further marginalize individuals with disability. Although compliant with accessibility guidelines, resulting products may not be usable by the specific intended audience [18]. Building on universal design approaches, Newell [18] proposed a *user-sensitive inclusive design*, which incorporates a user-centered approach and emphasizes working with target audiences to better understand and design for specific needs. Our framework expands on the user-sensitive inclusive design by emphasizing the relationships between software developers, rehabilitation researchers, and stakeholders as partners to effectively use technology to deliver evidence-based interventions addressing key needs. A user-centered approach and iterative design process are critical to supporting the needs of persons with a variety of disabilities [19], affecting both the efficacy of the intervention and the effective use of the mHealth technology. As such, involving the unique expertise held by rehabilitation researchers, software development researchers, and clinician and patient stakeholders at every stage of the design is critical for success.

Without a shared understanding between siloed areas of expertise, a variety of pitfalls can occur. Teams can experience frustration and conflict, deadlines can be missed, and unexpected costs can be incurred. This is particularly true when collaborators are in different types of institutions, for example, universities and private companies. Ultimately, an ineffective relationship between rehabilitation researchers, software development researchers, and stakeholders can and frequently does lead to the development of mHealth apps that do not meet the needs or standards of one or more of these groups. Poor design choices that fail to meet the requirements of the end user, lack positive user engagement, or do not demonstrate evidence of efficacy will be misused or underused and ultimately fail to meet their original objectives [20]. The proposed solution for these pitfalls presents itself in a collaborative partnership, in which rehabilitation researchers, software development researchers, and stakeholders are aware of each other's goals and expectations and can communicate more effectively. In this way, an idea can successfully become a tangible product.

Objectives

The objective of this study was to describe the collaborative process between a team of rehabilitation researchers, software development researchers, and stakeholders with unique areas of expertise. We provide a framework to guide the creation of a Web-based mHealth app intended for individuals with physical disability. We first describe the overall process used for app

development and then present a case study to describe our specific experience.

Methods

Participants and Team Members

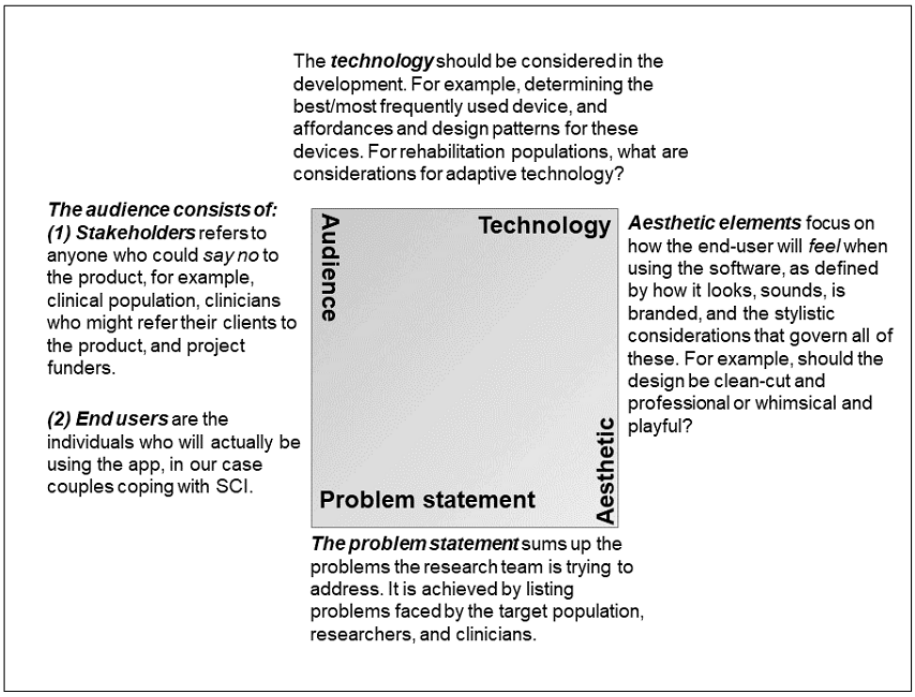
As previously noted, the key to the proposed app development approach is a collaborative partnership between 2 research teams and audience, which consists of stakeholders and end users (Figure 1).

