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Examining the Feasibility of Early Mobilization With Virtual Reality Gaming Using Head-Mounted Display and Adaptive Software With Adolescents in the Pediatric Intensive Care Unit: Case Report

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Abstract

Background: Early rehabilitative mobilization for adolescents is safe and feasible. However, there is a lack of published rehabilitation strategies and treatments that can maximize engagement and outcomes among adolescents in the pediatric intensive care unit (PICU). Virtual reality (VR) gaming using a head-mounted display (HMD) and adaptive software can allow active and nonactive gameplay at the bedside for people with limited arm mobility, making it a potentially inclusive and enjoyable treatment modality for adolescents in the PICU.

Objective: The purpose of this brief case study is to report on the preliminary feasibility of incorporating adaptive VR gaming using an HMD with 2 adolescents who received early mobility treatment within the PICU.

Methods: This study was a mini-ethnographic investigation of 2 adolescents (a 15-year-old male and a 13-year old male) in the PICU who underwent VR gaming sessions as part of their early mobilization care, using an Oculus Rift HMD and adaptive software (WalkinVR) that promoted full gameplay in bed. The Rift was plugged into a gaming laptop that was set up on a table within the patient's room before each session. The intervention was delivered by an adapted exercise professional and supervised by a physical therapist. Patients had access to a variety of active games (eg, boxing, rhythmic movement to music, and exploratory adventure) and nonactive games (eg, racing and narrative adventure). Gaming sessions were scheduled between usual care, when tolerable and requested by the participant. The interventionist and therapists took audio-recorded and written notes after completing each gaming session. These data were analyzed and presented in a narrative format from the perspective of the research team.

Results: Case 1 participated in 4 gaming sessions, with an average of 18 minutes (SD 11) per session. Case 2 participated in 2 sessions, with an average of 35 minutes (SD 7) per session. Both cases were capable of performing active gaming at a moderate level of exercise intensity, as indicated by their heart rate. However, their health and symptoms fluctuated on a daily basis, which prompted the gameplay of adventure or nonactive games. Gameplay appeared to improve participants' affect and alertness and motivate them to be more engaged in early mobilization therapy. Gameplay without the WalkinVR software caused several usability issues. There were no serious adverse events, but both cases experienced symptoms based on their condition.

Conclusions: The findings of this study suggest that VR gaming with HMDs and adaptive software is likely a feasible supplement to usual care for adolescents within the PICU, and these findings warrant further investigation. Recommendations for future studies aimed at incorporating VR gaming during early mobilization are presented herein.

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Introduction

Background

Rehabilitation services for adolescents admitted to a pediatric intensive care unit (PICU), referred to as early mobilization or mobility, have recently been identified as a core component of critical illness management [1,2]. Previously, the general belief system was that adolescents in the PICU were medically unstable and, for safety, should therefore remain immobile and sedated to recover from their ailment [2]. In recent years, this culture has changed rapidly due to randomized controlled trials among adults in the intensive care unit that have demonstrated improvements in pain, delirium, or agitation as a result of proactive treatment [3-7]. As observed in adults, early mobilization in adolescents has also been identified as safe and feasible [2].

Virtual reality (VR) gaming using *off-the-shelf* head-mounted displays (HMDs) is currently the most immersive form of active video gaming that is available to consumers. Owing to recent technological advances, HMDs, such as the Oculus Quest, Oculus Rift, or HTC Vibe, include built-in motion tracking with 6 df to capture bodily movement. Built-in tracking negates the need for externally mounted motion-tracking cameras and, therefore, makes HMDs much easier to deliver across a variety of settings. These HMDs also include high-resolution and framerate displays that provide a seamless gaming experience, which can reduce motion sickness [8,9]. Given that these HMDs are marketed as consumer-available game consoles, they have access to a wide variety of active and nonactive video games in both a single-player and multiplayer web-based format.

Previous studies demonstrated that HMDs can be used in formal rehabilitation to improve motor and executive function, fitness, movement quality, spatial orientation, mobility, and perceived levels of pain [10-13]. Outside of a rehabilitation context, HMDs have also been used to promote serious, health-enhancing exergaming at home among child wheelchair users with a chronic disabling condition [14]. In these applications, the impetus for incorporating HMDs is that most VR games require movements of only the arms for successful play, making it an inclusive and, most importantly, enjoyable treatment modality for adolescents with mobility disability (eg, wheelchair users).

HMDs can be further tailored to adolescents with minimal functional ability with the addition of a commercially available adaptive software, WalkinVR. WalkinVR allows the player or another person (eg, therapist) to adjust the controller, camera, and avatar position during VR gameplay. In addition, the movement of the controllers can be boosted in all directions to project small, real-world movements into large movements within the VR environment. These adaptations make VR gameplay possible from a seated to even supine position and for people with limited arm range of motion. Adaptive VR gameplay holds promise for promoting early mobility at the bedside of adolescents within the PICU, but this has not been investigated.

Objectives

A few questions must be addressed before designing structured adaptive VR gameplay interventions in the PICU. First, there is a need to identify whether adolescents within the PICU can tolerate active gameplay. Second, if gameplay is tolerable, what duration and intensity of gameplay can they comfortably achieve? Third, is gameplay safe? These questions must be addressed before considering what outcomes could likely be targeted or improved from a gaming intervention in the PICU.

Considering these questions, the purpose of this brief case study is to report on the preliminary feasibility of incorporating adaptive VR gaming using an HMD with 2 adolescents who received early mobility treatment within the PICU.

Methods

Overview

A mini-ethnographic case study design was used to explore the feasibility of VR gaming for a convenient sample of 2 adolescents in the PICU of the Children's Hospital of Alabama [15,16]. A mini-ethnographic case design (ie, focused ethnography) is used to retrospectively develop a rich understanding of the response of an individual or group to a program or study [15]. This approach is smaller in scope and generally shorter in duration than a full-scale ethnographic approach, whereby a researcher is embedded within a setting for a prolonged period to examine the lived experience through more pattern-focused analytical techniques (eg, grounded theory or thematic analysis) [15]. Ethnography is commonly used in medical marketing to investigate the potential of innovative products or programs [15,17].

This study presents quantitative feasibility metrics and supports the quantitative metrics with qualitative narratives.

Recruitment

This study purposefully selected a convenience sample of 2 adolescents from the PICU at the Children's Hospital of Alabama. Inclusion criteria were as follows: (1) age ≥13 years (as recommended by the HMD manufacturer), (2) ability to interact with the environment, and (3) limited mobility or conditioning. Exclusion criteria were as follows: (1) substantial visual impairment preventing participation; (2) invasive ventilation or oxygen therapy support, in case they would be compromised when fastening the HMD to the child's face; and (3) tested positive for COVID-19. This study was conducted in accordance with the case study guidelines set by the Institutional Review Board for Human Use at the University of Alabama at Birmingham. Written informed consent was obtained from a caregiver, with a waiver of assent for the adolescent, before participation.

Intervention Protocol

Adaptive VR gaming was delivered to participants in addition to their usual care from early mobility physical therapists within the PICU. The early mobility therapy encompassed all typical

physical therapy interventions, which were tailored to the patient's level of alertness, strength, and medical factors. This included range of motion, strengthening exercises, and mobility progression beginning with bed mobility and sitting tolerance up to the point of ambulation and dynamic balance activities. Given the exploratory nature of the study, the gaming intervention was delivered using a learn-as-you-go approach. The frequency of VR gaming sessions was determined by therapists' judgment on improvement goals for the patient as well as the patient's willingness to play. The duration and intensity of gameplay during each session was not established a priori, but instead, it was based on how much a patient could comfortably tolerate. Adaptive VR gaming was delivered by the research interventionist (BL), who was a disability exercise specialist, and was supervised by 1 of the 2 early mobilization therapists.

At the start of each session, the research assistant set up the laptop and headset, whereas the therapist prepared the patient for VR. The research assistant placed the laptop on a cooling stand, connected the laptop to the internet on his mobile phone via hotspot, unpackaged the headset and plugged it into the computer, designated the play space within the virtual area (referred to as the *guardian* within the Oculus HMD), opened the Steam and Oculus gaming platform on the laptop, opened and adjusted the WalkinVR software in Steam, fastened the HMD to the head of the patient and the controllers to the hands, and then executed a game on either the Steam or Oculus gaming platform. Participants were instructed to provide a verbal cue when they wanted to switch games or remove the headset. They were instructed to be careful about motion sickness, which can sometimes occur in beginner VR players. After completing the session, the research assistant cleaned and packaged the headset and laptop, whereas the therapist completed the remaining

interventions with the patient and provided assistance to return the patient to the starting position.

Equipment

The patients used an Oculus Rift HMD for VR gaming, which was coupled with 2 handheld controllers. The controllers were equipped with a Velcro strap that was placed over the knuckles (Kiwi design Knuckle Strap). The strap allowed the controllers to be fastened to the hand, thus removing the need to grip and hold onto the controllers during play. The HMD was plugged into a gaming laptop computer (processor: Intel Core i7-10750H, graphics card: NVIDIA, and RAM: 32 GB) on top of a laptop cooling pad, which was positioned on the adjustable tables within the patient's room. Each day, the research assistant carried the equipment to the patient's room using 2 shoulder-carried bags, one for the Rift and one for the laptop and cooling stand.

Intervention Software

The laptop was installed with software (WalkinVR) [18], which was capable of adapting VR movements for people with disabilities, to enhance the accessibility of gameplay. Specifically, WalkinVR could be set to boost the reach and speed of real-world movements within the VR environment as well as the position of the player's arms (Figure 1). The software also allows people to play from a range of 0° to 90° (ie, supine to sitting). In addition, the software also allows players to independently rotate and move their in-game character using the handheld controllers to replace the actual locomotion of the player avatar. The player's avatar could also be controlled externally by another person (eg, trainer or therapist) using an X-box controller (Figure 2). It must be noted that the WalkinVR software operates through the Steam game platform. Thus, only games downloaded from Steam work with the software.