Rehabilitation researchers included a team of 3 clinical researchers and a social scientist with expertise in relationships, behavioral interventions, communication, family care partners, positive psychology, intervention development, activity analysis, and adapting technologies to meet functional ability needs. The clinical researchers provided expertise for individuals with physical disabilities, specifically SCI for purposes of this project.

The members of this software development research team worked in a game and app development laboratory located on a health sciences campus. This laboratory offers specialization in inductive and co-design methods with expertise in development of patient and health system facing games and apps. The team included faculty, a project manager, student artists, engineers, and producers.

Individuals with SCI and care partners were included as stakeholders and end users. Stakeholders also included clinicians and therapists: occupational therapists with specific expertise in adaptive technology and SCI, a SCI rehabilitation physiatrist, and an adaptive recreation program coordinator.

Figure 1. Design box. SCI: spinal cord injury.



Process

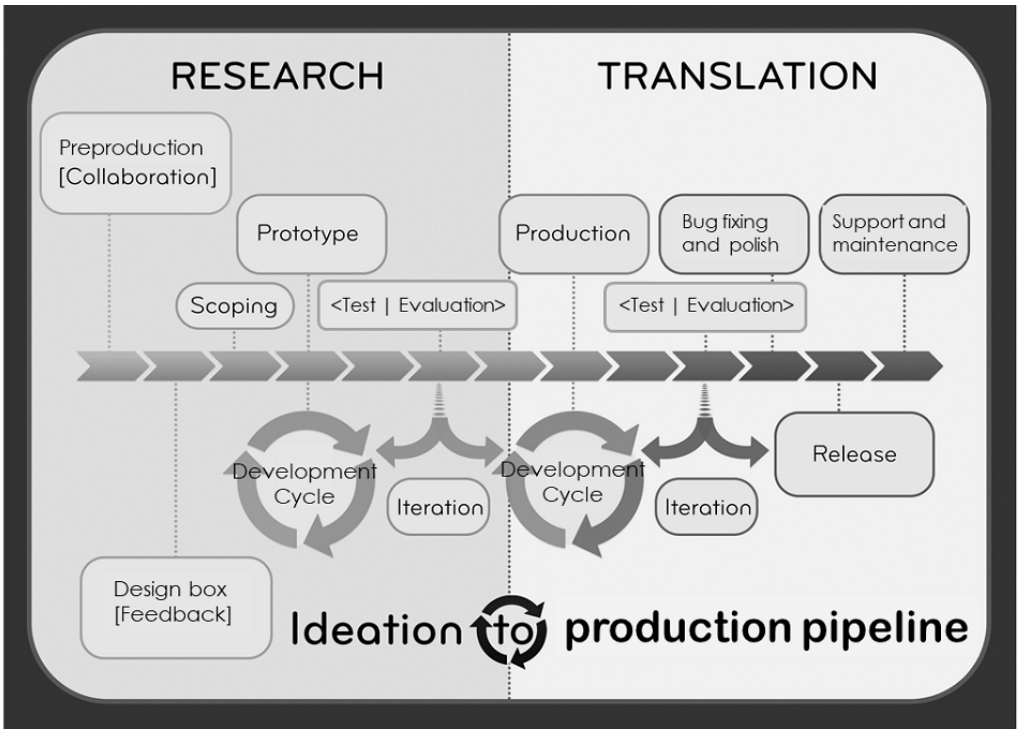
The software development researchers provided information early on about iterative software development, inductive and participatory approaches to design, and the development pipeline and process. These were all very helpful for rehabilitation researchers as the process has significant differences from developing pen-and-paper interventions.

The first major difference involved ideation, understanding the difference between a pitch and a hypothesis. Unlike deductive methods that start with a hypothesis and involve an experiment to support it, design and development precede the hypothesis. In other words, the rehabilitation researchers started the process with an idea, and then, using the design box process (see Figure 1), they worked with the software development researchers to explore the design space and come up with a more developed pitch. This developed pitch solved the same original problem but accounted for the technical affordances of Web-based apps and accessible websites, the end user needs, key stakeholder requirements, and the aesthetics (or content and design related to affect) of the project. This ideation process saved the project's time and money, as instead of building our initial idea, we used a rigorous process that identified hurdles and holes before spending resources on development.

We also created a plan for the development timeline to ensure resources would be available for all stages, including time for stakeholders to contribute design ideas and provide feedback regarding interfaces and processes. We also allocated time for *bug busting* or identifying technical issues. Many rehabilitation researchers fail to realize that making minor changes to the app design often requires additional costs. As many scholars rely on grants, it can be difficult to allocate additional funding to development after the budget has been spent. Initially, the rehabilitation researchers thought that we would go from the initial pitch, to production, to release, not thinking about the other phases. However, we quickly realized that multiple

iterations were vital to have a product that was most appropriate for the patient population. In addition, having a software development researcher who was also a faculty member meant that he could relate to the academic roles of the project but still guide the project through development. Figure 2 shows the map we used to pace our time and other resources.

Figure 2. Ideation to production pipeline.



Collaboration

Important to the collaboration component is creating the culture that unites the rehabilitation and software development teams. As part of the design box, collaborators are encouraged to use "yes, and..." as opposed to "no, but" to foster an open, collaborative environment. This model of positive brainstorming is based on improvisational acting culture as introduced to software development by Randy Pausch and Don Marinelli at Carnegie Mellon [21]. As an inductive and iterative process, the design box aims to elicit ideas from all parties (audience and researchers), allowing for both software that is responsive to user needs and creative. On the basis of the elements identified in the design box, the app developers then propose various solutions.

Iteration

We iteratively refined the app to meet the end users' needs while remaining true to the goals of the project.

Scoping

On the basis of available resources, both in terms of time and funding available, the scope of the project needs to be defined and often redefined throughout the development process.

Feedback

Stakeholders provide feedback regarding interfaces; contribute to the design ideas; and explain which aspects of mobile interfaces, functions, and tasks they found important.

Results

Case Study

The following case study describes the process described above, from initial app ideas to feasibility testing a prototype. Figure 3 shows a timeline of the project milestones. We offer our experience as an example of challenges and solutions.