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Figure 1. Screenshot of the WalkinVR motion range and boost.
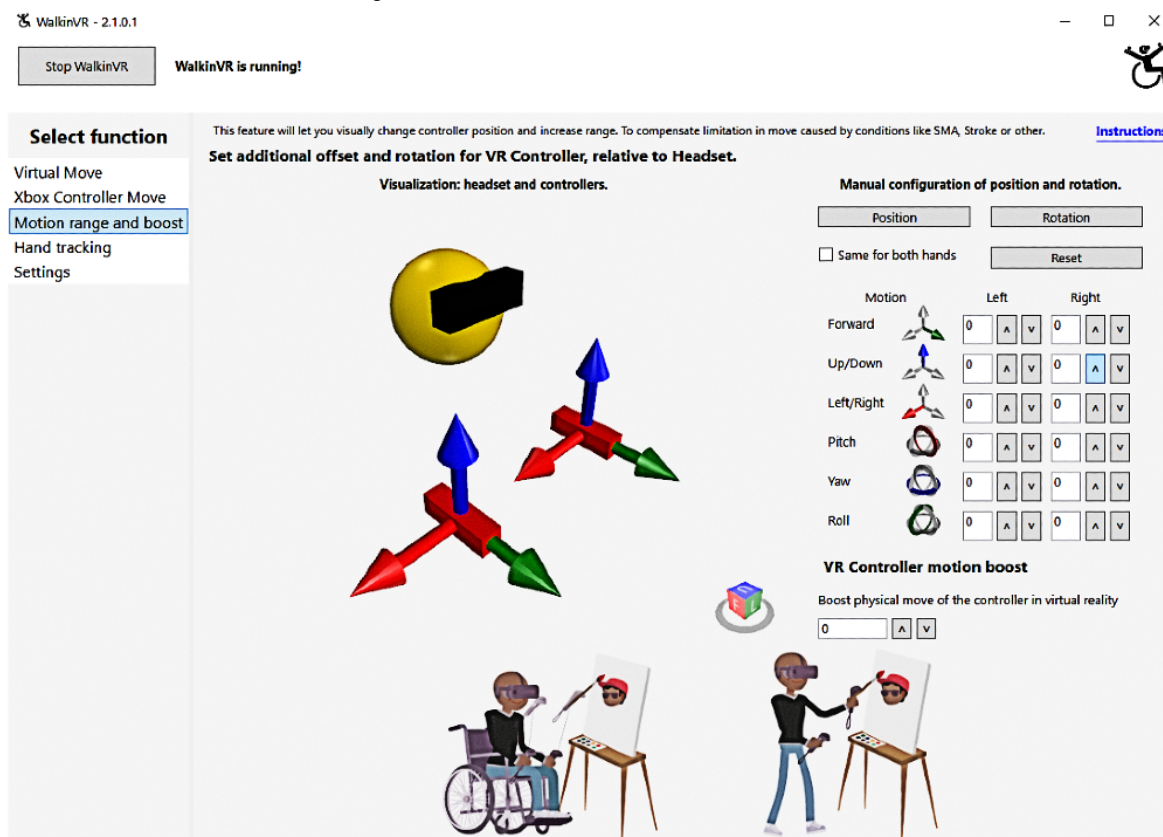
Figure 2. Screenshot of the WalkinVR controller move.
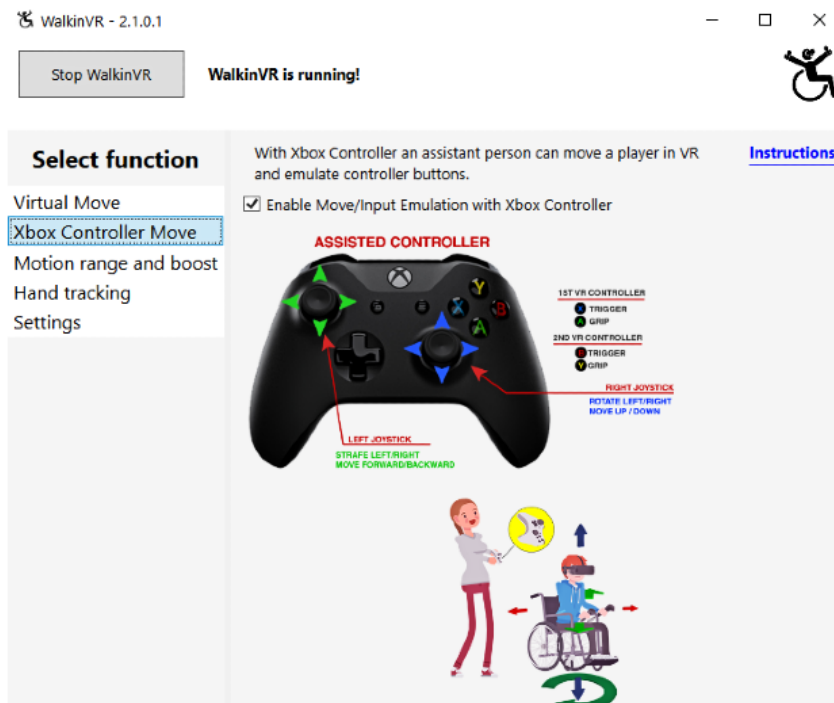
Intervention Games

Games for the intervention were installed on the laptop computer, which was connected to the Oculus Rift. The computer was preinstalled with a variety of single-player games to explore participants' preferences. Games were installed from 2 different internet stores: Steam and Oculus. Games from Steam

were active, rhythmic movements to music, sports, and recreation activities that used the WalkinVR software, whereas games purchased from the Oculus store were more narrative and exploratory games that required fewer arm movements. Core games were Beat Saber (movement to music), Thrill of the Fight (boxing), Wolves in the Walls (narrative story), Dirt Rally 2.0 (car racing), Epic Roller Coaster (first-person shooter),

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and Vader Immortal (adventure). Games were tested before being included in the intervention to ensure that they could be played in a seated position and had high development quality.

Feasibility Metrics and Case Narrative Description

Feasibility metrics included a variety of exploratory outcomes related to *process, resources, management,* or *scientific outcomes* [19]. The goal of these metrics was to provide a foundation for future trials to design more definitive intervention designs. Process measures included the frequency of gaming sessions and gaming duration in minutes. Resource measures included session setup time (min), session cleanup time (min), the number of staff necessary during the session, and the number of games played by the participants. Management measures included the frequency and type of technical issues experienced by the participants (eg, gameplay issues while seated or at the bedside or computer crashes). Scientific measures included safety, as measured by adverse events. Adverse events were defined by the university's institutional review board as "...any untoward or unfavorable medical occurrence in a human subject." An adverse event was recorded and reviewed by the session therapist who classified the event as serious or nonserious and who identified whether it was due to study procedures. Examples of adverse events would include falls, fainting, or nausea.

Narrative case reports were created for each gaming session with each participant. The narrative case reports were based on 2 types of data: (1) the qualitative experience of the research assistant reported via narrative [20] and (2) typed notes from the early mobilization therapists. After each session, the interventionist returned to his office and narratively described his experience of the gaming session. The duration of the audio recordings averaged 25 minutes. While narrating the audio recordings, the interventionist aimed to describe his account of the 4 feasibility metrics that could aid a future pilot trial [19]. The audio recordings were transcribed for review purposes. Similarly, therapists created written notes documenting their perspective on the feasibility of VR gaming. Patients provided verbal feedback regarding each game and the overall VR experience, but they were not interested in participating in a formal interview.

Analysis

This study was formative research aimed at presenting a comprehensive account of feasibility using exploratory quantitative metrics and qualitative case reports, whereby the reader can make their own interpretation of how feasible the intervention can be within their desired context. Accordingly, the outcomes were exploratory, in that there were no a priori criteria that each outcome had to meet to be deemed *acceptable*.

Feasibility Metrics

Feasibility outcomes were descriptively reported as means, SD, ranges, and frequencies, when appropriate.

Case Report Creation

Qualitative data were synthesized into case reports by the research assistant, who had a background in qualitative inquiry and over 10 years of research experience in exercise training for people with disabilities. Specifically, the research assistant created a narrative story for each gaming session by synthesizing the audio recordings and written notes from the therapists. The therapists reviewed and approved each narrative report. Given that this study was a mini-ethnographic case study, no pattern analyses were used (eg, latent thematic analyses or grounded theory) [15]. The philosophical assumptions that underpinned the data review were ontological subjectivism (multiple realities) and interpretivism (knowledge is created by the interaction of all parties). In other words, the research team acknowledged that the research assistant perceived a reality regarding feasibility, and this reality or experience was recreated by the data provided by the research assistant and therapists.

Results

Participant Characteristics

Characteristics of the 2 participants are presented in Table 1.

Table 1. Case characteristics.

Characteristic	Value	
	Case 1	Case 2
Age (years)	15	13
Sex	Male	Male
Race	African American	White
Height (m)	1.73	1.70
Weight (kg)	118.8	81.9
BMI (kg/m^2)	33.9	26.9
Reason for admittance	Rhabdomyolysis (unknown cause)	Severe pancreatitis
Patient notes	Rhabdomyolysis, acute renal failure requiring continuous renal replacement treatment, and hypertensive crisis. Globally weak and deconditioned from muscle damage and prolonged bed rest. Virtual reality intervention began on the 5th day of the patient's stay in the pediatric intensive care unit.	Hyperosmolar hyperglycemic state, acute respiratory failure requiring intubation, and acute renal failure requiring continuous renal replacement treatment. Globally weak and deconditioned from prolonged sedation and critical illness. Virtual reality intervention began on the 11th day of the patient's stay in the pediatric intensive care unit.

Quantitative Feasibility Results

The data for each feasibility outcome are provided in Table 2. In summary, each case completed 2 to 4 sessions of VR gaming in addition to their usual therapy, with an average game time of 27 (SD 14) minutes. Occasionally, other staff (eg, nurses) had to support the research assistant and therapist (described in more detail in the narrative reports). The average number of games played was 6. The average setup and cleanup times were 17 (SD 5) minutes and 8 (SD 3) minutes, respectively. The session setup and cleanup time were slightly increased by the COVID-19 sanitation procedures. Technical issues were not often encountered by the participant, unless the participant was not using the WalkinVR software, which accounted for 80% (8/10) of the technical issues experienced by case 2. Three adverse events were not related to the intervention, as described in detail in the narrative case reports.

Table 2. Feasibility results (n=2).

Outcome	Value	
	Case 1	Case 2
Process metrics		
Gaming sessions, n	4	2
Total gaming duration (min)	70	70
Gaming duration per session (min), mean (SD; range)	18 (SD 10.6; 6-30)	35 (SD 7.1; 30-40)
Resource metrics		
Session setup time (min), mean (SD; range)	14 (SD 4.6; 10-20)	19 (SD 3.6; 15-23)
Session cleanup time (min), mean (SD; range)	8 (SD 5.7; 5-12)	8 (SD 2.8; 6-10)
Staff during session, n (range)	2 (2-3)	2 (2-3)
Total games played, n	4	6
Management metrics		
Technical issues, n	1	10
Technical issue type	Game navigation difficulty	Game loading and usability issues without the adaptive software
Management metrics		
Total adverse events, n	1	2
Nonserious adverse event, n	1	1
Serious adverse events, n	0	1
Events related to the project, n	0	0

Qualitative Case Reports

Narratives for each case are presented below, followed by the recommendations for implementing VR gaming with HMDs in the PICU.