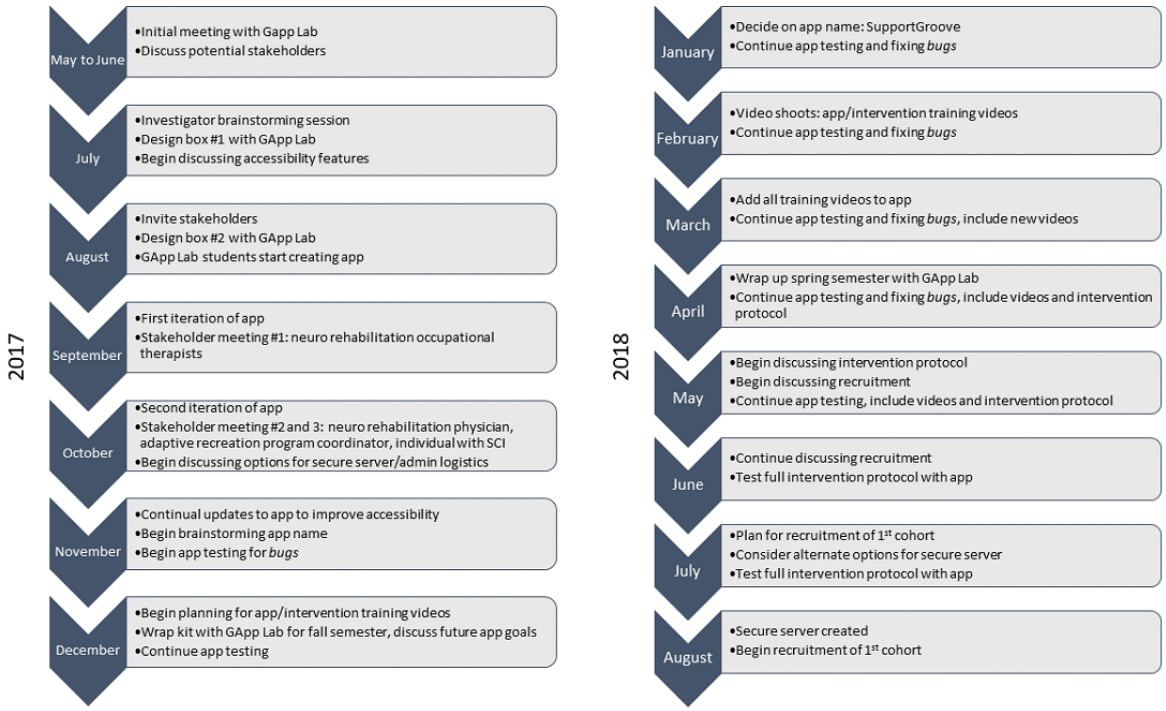
Context and Brainstorming

The rehabilitation researchers had previously developed and pilot tested a self-administered pen-and-paper behavioral intervention for couples coping with stroke. The existing intervention protocol, described in more detail elsewhere [22], included a 15-min in-person training session at an outpatient clinic, after which participating couples completed the 8-week intervention on their own, at home, using a paper *activity booklet* that described activities and a paper *tracking calendar* that acted as a log. Activities were based on positive psychology and included expressing gratitude, practicing acts of kindness, focusing on the positive, working toward goals, fostering relationships, savoring, and spirituality. As part of the intervention, participants completed at least four of these 15-min activities per week—2 as a couple and 2 individually—and were asked to log their activity and mood afterward in the pen-and-paper tracking calendar we provided. Participants also received check-in phone calls from a research assistant once a week to remind them to complete activities and send in tracking sheets by mail or email. Although the intervention was generally well received and participants reported finding it beneficial, there were some issues identified by participants and researchers.

First, there were accessibility issues; participants were required to travel to the clinic for pre- and postassessments, and they had some difficulties with the pen-and-paper tracking sheet (forgetting to record activities, not having enough space to write, and handwriting was difficult for many participants with hemiparesis). There were also issues with data collection, including missing data, inconsistencies in reporting, and difficulty reading handwritten responses.

Due to these issues and the rurality of our catchment area, moving the intervention to the Web was appealing to the research team. However, with limited app development knowledge, the app initially envisioned by the rehabilitation researchers was limited to what amounted to a direct translation of the existing pen-and-paper intervention, a simple Web page describing activities with video examples. The primary innovation was for the participant to be able to log an activity completed to allow for more reliable tracking. However, during the first meeting with the software development researchers, the rehabilitation researchers were encouraged to *Dream Big* and think about ways to enhance engagement with the app. The rehabilitation researchers were also encouraged to look at existing similar apps for appealing and unappealing features and evaluate user-friendliness.

Figure 3. Timeline of project milestones. SCI: spinal cord injury.



Some of the initial ideas focused on basic requirements of the app. For example, given the nature of the intervention, it was important for users to have their own space within the app but also the ability to share with a partner. As the intervention focused on doing activities in *real life*, the app was not required to house the actual activities, but rather house the reflections on those activities. Thus, a journaling aspect was desired to allow users to reflect on past activities, and given the target population, the use of voice recordings or pictures was discussed. Other ideas were brainstormed, including gamification of the intervention to enhance engagement, adding an avatar, and getting trophies when activities are completed. On the basis of other apps, important aspects to design also included a simple and clean interface, being able to share/engage in a familiar way, requiring little typing or text, and providing ideas for activities. Although not all ideas were included in the final app, this process helped the rehabilitation researchers to fully consider the options of what this app could be.

Design Box

Following the initial *brainstorming*, 2 design box meetings were held to identify the problems rehabilitation researchers were trying to address, type of technology to use, who stakeholders and end users were, and what aesthetic elements would look like.

The first design box meeting was held with rehabilitation researchers and the software development faculty and project manager. To facilitate collaboration between the rehabilitation and development teams and establish parameters for the app, the design box meeting started with rehabilitation researchers establishing what needs or problems they were trying to solve. Importantly, this did not include providing potential solutions. For example, there are various unmet needs in the SCI population. The 3 main needs addressed by this team included (1) high rates of depression and lower well-being in individuals with SCI and their partners, (2) limited accessibility of treatments that support mental health/well-being, and (3) little support for partners post-SCI. The rehabilitation researchers were also encouraged to describe what problems they had encountered with the previous pen-and-paper intervention projects, for example, inconsistent or unreliable data collection and missing data. All these *problems* were then distilled into a single *problem statement*: "Current self-reporting solutions that address the well-being of SCI patients and partners are not

effective in encouraging personal or dyadic driven activity engagement, nor measuring and recording useful data of a patient's and partner's well-being."

The second design box was held with rehabilitation researchers and all members of the software development research team (faculty, manager, and graduate student team). Once again, rehabilitation researchers provided a list of problems that the intervention app would address, highlighting accessibility, which included remote/rural access, problems identified with pen-and-paper completion, and inclusion of the care partner.

On the basis of design boxes 1 and 2, a *solution statement* was formulated: "The app provides a simple and clear web-based platform where patients and care-partners can log their experiences doing well-being activities, track how they feel, and interact on a daily basis, and identify positive and negative trends during recovery with tools for clinicians to collect and interpret data and progress." The development of the app was focused on taking actions to address these goals in the solution statement.

Stakeholders

In addition to defining our problem statement, another guiding principle was the inclusion of key stakeholders to provide feedback throughout the design process. These stakeholders were identified as content experts (clinicians) and intended end users willing to provide feedback on the app design, accessibility concerns, and usability issues. The rehabilitation researchers and software development researchers met on multiple occasions with stakeholders to discuss early iterations of the project and later to examine and test the app. Inclusion of both the rehabilitation researchers and software development researchers in stakeholder meetings enhanced appreciation of end user accessibility and usability barriers [18]. Feedback and ideas from stakeholders allowed improvement of app iterations (as shown in Figure 4), including ease of use, access, and interface with supportive technologies generally used among persons with SCI.

Figure 4. Stakeholders provided feedback on initial designs (above), revealing accessibility issues. Final prototype (below) included minimal scrolling, single click, and large buttons.

Addressing Challenges

In the development of the app, the research team faced key challenges beyond which activities to include in the app. These included data security, remote accessibility, mobile device logistics, and choosing aesthetic elements. Although peripheral to the app activities themselves, these aspects had important implications for the success of the app.

Security Aspects

Most general apps on the market do not obtain sensitive data; thus, many app developers may not be aware of additional security requirements for mHealth apps. Furthermore, regulatory guidelines and best practices vary across disciplines and location, and understanding what they are and how to apply them can be confusing [23]. mHealth apps developed for research often collect protected personal information, such as names or addresses. Even psychosocial information not considered protected, such as mood ratings, is still sensitive; thus, consent, privacy, and confidentiality are important requirements.

The most important thing teams can do to protect participant data is to make users aware of what data are being obtained and what will be done with it. Many existing commercial mHealth apps can bring in data, such as photos or location, from a variety of mobile device sensors and may also send or sell data to third-party companies, including high-risk data, without the

awareness or explicit consent of users [24]. Beyond purposeful sharing of data, teams should also be mindful of making data available only to authorized users. Especially on mobile devices, it is important to have secure log-ins to ensure only the intended user can access the app. This is important for privacy protection and ensuring research teams are collecting valid data from the correct user. In addition, research teams are responsible for protecting data on the back end; this includes storing data on secure servers and encrypted data transfer [24].