Case 1

Case 1 was a 15-year-old African American adolescent boy who was admitted to the hospital for rhabdomyolysis, acute renal failure requiring continuous renal replacement treatment, and hypertensive crisis. Before the first VR gaming session, early mobility therapists noted that the patient was not very responsive to physical therapy. He was asleep or lying down most of the day and did not communicate much with the hospital staff. His therapist noted that he was very interested in trying the VR gaming. His mother stated that he could spend many hours a day playing video games at home, but he had no prior experience playing VR games. His favorite console games were racing or sports games. Case 1 completed 4 video gaming sessions.

In session 1 (October 26, 2020), he completed 22 minutes of play. He had the most success and spent the most time playing a semiactive narrative game (Wolves in the Walls). He was very focused and engaged with the game and completed an entire chapter of the story within the game. The game required minor head or neck movements and active reaching and chopping movements of the arms. He tried a more active game, Beat Saber, using the WalkinVR software. The interventionist boosted case 1's arm movements and increased the reach using the WalkinVR software, which allowed case 1 to successfully chop the boxes, but case 1 had difficulty keeping up with the rhythmic arm movements to successfully chop the boxes in the virtual world. The therapist reported that difficulty chopping was likely due to arm pain caused by rhabdomyolysis. At the end of session 1, case 1 requested to play boxing or racing for his next session. The hospital staff were amazed at how active and engaged case 1 was during the session. The nurse and therapist noted that this was the most awake they had ever seen him, as he slept most of the day. The interventionist took 20 minutes to set up the laptop and HMD and obtain written consent. The therapist and nurse raised case 1's bed to an upright position (approximately

75°). The therapist performed manual stretching with the patient while waiting for the VR setup.

In session 2 (October 27, 2020), case 1 completed 12 minutes of play. Case 1 was woken from his sleep, and it took 15 minutes for him to be prepared in the upright position and be mentally awake for gameplay. The patient was noticeably more fatigued than in the previous session. Case 1's dialysis access had changed between sessions 1 and 2, and his vascular catheter was now in his right internal jugular vein, which caused him pain when he tried to turn his head. The therapist physically held the line throughout the session to avoid pain or interference during case 1's gameplay. The interventionist took 11 minutes to complete the setup. Case 1 completed 12 minutes of racing gameplay (Dirt Rally 2.0) using an X-box controller instead of the motion-tracking controllers (Figure 3). He reported that he played the same game on his gaming console at home and was thus heavily engaged in the game after putting on the headset.

He navigated the game menus and drove the cars with a high level of skill. He appeared comfortable during the 12 minutes of gameplay, so much so that he did not say a word during gameplay until the end. Near the end of the play, he reported that his stomach felt hot. The nurse and therapist positioned a portable fan near the bedside, which made him feel better temporarily. He chose to stop gameplay after 12 minutes because of this issue. The PICU staff concluded that the issue was because he did not eat or drink anything throughout the day. He reported that he wanted to sleep. The therapist lowered the patient in his bed to a near-supine position. He went back to sleep shortly after the interventionist and therapist exited the room. Overall, amidst these challenges, the PICU staff reported that case 1 participated well, and the gaming appeared to benefit his affect more than any sort of physical function (due to the dialysis circuit preventing him from any significant upper extremity movement).

Figure 3. Demonstration of virtual reality racing in the pediatric intensive care unit.

In session 3 (October 28, 2020), case 1 completed 6 minutes of moderate-to-vigorous intensity exercise in a boxing game (Thrill of the Fight) using WalkinVR. Before starting the session, the therapist found that case 1's foot was pressed against the bedframe and resolved the issue before play. Using WalkinVR, the interventionist provided case 1 with physical boost to his arm movements, adjusted the player height and arm positions, and moved the player avatar with an X-box controller during gameplay. The interventionist also moved case 1's player avatar

to complete the initial setup within the game. The game asks the player to stand up on a virtual scale to calibrate the player height, which was not necessary for the intervention because the player height could be adjusted within WalkinVR. This setup took 15 minutes. Case 1 then proceeded to complete a 3-minute round of seated boxing against a virtual heavy bag and training dummy, which was followed by one 3-minute round of boxing against a computer opponent (Figure 4; Multimedia Appendix 1). He appeared very focused on the gameplay and

was throwing flurries of straight and hook punches. Case 1 achieved substantial reach on his punches, which was amazing as none of the hospital staff had seen case 1 as active as he was while boxing. The interventionist, being an ex-amateur boxer, prompted case 1 to remember to breathe while boxing and throw boxing punch combinations (eg, jab, cross; and jab, jab, cross). The interventionist and case 1 worked together as a team to beat the computer opponent. Unfortunately, the session was interrupted because case 1 had to be moved to another room and undergo an x-ray and other medical procedures. It must be noted that case 1's punching would sometimes cause his catheter to get caught on the bedside, which required constant monitoring by the therapist.

Figure 4. Demonstration of virtual reality boxing in the pediatric intensive care unit.

In session 4 (November 3, 2020), case 1 completed 30 minutes of play. Case 1 had not undergone a VR session for several days because of pain due to rhabdomyolysis. Case 1 was feeling much better than his last session. He was ambulatory, conversive, and had a positive affect. He was transferred to an acute care floor of the hospital. He chose to play the games in a lounge area of the hospital floor and was connected to an intravenous drip during play. Setup took 10 minutes. Case 1 played Thrill of the Fight and Beat Saber. He played 2 rounds of boxing and required very little physical boost in WalkinVR. He played 3 rounds of Beat Saber, with high success in box chopping. He tried the easy and hardest level of difficulty and was highly engaged in the play. Case 1's movements were very dynamic and near full range of motion. He reported that he was playing at a moderate intensity, as indicated by his breathing rate and a verbal rating of perceived exertion of 6 on a 1-10 scale. Overall, case 1 was exercising for nearly the entire 30-minute session. He was willing to play longer but had another medical appointment that he needed to attend.

In summary, case 1 had a linear progression in the game genre from nonactive exploratory games to active exergaming. This progression was achieved across a small number of sessions. Adaptations from the WalkinVR software were heavily relied upon during the earlier gaming sessions but could be gradually reduced over time to accommodate patient progression. The interventionist acted as the gaming instructor and handled several technical nuances during gameplay (eg, setting up the play area, equipping the headset to the participant, managing adaptations to gameplay in WalkinVR, and coaching the patient on game mechanics). The therapist ensured that the gameplay was safe and comfortable for the participant. The therapist briefed the interventionist on the patient's medical status before each session. No serious adverse events occurred during gaming using the HMD. Following completion of VR treatment, case 1 remained hospitalized for 2 more weeks for the management of renal and nutritional issues. He participated well in therapy throughout this time and was motivated to improve. When he left the hospital, he was able to walk >1000 feet independently with no shortness of breath or loss of balance and appeared to be close to his baseline level of function.

Case 2

Case 2 was a 13-year-old White adolescent boy who was admitted to the hospital for severe pancreatitis, hyperosmolar hyperglycemic state, acute respiratory failure requiring intubation, and acute renal failure requiring continuous renal replacement therapy. Case 2 had global weakness and poor cardiovascular endurance after 7 days of mechanical ventilation and 4 days of paralytics due to critical illness. The therapist reported that initially the patient was shy and difficult to converse with. Similar to case 1, case 2 was asleep or lying down most of the day and was excited to try VR gaming. He reported that he was familiar with video games, knew about the

headset, and watched demonstrations of VR gaming on YouTube. Case 2 completed 2 sessions.

In session 1 (November 2, 2020), case 2 completed 40 minutes of play in bed. Case 2 had an additional 15-minute physical therapy session earlier in the day, focusing on traditional strengthening exercises. The setup took 15 minutes, which included obtaining written consent. Case 2 started playing Beat Saber and was highly engaged during play. He voluntarily transitioned from supported sitting with the head of the bed elevated to 75° to unsupported upright sitting and leaning forward during gameplay. Similar to case 1, case 2's real-world movements were small and dependent on physical boosts and the extended reach provided by the WalkinVR software. He chopped the boxes with moderate success during gameplay. After completing 3 songs on Beat Saber, case 2 asked to try as many games as possible. He played Dirt Rally 2.0 using the X-box controller. When he was handed the controller, he had a noticeable familiarity with it. He demonstrated a high level of skill in racing a virtual car. He completed 3 levels in Angry Birds, which requires handheld controller movements that replicate shooting a slingshot. He played 2 rounds of boxing (Thrill of the Fight) and had a high level of engagement. He punched sporadically throughout the rounds and appeared fascinated by the immersion within the virtual environment (he looked at his surroundings and the realness or interactive quality of his virtual gloves). Case 2 and the interventionist tried a few other games, but some games would not load on the laptop (likely because of poor internet connectivity). Case 2's heart rate was around 130 beats per minute, with an oxygen saturation level between 99% and 100% during gameplay. At the end of the session, case 2 reported that he enjoyed the gameplay and was noticeably more conversive and alert than he was before the session. The therapist noted that he was more interested in VR activities than therapeutic exercises. He appeared physically tired at the end of the session, and he laid back in bed after the session. It appeared that completing the session motivated the participant to become more active in the real world. He was able to take off the headset himself. Case 2's mom stated that the VR session was the most awake and active she had seen him in the hospital. Case 2 did not report any pain, nausea, or dizziness.

In session 2 (November 3, 2020), case 2 tolerated 50 minutes of out-of-bed activity and 30 minutes of play. The setup for gameplay took 23 minutes, as the patient was transferred from a bed to a chair. The patient was asked to rest quietly before starting the session. The therapist noted that it would be beneficial for the patient to get out of the bed and transfer into the bedside chair to progress his functional mobility and then remain seated in the chair for play. The patient was carefully transferred to the chair with the assistance of the therapist, and he played all games in a seated position. He maintained an upright position with the trunk unsupported, while being seated on the edge of the chair throughout gameplay and using abdominal musculature to maintain seated balance. The therapist and interventionist supervised him and verbally cued him not to reach too far to avoid loss of balance or falling out of the chair. He reached outside of his base of support multiple times in several movement planes. Given that this participant

performed a considerable amount of exercise the day prior, the interventionist chose to have the participant test an adventure game. The participant noted that he was interested in Star Wars. Thus, the interventionist chose to have the participant play the Star Wars game Vader Immortal: an adventure game, with many handheld interactions within the virtual environment and sections of active play with a laser sword. As the game was only available on the Oculus store, WalkinVR software could not be used, and this caused several usability issues during gameplay in the seated position. On several occasions, the game would ask the participant to reach down or forward to interact with an object, a movement that was not achievable while seated, and the patient was not yet strong enough to tolerate dynamic standing activities. To overcome this obstacle, the interventionist had to equip the headset and complete the task and then reequip the headset to the patient. Nevertheless, the patient was so engaged and interested in the gameplay that he did not want to switch to another game. He completed nearly the entire game during the available playtime (maximum of 1 hour due to other appointments). Again, the therapist noted that, before VR gaming, he would never have participated in 50 minutes of physical therapy. The 2 sessions of VR gaming allowed the physical therapist to build rapport with the patient. For the remainder of his hospital stay, he was more willing to participate in progressive strengthening exercises and higher-level mobility activities.

It must be noted that the patient was receiving a blood transfusion via the peripheral intravenous drip line. This line was occluded a couple of times throughout play, sending alerts to the nursing staff, who came in and helped fix the occlusion while the participant continued playing. Physicians also came in to check the status of the patient and asked him several questions, all while the headset was still equipped and the patient was playing. He appeared to enjoy the gameplay, and thus, the physicians did not want to disturb him because he was highly inactive throughout his stay. After completing the session, taking off the headset, and being transferred back to the bed, the patient vomited a few times. The patient had a history of emesis throughout the day due to his underlying pancreatitis. The patient's mother and hospital staff did not believe that the issue was due to the VR play. The patient also did not report feeling motion sick. It must be noted that this was case 2's last session because his therapists felt that he was now motivated to engage in physical therapy interventions outside of his room to progress toward his functional baseline.

In summary, case 2 was able to start immediately with active exergaming and long gaming sessions. The sessions encouraged him to be more active in the PICU and provided a motivational boost to engage in physical therapy. Gaming without the adaptive capabilities of the WalkinVR software was noticeably difficult and interruptive. The teamwork between the therapist and nurse was needed to ensure the safety of the treatment by providing line management and stand-by assistance to decrease fall risk, whereas the interventionist was focused on the technical aspects of the equipment and gameplay.

Discussion

Principal Findings

This case study was the first to examine the feasibility of using HMD gaming with early mobilization therapy among adolescents in the PICU. A novel component of this study was that it used adaptive software with one of the latest consumer-available gaming HMDs that have replaced the less immersive forms of VR gaming (Nintendo Wii, X-box Kinect, and PlayStation Eye, all of which have been discontinued by their manufacturers). Overall, the findings suggest that HMDs could be delivered by an early mobilization physical therapist and research assistant to pediatric patients. Patients were able to participate in both active and nonactive single-player games. No serious adverse events that appeared directly related to VR gameplay occurred. Nevertheless, adverse events did occur (stomach hotness and vomiting). Thus, the safety of this treatment must be explored in a larger feasibility study. The findings of this study regarding process, resources, and management should assist in informing the development of a feasibility study with a more structured intervention dose and should help in assessing the impact of this dose on a precise health outcome.

For example, moderate exercise is a critical method of improving physical fitness and preventing deconditioning and comorbidities among adolescents with disabilities both within and outside of a formal rehabilitation setting [21-23]. This study demonstrated that adolescents in the PICU could potentially reach moderate intensities of exercise using only their arms for exercise. This finding agrees with the current early mobilization paradigm: early exercise therapy is likely safe and beneficial for pediatric patients [2]. Further research is needed to quantify both physiological responses and adaptations to VR exergaming in the PICU.

Perhaps the greatest benefit of VR gaming was that it motivated the adolescents to become more active, alert, and engaged with their typical physical therapy treatment. Both patients were resting most of the day in the PICU until they received VR treatment. After 2 sessions, the patients could more easily be persuaded to participate in early mobilization physical therapy. The underlying mechanisms of this behavioral change warrant further examination so that this response can be replicated. Moreover, future research should examine the potential effects of VR treatment plus early mobilization therapy on critical psychosocial outcomes in the PICU, such as anxiety, pain, and depression.

Recommendations for Implementing HMD Gaming in the PICU

Process

Process recommendations for implementing VR in the PICU are listed below:

- Prepping the patient for gameplay will require joint support from an early mobility therapist and nurse.

- Begin with an introductory game to VR (use more exploratory games with minimal required activity or movement).
- During the introductory session, adjust the movement boost and location of the controllers within the WalkinVR software while the person is playing the game (record the settings for each game, to quickly input in subsequent sessions).
- Introduce active games (eg, Thrill of the Fight or Beat Saber) once the patient becomes comfortable with the VR environment.
- Provide positive verbal encouragement to enhance motivation.
- Gradually reduce the movement boost of the controllers in WalkinVR as the patient progresses in the game and successfully completes tasks, to increase energy expenditure.
- Sessions should last approximately 45 minutes, with 30 minutes of playtime and 15 minutes for setup and cleanup.

Resources

Recommendations for VR gaming resources in the PICU are listed below:

- WalkinVR software is required for playing most games adequately from the bedside.
- The gaming laptop must have adequate processing and graphics power to maximize the frames per second display of the HMD.
- Gaming genres should include active video games, narrative adventure games, recreation or sports, and potentially mindfulness or meditative games.
- Staffing should include supervision by an early mobility therapist and an interventionist and support from nearby nursing staff due to the potential for adverse events, including line or equipment dislodgement, unsafe change in vital signs, or severe patient discomfort.

Limitations

Inherent within a case study design, study findings should be interpreted with caution and will need to be confirmed in a larger feasibility study. The study only included 2 males, and we are unsure whether females will respond similarly to the treatment. Another limitation was the lack of objective outcomes, which could have provided estimates for treatment effects in an efficacy trial. Moreover, both the participants were experienced with video games. Further research is needed to identify whether VR gaming with HMDs is acceptable in the PICU among nonexperienced gamers. Finally, the narrative report was presented from the lens of the interventionists, not the participants. The adolescent participants did not express a desire to be formally interviewed. This prevented the study from providing a user-centered perspective on usability or feasibility.

Conclusions

This study demonstrated that incorporating consumer-available VR gaming within the early stage of early mobilization therapy is likely feasible among patients in the PICU. However, further quantitative and qualitative research is needed to confirm the

safety, acceptability, and potential benefits of such treatments   on scientific outcomes.

Authors' Contributions

BL drafted the initial manuscript. All authors contributed equally to the drafting of the manuscript. LH, MP, and AGC assisted with recruitment.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Video demonstration of virtual reality with a head-mounted display in the pediatric intensive care unit.
[MOV File , 14726 KB - rehab_v8i2e28210_app1.mov]

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Abbreviations

HMD: head-mounted display
PICU: pediatric intensive care unit
VR: virtual reality

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Parents' Perspectives on a Computer Game–Assisted Rehabilitation Program for Manual Dexterity in Children With Cerebral Palsy: Qualitative Analysis of Expectations, Child Engagement, and Benefits

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Abstract

Background: Children with motor impairments affecting the upper extremity benefit from task-specific therapy, such as constraint-induced movement therapy. However, there is a need to improve engagement and compliance with task-specific exercise programs that target manual dexterity for children with cerebral palsy (CP). A computer game–based rehabilitation (GRP) platform was developed that combines fine manipulation and gross movement exercises with engaging game activities appropriate for young children with CP.

Objective: The objectives of this qualitative analysis were to compare parents' perspectives and opinions about expectations, challenges, and benefits between 2 interventions.

Methods: A mixed methods, randomized controlled trial (RCT) was conducted to examine the feasibility and estimate the effect size of 2 exercise programs for rehabilitation of manual dexterity of children with CP using either GRP or conventional therapy. Parents of 26 of the children who completed the GRP program (n=33) and parents of 15 of the children who completed the conventional therapy program (n=27) participated in the interviews. A general conductive approach was used to analyze the data recorded during the parents' interviews.

Results: Five themes captured the range of the parent's experiences, viewpoints, and ideas: (1) parents' expectations, (2) child's engagement with therapy, (3) positive effects of the interventions, (4) challenges, and (5) improving the protocol.

Conclusions: Parents from both groups recognized that their expectations related to improving children's object handling and manipulation skills including participation in activities of daily life were addressed during the 16-week therapy program. Parents perceived a change in the children's level of independence in their daily tasks at home, school, and leisure activities.

Trial Registration: ClinicalTrials.gov NCT02728375; https://clinicaltrials.gov/ct2/show/NCT02728375

Introduction

Children with motor impairments of the upper extremity due to cerebral palsy (CP) face numerous difficulties in their activities of daily living (ADL), in participation in school, and during play. Task-specific rehabilitation programs such as Constraint Induced Movement Therapy (CIMT) [1] and hand-arm bimanual intensive training (HABIT) [2] have shown positive results when provided by therapists in a one-on-one clinical setting with high repetitions of task practice [3].

Recent studies have introduced digital media to enhance the play-based therapy protocols for children with CP [4]. These include the Wii [5] and Kinect [6] commercial gaming systems and custom gaming systems that use robotic manipulanda [7] or sensor-equipped gloves [8]. These gaming systems can detect arm segment motion or finger motion in the case of the instrumented glove. These sensor motion signals are used to interact with virtual objects or to control a game paddle for play; however, these cannot be used to couple goal-directed object handling and manipulation exercises with computer games. In addition, these gaming systems come with a limited number of games suitable for young children with motor impairments, whereas there is a large number of inexpensive and readily available common and modern commercial games that are engaging and can be played with a computer mouse or equivalent.

Using game-assisted rehabilitation technologies is still a relatively new discipline. There is a need to develop study designs to explore the implementation, acceptability, and appropriateness of these technology-based interventions [4-15]. Based on this information, a computer game–based rehabilitation platform (GRP) was developed [9-11] to focus on object handling and manipulation tasks. The GRP uses a miniature commercial wireless inertial based (IB) computer mouse, which links physical movements with engaging, interactive computer games. The precision and responsiveness of the IB mouse are equivalent to that of a standard optical computer mouse. When the IB mouse is attached to an "exercise" object, the manipulation of the object is used to control the motion of a computer cursor or game paddle. Importantly, the IB mouse can be attached to a broad range of objects with different physical properties and functional demands. Therefore, many objects of varied size, shape, weight, and surface properties can be used in the game-assisted exercise program. Several principles of motor learning are incorporated in the GRP [12-14], including task-specific training of object handling and manipulation, multisensory stimulation, and feedback or knowledge of performance.

A mixed methods, exploratory, randomized controlled trial (RCT) was conducted to explore parental views of children's experiences with their respective exercise programs and to provide an estimate of the treatment effect size that would direct a future full-scale RCT.

Qualitative analysis is important to gain knowledge from parents' experiences with the GRP program and to reinforce and strengthen the evidence obtained from a quantitative analysis of treatment effects [16]. It is necessary to explore whether the children's goals were met. Children's experiences and beliefs can directly influence engagement in the intervention [17]. The results of the qualitative analysis are presented in this paper, while the quantitative findings will be reported in a separate paper. The objectives of the present study were to investigate parental views of children's experiences about expectations and benefits of the GRP exercise programs targeting the hand and arm function of young children with CP, expectations and benefits of the conventional therapy programs targeting the hand and arm function of young children with CP, engagement with the therapy, positive effects of the interventions, and challenges with implementing the exercise program.