Our research team benefited from being housed in a university setting, where regulatory professionals were available to advise us and where a secure infrastructure (eg, encrypted, secure data collection tools, and Health Insurance Portability and Accountability Act of 1996 [HIPAA]-compliant server) was already available. However, understanding which regulations were applicable and ensuring the protections were in place to mitigate risks was still a challenge. Our research team reached out to several offices on campus before we were able to find the right people to help identify and meet our needs. In addition, we had to consider how much protected personal information to include within the app itself. As we were interested in collecting demographic, health, and psychosocial information for research, above and beyond what was critical to the tool, we elected to use Research Electronic Data Capture (REDCap) for our questionnaires [25,26]. REDCap (project-redcap.org) is a data collection and management software used by universities; a major advantage to this was that the security of the server and security of the data were already well managed institutionally. Although our app itself is hosted on a HIPAA-compliant server and the data collected are encrypted, we wanted to ensure that the most sensitive data were even better protected.

Remote Accessibility

Remote accessibility is a key part of the development of this app. As a core purpose of this app is to promote accessibility for individuals who are unable to meet in person because of disability or location (eg, rural), a focus on remote accessibility is imperative. To address this, instructions for how to use the app are emailed, and videos are embedded in the app to provide instructions on how to complete the activities. REDCap is not only used to securely gather data through pre- and postassessments but also to send automated weekly reminder emails. Brief surveys are embedded in the app to collect data on mood every week. We also include a *Contact Us* button in the app. Finally, our pilot study protocol includes in-person or virtual meetings with participants, if needed, to troubleshoot the app.

Mobile Device Logistics

Given our focus on accessibility, there were other technology specifications that we had to consider for the SCI population. One of the first decisions was to determine the type of device to use as this would drive many of the other decisions. On the basis of demographic statistics on mobile phone use and feedback from stakeholders, we determined that most individuals with an SCI have access to a mobile phone, generally enabled with accessibility options, but do not necessarily have as easy access to a computer. Moreover, most people generally carry a phone with them everywhere they go, increasing ease of activity logging anytime rather than having to wait until they have access to a computer. Although the mobile phone is the preferred device for displaying the app, we decided that a Web-based app would be more appropriate than a downloadable native app to ensure the intervention could be accessed from any connected device.

Technology

Various accessibility options we initially discussed included eye gaze, switches, large buttons, text to speech, speech to text, mouthstick, control from a power chair (eg, Bluetooth), and drop-down menus. However, including all these options would have exceeded our budget and timeline. Considering input received from stakeholders, we decided to target accessibility for individuals with higher-level spinal cord injuries (eg, injury above the sixth cervical vertebrae, C6), rather than those with lower-level injuries, because those with higher-level injuries generally have more mobility restrictions. Our main design goal was *simpler is better* so that in the future, more accessibility features could be added. For example, we minimized the number of buttons to push when navigating the app and minimized open-ended responses as we found these are often difficult to navigate with accessibility features in other apps.

Aesthetic Elements

The previously described choices also fed into the choices surrounding the aesthetics of the app. For example, the overall aesthetic *feel* of the app was intended to be polished and clean, which also coincided with the practicality of using adaptive technology and the desire for the app to be a calming experience. Other apps may want to elicit a more *silly* or *energetic* feel. The color palette for the app (colors from nature) was selected based on our aesthetic preference for a more calming experience as well as wanting to make the app useable for those who are colorblind. The nature theme and desire for simplicity also extended to our logo.

Choosing an app name was a somewhat unanticipated challenge. Our goal was to convey the purpose of the app in a concise way. However, it was also important to consider the availability of the domain name and social media handles for branding purposes. Furthermore, we wanted to avoid any potentially insensitive connotations, for example, steering away from “Stepping Up” for an app designed for someone with SCI. The team used a positive brainstorm idea in which it declared a set of values and had team members quickly write words on a whiteboard similar to a free association process. Once the team had exhausted the words or reached theoretical saturation, they attempted to draw connections between them to come up with a name.