Methods

Children diagnosed with CP, aged 4-10 years, who were scheduled to receive therapy and met the following inclusion criteria were recruited: Gross Motor Function Classification System (GMFCS) levels 1-3 [18], manual Ability Classification System (MACS) levels 1-3 [19], level of spasticity on the Modified Ashworth Scale (MASH) from grade 1 to 1+ [20], score ≥17 on the pediatric version of the Mini-Mental State Evaluation (MMSE) [21].

After the initial screening process, parents provided written informed consent.

The initial session included the following assessments: Grasp and Visual-Motor Integration (VMI) subtests of the Fine Motor Quotient of the Peabody Developmental Motor Scale-2 (PDMS-2) [22] and a computer game–based assessment. A miniature wireless IB computer mouse (Scoop Pointer Remote Model RXR1000-0302E, Hillcrest Lab, Rockville, MD) was secured using Velcro to 5 test objects chosen for the assessment of manual dexterity. Performance measures for the 5 object manipulation tasks included the success rate, response time, and movement error developed [9-11].

In the experimental group (XG) intervention, the initial exercise protocol for each participant was established based on the child's and parents' goals, level of impairment, and functional status. A typical session for the XG consisted of a computer game–assisted exercise program.

Children were provided between 6 and 8 IB mouse–equipped objects for exercise, which were used to play several computer games. The objects were everyday items such as balls of various sizes; daily objects like spoons, glasses, and cups; school-related objects such as markers; and play-based objects such as toys. These objects represented a wide range of physical properties requiring different modes of manipulation and functional demands. The GRP can take advantage of ergonomic properties of common objects to amplify limited and small voluntary movements during gameplay and then allows opportunities to use exercise objects with more challenging demands. Figure 1 presents a description of several object manipulation tasks used in this study for game-assisted repetitive task practice (RTP).

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Figure 1. Example object manipulation tasks illustrated by a therapist: (A) handling a plastic cup with wrist radioulnar deviation while a midprone forearm is maintained with elbow resting on a surface; (B) handling a sponge ball (12-cm diameter) using wrist flexion- extension while maintaining a palmar grasp and midprone forearm with elbow resting on a surface; (C) rotation of a jar lid (opening and closing) using a 5-finger grasp over the lid and wrist radioulnar deviation and 5-finger flexion-extension with elbow resting on an elevated surface; (D) rolling movement of a toy wheel, manipulated using the index and middle fingertips and moved using shoulder flexion-extension; (E) bimanual beach ball manipulation using open hands and elbow flexion-extension for movement while forearms are maintained in a midprone position and shoulders maintained in mild flexion; (F) rolling a stick using index and middle fingertips and thumb opposition, while maintaining a neutral wrist and midprone forearm with elbow resting on an elevated surface; (G) manipulating a pen with index and middle fingers and thumb opposition using a tripod grip and maintaining a neutral wrist resting on the table; (H) bimanual roll of a pool noodle using thumbs and finger flexion-extension and fingertips for manipulation while a midprone forearm is maintained with elbow resting on a surface; (I) fork manipulation using a tip-to-pad grip with the index and middle finger, thumb opposition, and forearm supination-pronation with elbow resting on an elevated surface.
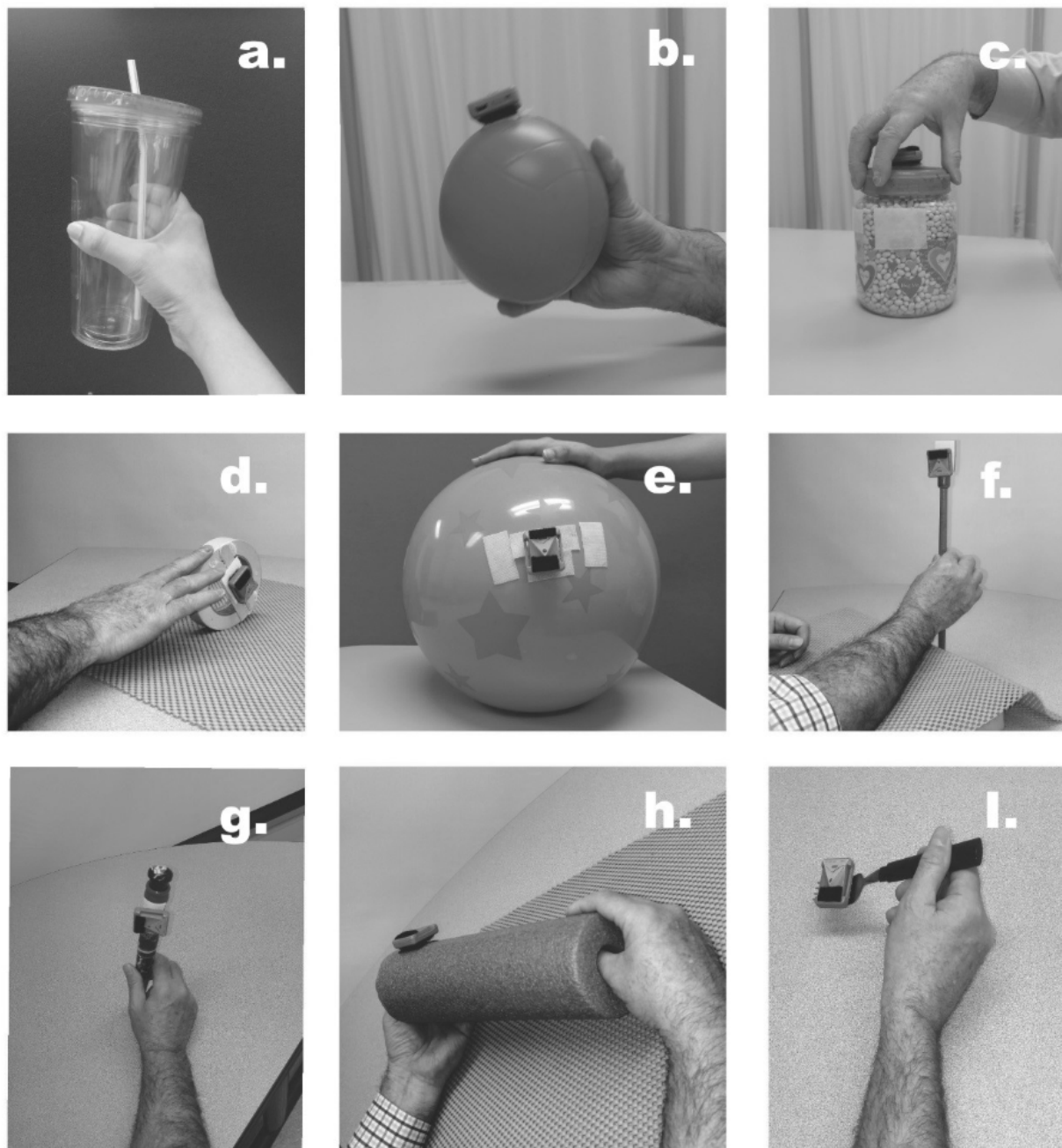
Treating physiotherapists instructed children how to perform the various tasks with the desired hand and arm segment motions and to avoid substitution with associated movements. Computer games that best suited the object manipulation tasks were chosen for the exercise program. The games were chosen based on the following game properties: (1) movement amplitude required to move the game paddle, (2) game speed, and (3) game precision requirement. Many inexpensive arcade-style computer games are readily available online and can be downloaded from websites such as Big Fish games [23]. Multimedia Appendix 1 presents a list of computer games used and a description of movement and cognitive requirements.

This protocol was updated every 4 weeks based on the child's improvements, current goals, and functional demands.

The protocol was updated on week 4, week 8, and week 12. The intervention was performed for 16 weeks. For example, certain features of the object manipulation tasks and variables of the computer games were adjusted, as tolerated, to increase the challenge and progress the exercise program. Of note, objects with different sizes, shapes, weights, and surface frictions were used to increase the physical demands of the tasks. Surface friction was adjusted using various materials such as kitchen drawer liner material, various rubberized materials, as well as plastic and Styrofoam objects versus objects with leather coverings. Game speed and then movement precision (size of target objects and game paddle) were increased (ie, the speed-accuracy relationship). Movement amplitude was increased by adjusting the mouse sensitivity. In addition, cognitive load was increased by selecting games with an increasing number of distractor objects (ie, dual-task interference). Of note, most children were competitive and became frustrated if they were not successful in game play. Therefore, game play success was usually set to 60% or higher for all combinations of objects, game settings, and game types.

In the control group (CG) intervention, we used a comprehensive physical therapy protocol based on the goal-oriented, repetitive task practice–based principles of modified CIMT and HABIT. Therapy protocols were individualized for every participant according to their level of impairment and pre-set goals. A variety of arm and hand activities were practiced, such as reaching for rings, ball throwing, clay activities, picking marbles from sand, and putting pellets and pegs into sockets. These tasks were practiced by the child with the guidance and assistance of a therapist.

Both the XG and CG protocols were designed and updated based on the recommendations of RTP-based protocols such as CIMT [24,25]. The recommended period for such protocols is 3-4 weeks in order to see improvement in functional goals [24-26].

For the qualitative data collection, parents of children in the XG and CG were invited to participate in interviews conducted at the end of the intervention. The purpose of the interviews was to understand parental views of children's experiences with the interventions. An interviewer who was blinded to the intervention received by the parent's child conducted all the interviews using a semistructured interview guide (Textbox 1). Interviews were conducted in local languages or parents' preferred language. Parents were encouraged to describe and explain their ideas, thoughts, and opinions. The interviewer noted any nonverbal communications and other observations in field notes. The interviews were audio recorded. Audio recordings were both professionally transcribed and translated to English.

Textbox 1. The interview guide.

1. When you agreed to participate, how did you hope your child would benefit from the therapy program?

2. What did you like about the therapy program?

3. What was difficult or challenging about implementing the therapy program for your child and you?

4. What did you think about the computer games/exercises your child was asked to play?

5. How did your child respond to the games/exercises? Were there games/exercises which your child did not seem to enjoy?

6. How did technology integrate into your daily life?

7. Would you want your child to continue with the same type of therapy program? Why or why not?

8. Any other suggestions?

The analytical framework of interpretive description was used for thematic interpretation [27]. Translated transcripts and the field notes were initially read by one researcher who developed the coding system by paraphrasing, generalizing, and abstracting the written transcripts of each interview. A second researcher scrutinized the coded data and identified any additional unique responses and codes. The 2 researchers then met via video calls to compare their analyses and resolve disagreements in a final code system.

These coded responses and direct quotes from the interviews were back-translated to the parents' preferred languages. Parents were asked to review this material and provide feedback about the accuracy of the researchers' interpretations. This was done as a member-checking procedure to promote trustworthiness and fidelity [28]. After receiving parent feedback, the data and coding were again reviewed by both researchers and organized into final themes and subthemes described in the Results section.

Results

Table 1 presents the demographic and clinical data by group (XG: n=33, mean age 7.2 years; CG: n=30, mean age 7.8 years). There were no significant differences between groups at baseline in age, MMSE, or PDMS-2 Grasp/VMI scores. The majority of children were at GMFCS levels I-III and MACS levels I-III. Both groups had 6 children at a level I.

Table 1. Demographic and clinical characteristics of the groups.

Characteristics	Control group (CG; n =30)	Experimental group (XG; n=33)	P value[a]
Age (years), mean (SD)	7.8 (1.9)	7.3 (2.1)	.20
MMSE[b], mean (SD)	27.7 (1.4)	29.0 (0.3)	.40
GMFCS[c]	I, n=6; II, n=14; III, n=7	I, n=8; II, n=15; III, n=10	N/A[d]
MACS[e]	I, n=6; II, n=16; III, n=11	I, n=4; II, n=15; III, n=8	N/A[d]
PDMS-2[f] Grasp, mean (SD)	38.8 (4.2)	38.5 (3.1)	.80
PDMS-2 VMI[g], mean (SD)	110.4 (10.1)	107.6 (8)	.50

[a]*t* test results.

[b]MMSE: Mini-Mental State Examination.

[c]GMFCS: Gross Motor Function Classification System.

[d]N/A: not applicable because *t* tests were not performed for comparisons.

[e]MACS: Manual Ability Classification System.

[f]PDMS-2: Peabody Developmental Motor Scales - Second Edition.

[g]VMI: Visual-Motor Integration.

Three participants from the CG withdrew from the study due to a change of school, the commute, and transportation-related issues (see the CONSORT diagram in Multimedia Appendix 2). Parents of 26 of the children from XG and parents of 15 of the children from the CG agreed to participate in the interviews. However, after the member-checking procedure, only 24 parents from the XG and 14 parents from the CG responded in person or via phone in addition to their written feedback.

The following 5 themes and subthemes captured the range of parent's experiences, viewpoints, and ideas: parents' expectations, use of computers, child's engagement with therapy, positive effects of the interventions, challenges, and improving the protocol. Examples of the parents' direct quotes for each theme are provided.

Parents' Expectations

All participants had been undergoing conventional therapy for at least 2 years, and their reported reasons for joining the study were varied. Most parents expressed their willingness to join the trial because therapy would focus on manual dexterity (Table 2, quotes 1 and 2). Many parents from both groups (XG, n=22; CG, n = 11) expressed concerns regarding a gap in current therapy services that often focus on arm movements and not on manual dexterity (Table 2, quote 1). Many parents from both groups (XG, n=13; CG, n=5) expressed their concerns regarding their child's inability to participate in both play and school activities due to lack of hand-eye coordination (Table 2, quotes 3-6). Considering that the protocol required children to focus on the computer screen while performing fine motor tasks, some parents assigned to the GRP program believed that this therapy might improve their children's hand-eye coordination as well as their attention span (Table 2, quote 4). Eight parents made the decision to join the study with the hopes the intervention would improve their child's handwriting (Table 2, quote 4).

Table 2. Parents' expectations when joining the program.

Group, parent, and ID	Quote number	Example quote
XG[a]		
Mother 12	1	"My daughter had hand and leg weakness for a few years. We have tried many places; they worked with her hand for picking up toys and playing with putty and elastics, but she is still not able to use her hand independently and normally. The therapy is just not working so far, so we decided to come here to SDM. Then, (the therapist) told us about this new study. I approached this treatment because I hoped she will practice activities using different objects with her hands, and with time and practice, those actions will improve."
Mother 4	2	"My child had problems with fine finger movements. Our consultant physician had told us that he was never going to use his fingers. When we heard about this program, we thought that this program might help."
Mother 5	3	"My daughter had difficulty in moving her right hand, that was the main thing, but we are hoping that this (CRP[b] protocol) will also help her in analyzing things and improve her concentration."
Father 23	4	"We joined this therapy with the hopes that it will improve her handwriting along with hand-eye coordination."
Mother 15	5	"When we started this therapy, we hoped this therapy with computers will increase his interest and attention in studying."
Mother 18	6	"Knowledge of technology is always helpful as today's life is full of technology; it would help him in concentration, overall development using technology, and hand movement and motivate him to play and learn."
Mother 22	7	"It is very useful to communicate and relate to the world. In this way, it helps my child to learn and use a computer through this therapy."

[a]XG: experimental group.

[b]CRP: computer games–based rehabilitation protocol group.

Use of Computers

The use of computers for participants from a developing country, such as India, was a novelty. Most participants and many of their parents do not have access to computers and electronic devices. Many parents joined the GRP protocol with the goal of getting their child acquainted with computers (Table 3, quotes 1-3). In addition, many parents expressed that technology would play a major role in helping children achieve future goals such as employment and university-level education (Table 3, quote 1). Most parents from the XG reported that their child had never interacted with computers before (Table 3, quotes 1 and 2). Most parents presented an overall positive attitude towards the use of computer games and allowing their children to play computer games as part of therapy (Table 3, quote 1).

Table 3. Parents' responses about the use of computers.

Group, parent, and ID	Quote number	Example quote
XG[a]		
Mother 15	1	"When we started this therapy, we hoped this therapy with computers will increase his interest and attention in studying. It will help him in his future, when he goes to college or work."
Mother 18	2	"Computers seem so attractive, and he wants to learn how to use them. Knowledge of technology is always helpful as today's life is full of technology; it would help him in concentration and overall development using technology. We hope he improves his hand movement, and it motivates him to play and learn along with his classmates."
Mother 22	3	"It (technology) is very useful to communicate and relate to the world. In this way, it helps my child to learn and use a computer through this therapy. I think it will be more fun also, which means less complaints."
Father 23	4	"From this treatment, she acquires the knowledge of computers and also gets to know other information in technology."

[a]XG: experimental group.

Many parents believed that introducing their children to computers while performing play-based therapy would create positive learning experiences (Table 3, quote 3). Parents expressed their intentions to join the therapy and later continue the therapy so that their child's communication skills could improve by boosting their confidence while also improving their social interactions in schools and later in life (Table 3, quotes 3 and 4). Parents expressed that basic knowledge of computers and getting used to using computers will help children

because it is useful to communicate and relate to today's world of technology (Table 3, quotes 3 and 4).

Child's Engagement With Therapy

Many parents expressed the view that, as the children get older, conventional therapy becomes repetitive and boring. In the XG, 19 parents commented that it was easier to convince children to perform exercises using the GRP than conventional exercises

(ie, based on prior therapy; Table 4, quotes 1 and 2). Many parents perceived that their child found most of the chosen computer games to be engaging and viewed the exercises as play (Table 4, quotes 3-5). From the CG, 7 parents commented on a lack of interest in their child in participation during the therapy session (Table 4, quotes 6-9). Often, parents observed improvements in their children during the initial sessions, but the children lost interest with time (Table 4, quotes 6-8).

Table 4. Parents' responses about their child's engagement with therapy.

Group, parent, and ID	Quote number	Example quotes
XG[a]		
Mother 12	2	"Earlier during (conventional) therapy sessions, my child used to get frustrated and annoyed quite easily. Then, we started the computer games therapy, and now my child feels relaxed and enjoys these therapy tasks while playing computer games. Because of this, we have observed a lot of progress in her behavior; it's positive."
Mother 24	3	"She does really well in the game. She likes to play the fish game because of the variety of fish there in that game where one fish attacks and eats all the other fish. So, by this, the memory power is increased."
Mother 57	4	"In this treatment, my son liked all the therapy games. He learned to play games using various objects. His grip has become stronger now, and the main thing is that he is liking therapy now."
Mother 47	5	"Maybe the kids would enjoy this more than conventional therapy. He was bored with conventional therapy; now, he is coming more easily for computer games (for CRP[b]-based therapy) than conventional therapy."
CG[c]		
Parent 1	1	"Kids nowadays do not like traditional therapy. My child gets annoyed and bored easily there."
Mother 26	6	"She is a bit tired after all this time, but she was giving good responses at first; she has improved a lot"
Father 10	7	"We have been doing therapy for almost 10 years now; he is very bored of therapy, and he gets angry and cranky now."
Mother 34	8	"Well, as she is growing up, she is certainly developing moods, so the therapy needs to be made more interesting for her"
Mother 2	9	"Uhh, (child's name) is still small, I hope that when she grows up, she gets a little bit more motivated to do this. This is for her own good."
Mother 56	10	"She is doing well. She likes to play with the ball and other fun things."

[a]XG: experimental group.

[b]CRP: computer games–based rehabilitation protocol group.

[c]CG: control group.

Positive Effects of the Interventions

From the XG, 22 parents reported that they perceived improvements in their children's manual dexterity, object manipulation skills, and hand-eye coordination (Table 5, quotes 1-4). Some parents reported that their children improved not only in their "ability to pick up and hold objects" but also in

their ability to "manipulate objects with more precision" and "stability" in unimanual as well as bimanual activities (Table 5, quotes 1 and 2). Improvements were also observed by parents from the XG in using technology-based gadgets like phones and laptops due to improved confidence levels (Table 5, quotes 3 and 4).

Table 5. Parents' responses about the positive effects of the interventions.

Group, parent, and ID	Quote number	Example quotes
XG[a]		
Mother 25	1	"I'm happy to see my daughter using both hands to hold toys (objects) and playing games. I also assume that she tries to catch the game toy (practice object for therapy) and play the (computer) game. So, I think now she knows how to move her hands (using therapy objects) while playing the (computer) game."
Mother 42	2	"He learnt to play games holding various objects. I can see him using his hands more now when eating and playing."
Mother 38	3	"With this game therapy, he is able to play and understand other game concepts even when he is playing in the apartment with friends."
Father 33	4	"In our day-to-day life, we hardly have any need for technology-based things. Since this therapy program has started, we have observed drastic changes in my child's day-to-day life. My child's handwriting is improved."
Mother 22	5	"Yes, he seems smarter, he knows about colors, and he knows about shape and directions, He sits back properly, His hand fingers are more active, and he also gets some exercise for the eyes."
Mother 4	7	"He has done well so far; he is more independent. This therapy program helped him with that."
CG[b]		
Mother 7	6	"Dr. (therapist's name) is simply the best! We can already see that he is using his right hand for more activities; he pays more attention."
Mother 26	8	"I like that the sessions are one-on-one and that the therapists look after her alone for the whole time. You can see the difference in her. She is not irritated and angry like she used to be all the time."