Existing branding may also dictate choices in colors and even app names to conform or coordinate with standards or aesthetics of various institutions. For example, if a university or funder logo will be featured prominently within the app, the app aesthetic should not clash with the color scheme. Similarly, some institutions may develop a suite of apps; the names of these apps should also coordinate with each other, yet distinguish themselves. In addition, if there is the intention of letting other universities use it, a process called *white labeling* will allow other institutions to replace it with their branding.

Play Testing

To make sure the app was as close to a working prototype as possible, we had a number of individuals, including stakeholders, test the app. This included following verbal and/or written instructions, providing detailed feedback of things they liked/did not like, and providing feedback about features that were not working correctly (included sending us screenshots). We asked them to focus on the more mechanical aspects but also asked for general feedback about aesthetic qualities. For the initial app testers, we gave them as little information as possible before testing the app to see how intuitive the app was to use. After making changes as necessary following this feedback, we then gave new testers instructions similar to what we will give participants to test both the app and the instructions (eg, if the instructions were clear enough).

Discussion

Building More Effective and Accessible Mobile Health App Interventions

mHealth is a promising way to deliver behavioral health interventions to high-need and high-risk populations, including those with physical disabilities who are otherwise unable to easily access health care resources. However, there are mixed findings concerning the effectiveness of existing mHealth apps. Although some of the problems may be because of ineffective interventions, the implementation of these interventions as apps may also be important to consider. A primary reason why mHealth apps can be poorly implemented is a lack of specialized knowledge, understanding, and communication between rehabilitation researchers, software development researchers, and stakeholders. A collaborative process is key to mHealth; we share our key lessons learned to encourage other research teams in their own work. Our team's next goal is further refinement of the app based on participant evaluation and eventual broader dissemination.

Key Lessons Learned

On the basis of our experience, we have provided a summary of lessons learned (see Textbox 1 for a brief overview).

Textbox 1. Brief guide to success: key lessons learned.

Key lessons learned:

Establish clear guidelines and ground rules for the process:

- Researchers and developers jointly establish clear goals and timelines
- Researchers, developers, and stakeholders establish shared goals
- Make joint decisions about scoping and modifying goals
- Open communication

Understanding stakeholder and end user needs:

- Early and regular engagement is key
- Include those with clinical content expertise and lived experience
- Obtain iterative input
- Understand and use strengths of all members of the research team

Less may be more:

- Clean design and universal design may sometimes not meet specific needs of the end user
- Usability is key

Importance of testing:

- Researchers leverage expertise against design
- Developers test app against common best practices
- Stakeholders and end users test for usability and provide valuable input on specific needs
- Tech-savvy and nontech-savvy playtesters identify bugs and determine how intuitive the design is

Planning ahead:

- Pipeline for publishing software varies at different institutions
- Delays are not uncommon

Establishing Guidelines and Ground Rules for the Research and App Development Process

Although our software development researchers are familiar with the research process, we had an introduction meeting where everyone shared and explained their goals. Importantly, partners often may not know what they do not know. As an example, rehabilitation researchers frequently do not know the software development pipeline when developing an app, and software development researchers often do not know the clinical needs. By clearly describing both the research goals and timelines as well as the developer goals and timelines, everyone is better able to understand the mission and what is feasible early on, including where goals differ and overlap. Similarly, the process should also be described to stakeholders. It is important to know the goals of partners and stakeholders involved, and communication should be ongoing to ensure the project continues to move toward shared goals. It was important for everyone's input to be considered and to make joint decisions about scoping and modifying goals as necessary to meet time and resource demands/limitations. Without knowing why people are asking for things, conflict can arise. In our team, rehabilitation researchers and software development researchers are partners in the development process as opposed to having a developer-client relationship more commonly found in the industry. Being partners allowed for a more collaborative process with effective mutual problem-solving. We recognize that this may not be available to everyone; however, it should be noted that clear expectations for the rehabilitation-developer partnership need to be established early for the project to be successful. By initiating the conversation early, expectations for partnership are established, and the door is opened to continued communication.