[a]XG: experimental group.

[b]CG: control group.

Some parents commented that they observed improvements in the quality of arm movements as well as posture and balance while sitting and playing computer games (Table 5, quotes 5 and 6). Many parents commented about their perception that the use of computer games had a positive impact on their child's cognitive abilities (Table 5, quote 5), hyperactivity (Table 5, quote 5), reduced attention span (Table 5, quote 6), and anger (Table 5, quote 8). One set of parents mentioned that their 4-year-old child developed better color and pattern recognition in addition to spatial orientation (Table 5, quote 6).

Most parents in the CG also provided positive feedback. Parents appreciated the one-on-one therapy sessions (Table 5, quotes 7 and 8). Parents gave positive feedback using words such as "improved independence," "good results," "happy," and "thankful for therapy" (Table 5, quote 7). Many parents in the CG reported improvements in the child's upper extremity function and increased level of independence (Table 5, quote 8). Parents from the CG observed that the children were actively performing daily tasks such as self-feeding and dressing activities since their participation in the GRP protocol.

Challenges

The experimental GRP protocol was updated every 4 weeks. Four parents felt that the 4 weeks was too long a period between exercise or game updates and commented that their child lost interest with their exercise when a game was used over the 4-week time period (Table 6, quotes 1 and 2). Parents expressed that it was challenging to understand the protocol during the first couple of sessions and 2-4 sessions were required for the child to learn how to use the gaming system (Table 6, quote 5).

The most common challenges reported by parents from the CG were about their child's compliance with therapy and engagement or interest with the exercise program (Table 6, quotes 3 and 4).

Table 6. Challenges faced by parents.

Group, parent, and ID	Quote number	Example quotes
XG[a]		
Mother 57	1	"We didn't have any difficulties during computer therapy, but I would have liked to see him do more games. Once he has achieved one game, see to it that you please give him other challenging games that will help him to improve more."
Mother 57	2	"When we started this therapy, our hope was that this will help our son in learning computers and his hand and arm will get stronger, more skillful."
Mother 18	5	"First 3-4 sessions, he struggled. It took time to realize what he was supposed to do, but now after so many sessions, he enjoys it."
CG[b]		
Mother 1	3	"Sometimes my child doesn't like the objects because he finds it a little difficult to hold and move the object."
Mother 10	4	"Well, the session takes really long; it's time consuming, I wish we could reduce the duration of the activities. He is starting to get tired of the things to do on the table."

[a]XG: experimental group.

[b]CG: control group.

Improving the Protocol

Many parents suggested adding educational games such as math and language games as well as computer games with a broader range of cognitive content (Table 7, quote 1). One parent from the CG suggested that the activities should be changed more regularly and to incorporate play-based, child-parent activities in the protocol (Table 7, quote 2). Most parents in the XG expressed their interest in continuing to use GRP instead of conventional therapy for their child's exercise program (Table 7, quote 3). Many parents from the XG suggested to provide the GRP platform as a home-based protocol and therefore to avoid costly and time-consuming travel to the rehabilitation center (Table 7, quote 4).

Table 7. Parents' suggestions to improve the protocol.

Group, parent, and ID	Quote number	Example quotes
XG[a]		
Mother 22	1	"Yes, this technology-based program is helping a lot in children's daily life. Integrating educational games, quiz games, and puzzle games would be a lot more helpful."
Mother 47	3	"We noticed a lot of changes during and after the computer (based) therapy program. Compared to his previous reports, we saw a lot of positive changes in his object handling and behavior. Whole-heartedly, I would request the treatment to be continued."
Mother 24	4	"My suggestion is that we should make these kids play these games more often, or if I could get her to do it at home, she will have more practice."
CG[b]		
Mother 7	2	"My suggestion would be to add more variety of activities to his therapy. In one session, he does a lot of activities, but it's the same every time we come. He needs something more fun and games, something more age appropriate."

[a]XG: experimental group.

[b]CG: control group.

Discussion

Principal Findings

The findings from this study establish that the parents recognized that their expectations related to improving their children's object handling and manipulation skills, including participation in ADL, were addressed during the 16-week therapy program. Parents perceived a change in their children's level of independence in their daily tasks at home, school, and leisure activities. Parents also shared the challenges they faced regarding children's participation in therapy and the experiences with the game-assisted exercise program.

Therapies such as CIMT and HABIT have established the importance of task-specific training [29]. Most parents identified the focus on handling and manipulating objects as an important feature of the GRP exercise program and that it included many different objects used in day-to-day life. Parents from the XG commented on several benefits of coupling object manipulation exercises with common computer games. Interaction with the game activities required children to manipulate each object using precise movements of varying speed and amplitudes.

Different games were chosen to increase the precision level of the task (ie, small game paddles and game targets). Several studies also support the principles of goal-directed therapy for improved motor learning outcomes in children with CP [30-32].

The main focus of the game-assisted exercise program was to increase the number of repetitions. Typically, each game was played for 5-7 minutes, and the duration of each game event lasted an average of 2 seconds. Therefore, each of the objects was moved at least 100 times, which is a high number of repetitions of goal-directed activity. For most games, the game targets appear at random locations or move in unpredictable trajectories or directions (ie, variable practice). In addition, visual feedback of the game paddle was used to initiate and guide the movement responses; the child views the game events and not the object being manipulated. This type of practice would promote implicit learning of hand-eye coordination [12].

Parents from the XG reported that the exercises were challenging, yet engaging, and their children enjoyed playing the games. They felt that this gratification was important and improved the children's compliance with the therapy program. Previous studies that have compared the results of the use of computer games versus conventional therapy in terms of patient acceptability have observed similar results [33].

Many parents from the XG asked about where they could obtain other low-cost or free computer games suitable for use with the IB mouse. Understandably, updating and progressing the protocol regularly to maintain the level of difficulty and providing a new set of games to play were noted by the parents as important aspects to maintain interest and participation. Parents commented that this would likely require a large pool of different computer games. Practically, this can be difficult to achieve because, although there are a number of commercial games readily available online, not all games are suitable for each object manipulation task or for young children who have substantial motor impairments of the upper extremities.

Initially, children with severe impairments could only play games that involved slow movements and low precision (ie, large paddle size and large game target objects). On the other hand, children with moderate to mild impairment could play a larger variety of games with increased movement speeds, higher precision levels, and added cognitive content.

Parents from the CG provided mixed reviews regarding the children's interest and compliance in their exercise programs over the 16 weeks. Previous studies reported caregivers' and children's increased levels of frustration and discomfort due to the restraint used for modified CIMT and CIMT protocols [26,28-34]. Parents perceived that the cognitive activities of the GRP did contribute to improvements in their child's manual dexterity, handwriting, hand-eye coordination, and cognition, as well as notable improvement in some ADL (ie, feeding, dressing, and participation in play activities). For example, the games selected included activities for logic, problem-solving, visual search and attention, cognitive inhibition, set-shifting, verbal and nonverbal memory, color and shape recognition, and others. Previous studies have reported that the use of computer games as well as educational computer programs can benefit from academically relevant content and other cognitive skills [35]. Parents from the CG also reported that, following the supervised therapy program, their children had improved fine motor skills. They identified that one-on-one supervision provided by the therapist was important in getting the children to practice their respective exercises.

The results of the quantitative analysis (in preparation) will allow us to determine the treatment effect size and whether an exercise program using the GRP is superior to the conventional therapy program.

Limitations

One limitation of the study was not obtaining the views of the children directly. Future studies should take into account the views and experiences of the children and not just rely upon their parents to provide this information. The number of interviews in the XG was higher than the number of interviews in the CG. It is not known why more parents in the CG declined to consent to be interviewed as compared to parents in the XG.

Conclusion

This study demonstrated the feasibility and acceptability of the GRP platform for hand and arm function rehabilitation in children with CP. Parents who participated in the interview responded positively towards the use of the GRP and requested to continue with this therapy program after completing the 16-week intervention. Parents from the XG expressed that their children were more engaged during the GRP protocol as compared to the conventional protocols from the past. The challenges faced by parents regarding children's engagement in the protocol might be easily resolved by updating the protocol more often or by changing the difficulty levels of the tasks.

Conflicts of Interest

None declared.

Multimedia Appendix 1
List of games.
[PDF File (Adobe PDF File), 208 KB - rehab_v8i2e24337_app1.pdf]

Multimedia Appendix 2
CONSORT diagram.

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[PDF File (Adobe PDF File), 335 KB - rehab_v8i2e24337_app2.pdf]

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Abbreviations

ADL: activities of daily living
CG: control group
CIMT: Constraint Induced Movement Therapy
CP: cerebral palsy
GMFCS: Gross Motor Function Classification System
GRP: computer game–based rehabilitation platform
HABIT: hand-arm bimanual intensive training
IB: inertial based
MACS: Manual Ability Classification System
MMSE: Mini-Mental State Examination
PDMS-2: Peabody Developmental Motor Scales - Second Edition
RCT: randomized controlled trial
RTP: repetitive task practice
XG: experimental group

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Original Paper

Zero-Effort Ambient Heart Rate Monitoring Using Ballistocardiography Detected Through a Seat Cushion: Prototype Development and Preliminary Study

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Abstract

Background: Cardiovascular diseases are a leading cause of death worldwide and result in significant economic costs to health care systems. The prevalence of cardiovascular conditions that require monitoring is expected to increase as the average age of the global population continues to rise. Although an accurate cardiac assessment can be performed at medical centers, frequent visits for assessment are not feasible for most people, especially those with limited mobility. Monitoring of vital signs at home is becoming an increasingly desirable, accessible, and practical alternative. As wearable devices are not the ideal solution for everyone, it is necessary to develop parallel and complementary approaches.

Objective: This research aims to develop a zero-effort, unobtrusive, cost-effective, and portable option for home-based ambient heart rate monitoring.

Methods: The prototype seat cushion uses load cells to acquire a user's ballistocardiogram (BCG). The analog signal from the load cells is amplified and filtered by a signal-conditioning circuit before being digitally recorded. A pilot study with 20 participants was conducted to analyze the prototype's ability to capture the BCG during five real-world tasks: sitting still, watching a video on a computer screen, reading, using a computer, and having a conversation. A novel algorithm based on the continuous wavelet transform was developed to extract the heart rate by detecting the largest amplitude values (J-peaks) in the BCG signal.

Results: The pilot study data showed that the BCG signals from all five tasks had sufficiently large portions to extract heart rate. The continuous wavelet transform–based algorithm for J-peak detection demonstrated an overall accuracy of 91.4% compared with electrocardiography. Excluding three outliers that had significantly noisy BCG data, the algorithm achieved 94.6% accuracy, which was aligned with that of wearable devices.