Understanding Stakeholder and End User Needs and Context

Engaging stakeholders and end users early and regularly from initial design ideas to prototype testing is critical. Inclusion of representatives from all partners (rehabilitation researchers, software development researchers, and various stakeholders) is important to fully appreciate accessibility needs of the end users [18], such as identifying specific app features and hardware that are most preferable, acceptable, and compatible with end user needs. In addition, listening to clinicians and patients is important to get a sense of what fits in clinic workflows or practices as well as daily routines and physical requirements of patients (eg, colorblind and eye gaze). The research team should possess knowledge, skills, and resources to develop and implement the mHealth solution developed with the input provided by the end users in an iterative process. We kept an updated backlog of features and improvements, some of which we were able to address immediately and some of which we needed to resource for future updates.

As a consequence of this understanding, team members learn the other disciplines' *soft skills*, for example, software development researchers learning about person-first language and rehabilitation researchers learning about the possibilities and pitfalls of software development. However, *hard skills* are kept within one's own discipline; software development researchers will not be providing psychotherapy, and rehabilitation researchers will not be writing code. This mutual understanding facilitates coherence within the project while supporting unique professional identities and responsibilities. Importantly, there is a synergy in interdisciplinary collaborations that result in better ideas, questions, and solutions than by any one single discipline.

Less May Be More

Often teams struggle with fitting more on the page versus simplicity in design to meet usability requirements. Our group often went beyond universal design principles to a user-sensitive inclusive design to include engagement from individuals with varying abilities and needs. Although even those without disability and the need for adaptive technology can appreciate clean design, sometimes there need to be compromises to better meet the needs of specific populations. For example, drop-down menus were a solution for us to keep clutter at a minimum, but we needed to pivot to multiple large buttons to be compatible with eye gaze technology.

Importance of Testing

The following 3 groups of testing were included: (1) researchers test the app to leverage their expertise against the design; (2) it is important for the software development team to test themselves or have other developers test it against common best practices; and (3) most importantly, to test with end users on a regular basis, who will not only catch things with a fresh set of eyes but also provide the most valuable feedback of what they will and will not use. All testing data should be interpreted by the team at large to determine whether and in what way an item is actionable. Stakeholders and end users should engage with the app during development to better understand the needs of the target population and receive valuable feedback on design elements. Play testing should be conducted to identify bugs and ideally include 4 types of play testers: those who are or are not tech-savvy and those who are or are not familiar with the specific project. During the testing process, only minimal instructions should be provided to play testers to determine how intuitive the design is. Among play testers, varying abilities and needs should be represented.

Planning Ahead

Researchers and developers should familiarize themselves with the pipeline for their health system or school. In some places, it might take longer to establish HIPAA-compliant servers and/or run through security checks. Unlike publishing a paper, the pipeline for publishing software can vary greatly from institution to institution. The team should establish timelines and milestone goals early in the process.

Conclusions

We have developed a guide—from rehabilitation researchers' and software development researchers' perspectives—to serve as a model for other teams who are interested in app-based intervention development. Our model is based on the needs of individuals with physical disabilities; however, it can be adapted to develop apps for other populations with other needs. mHealth solutions are cost-effective, yet there is limited research available that supports successful implementation and

sustainability of these types of interventions. End user engagement, clinician buy-in, and funder support are necessary to ensure sustainability. This requires an interdisciplinary approach, which can strengthen and improve accessibility of the end product.

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Conflicts of Interest

None declared.

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Abbreviations

HIPAA: Health Insurance Portability and Accountability Act
mHealth: mobile health
PI: principal investigator
REDCap: Research Electronic Data Capture
SCI: spinal cord injury

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