Conclusions: This study suggests that BCG acquired through a seat cushion is a viable alternative to wearable technologies. The prototype seat cushion presented in this study is an example of a relatively accessible, affordable, portable, and unobtrusive zero-effort approach to achieve frequent home-based ambient heart rate monitoring.

Introduction

Cardiovascular diseases are a leading chronic illness and are cited as the cause of death for nearly 17.9 million people worldwide every year [1]. In Canada alone, 2.4 million people are living with a diagnosed heart condition [2]. Cardiovascular diseases have large associated costs, which are estimated to exceed US $1 trillion by 2035 [3]. Population aging is one of the most significant social changes of the century, in part

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because the number of older adults with chronic health conditions who are living independently is increasing [4]. Most chronic conditions require frequent and continuous monitoring of vital signs and other health information to support ongoing treatment. The rapidly increasing number of older adults, who have a higher prevalence of chronic conditions, is leading to an unavoidable and significant increase in health monitoring for our global population [4,5].

The most important step toward the prediction, prevention, and treatment of cardiovascular diseases is cardiac vital monitoring, as it provides important information about a person's cardiac health, which, in turn, supports ongoing management and care [6,7]. This is performed through routine visits to a clinic to record vital signs (ie, measures of the state of one's body, including heart rate, blood pressure, temperature, and respiration). In addition to the financial cost and resources required to conduct a clinical assessment, accessing a clinical setting on a regular basis is not feasible for many people. This is especially true for people with limited mobility, who live in rural or remote areas or who have cognitive decline (eg, dementia). These situations can make frequent trips to a clinic for vital sign measurements expensive, difficult, and unrealistic.

To address this need, there is an increasing demand for technologies that enable the monitoring of vital signs from one's home. The most common method for at-home vital sign monitoring is wearables [8-13]. Wearables are smart electronic devices that can be worn as accessories or integrated into clothing, such as smartwatches or smart clothing. Although wearables can be effective, they are not an ideal or feasible solution for everyone. Incorrect usage, noncompliance, and instances where users forget to use them can cause these technologies to be ineffective. These considerations are especially relevant for older adults, as they tend to have a lower adoption rate of monitoring technologies and have more difficulties using them. Older adults also have a much higher prevalence of cognitive impairment, such as dementia, which can make it difficult or impossible to intentionally and reliably interact with, wear, or charge a technology.

Ambient assisted living (AAL) is increasingly being used to support independent living, namely, information and communication technologies that support healthy living and well-being. AAL systems can monitor a person's health status using sensors installed in their environment (eg, their home). Zero-effort technologies (ZETs) are a special class of technologies relevant to this area that are designed to require minimal or no explicit effort from the person using them. In this way, ZETs support users in such a way that they do not need to make modifications to their daily life activities nor do they need to focus their attention on the ZET to get support from it [14]. There has been some development in textile-based clothing for vital monitoring using textile electrodes, conductive fibers, and optical sensors [8-13]. However, these systems are not yet feasible because of issues related to cost, comfort, and durability. Therefore, given the increased costs and decreased feasibility of clinical monitoring and the problems associated with technologies such as wearables, there is room for improvement in at-home cardiac monitoring with easy-to-use technologies that operate autonomously.

While clinical monitoring and wearable technologies use electrocardiography (ECG) and photoplethysmography (PPG), another method of obtaining cardiac vital signs is through ballistocardiography (BCG). BCG is a cardiovascular signal that corresponds to the measurement of recoil forces generated by the body in response to blood flowing through a person's vascular system [15,16]. Every time the heart beats, blood is pumped throughout the body, leading to a change in the center of mass. Microforces are then generated in the body as a response to the heart pumping blood to maintain the overall momentum. BCG is a recording of these micromovements and can be obtained using appropriate transducers, such as displacement, force, or acceleration.

BCG was first observed in 1877 [17], but ECG became the fundamental cardiovascular signal for clinical assessment because the noisy nature and hardware requirements of BCG were not practical during most of the last century. Since the 1990s, the scientific community has revisited BCG because of its simpler and more compliant instrumentation hardware and modern signal processing methods. This has resulted in the development of many BCG-based systems for cardiac monitoring and assessment, which are discussed as follows.

BCG has commonly been acquired in a standing position using a platform incorporated with force sensors, such as a bathroom scale [17], force plate [18], or custom-built floor tiles [19]. Although the standing upright position provides the least distorted BCG signals [20], a disadvantage of this approach is that the noise caused by the person moving to maintain balance is far greater than the BCG signal itself; therefore, the balance-induced noise masks the BCG signal. The measurement duration is often limited, as a person generally only stands still for only a few seconds at a time, even in specific locations such as in front of a sink. Wearable BCG systems have been reported in the literature. These systems use low-noise accelerometers to obtain BCG [21,22]. Wearable BCG systems are prone to the same noise issues as standing-position BCG systems as well as compliance and maintenance issues related to wearables, in general.

There has been some progress in BCG acquisition methods in the seated position. Most of these systems use electromechanical film sensors to obtain BCG, which is a charged polypropylene film that undergoes changes in the charge when pressure is applied to its surface [23]. Most chair-based systems have sensors embedded in the back or seat of a chair [24-27]. A toilet seat–based cardiovascular monitoring system has been reported to obtain BCG, ECG, and PPG from sensors embedded within the seat [28]. The seated position mitigates much of the noise interference problems associated with the standing position, as people tend to remain still in a seated position for a long period. However, current BCG systems in the seated position have disadvantages; most of these systems have used films, which are costly and have very limited commercial availability, and these systems are usually installed in a piece of furniture, which is less practical to do and not portable (ie, you need a special chair and it cannot be moved easily).

There is a need for novel solutions for cardiac monitoring that are autonomous, portable, and cost-effective. This research

focuses on the development of an unobtrusive, portable, zero-effort seat cushion that uses BCG for cardiac monitoring.

Methods

Overview

To develop a method for BCG acquisition that is portable, easy to integrate into most environments, and requires minimal effort from the user, a seat cushion was chosen as the form factor of the proposed prototype. As BCG corresponds to recoil forces in the body due to blood flow, load cells are commonly used to sense and convert these forces to electrical signals and are a robust, well-understood sensor. To ensure minimal cost and relative ease of development for the prototype, a commercial

weighing scale (with load cells installed underneath) was modified and inserted into the seat cushion, as described in the following section.

Seat Cushion Prototype

Figure 1 shows the seat cushion prototype. The seat cushion was constructed by modifying an ObusForme Gel Seat cushion and consists of three layers. The top layer is a polyurethane foam wrapped over and around a modified weighing scale (NY-H05), which forms the second layer. The weighing scale has four strain gauge–type load cells, one mounted on each corner of the bottom of the scale. The third and bottom layer is a custom-built thin (0.8 mm) metal plate placed under the modified weighing scale, so that the load cells were placed on a solid surface.

Figure 1. The developed prototype seat cushion (left) and a participant seated on the cushion (right).


Signal Conditioning and Data Acquisition

The four load cells were connected in a bridge configuration and excited by a 9V direct current (DC) power source. As the microforces in the body in response to blood flow (corresponding to the BCG) are very low in magnitude, signal amplification was required. An analog signal-conditioning circuit was developed, which consists of three stages, as shown in Figure 2. The first stage is an alternating current

(AC)–coupled instrumentation amplifier (acting as a high-pass filter with f_c of 0.15 Hz) to ensure that the time-varying component (the BCG) from the load cell voltage is enhanced, and the DC component corresponding to the body weight is suppressed. The BCG signal has most of its power in the frequency range of 1-10 Hz [29]; therefore, the second stage is a low-pass filter with f_c of 25 Hz. The third and final stage further amplifies the filtered signal. The circuit has an overall gain of 88 dB and a passband of 0.15-25 Hz.

Figure 2. The analog signal-conditioning circuit. BCG: ballistocardiography; IN-AMP: instrumentation amplifier; REF: reference; Vout: output voltage.
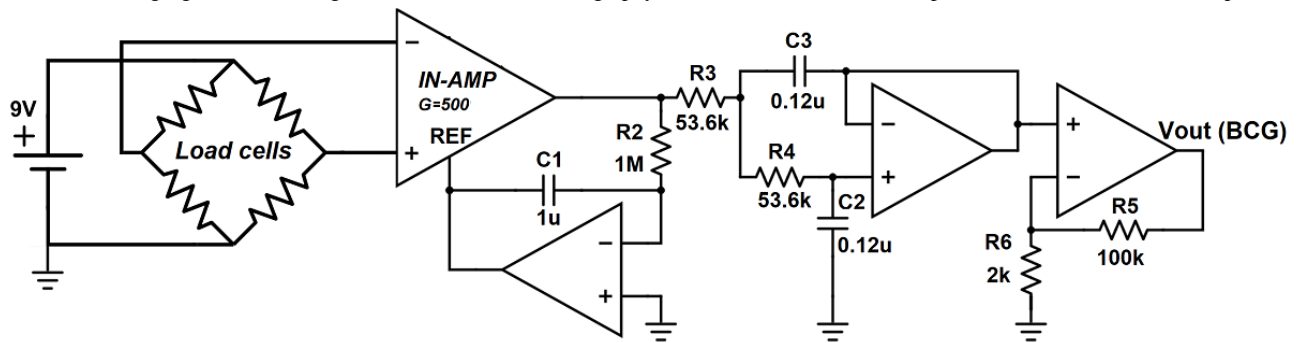
The filtered and amplified signal output was then converted to digital form using a data acquisition system (National Instruments USB-6351). A digital bandpass filter (0.5-15 Hz) was applied before further processing for heart rate calculation.

Study Protocol

The physical movement exerted by the person being monitored dominates the signal, leading to the BCG information being unrecognizable. It was hypothesized that a few seconds of relative stillness per minute would be sufficient to obtain a BCG signal and that there would be appropriate windows during typical activities that people do while seated (eg, reading and watching television). To evaluate the prototype efficacy, a study was conducted to emulate real-world activities to determine whether usable BCG data could be extracted from the seat cushion prototype. Five daily life activities were selected: (1) sitting as still as possible, (2) watching a video on a computer screen, (3) reading a magazine, (4) surfing the internet on a computer, and (5) having a conversation with another person.

After obtaining ethical approval from the University of Waterloo Office of Research Ethics (ORE #40503), recruitment for 20 participants aged ≥18 years was determined. Each participant completed a demographic form asking for their age, sex, weight, and height. The participant was then asked to sit on the prototype seat cushion, which was placed on a chair. ECG electrodes were attached, and the ECG recorded to serve as a gold standard comparison for validating BCG data; ECG was captured using a Finapres Medical Systems ECG Module in a Lead-II configuration. Participants were asked to perform each of the five activities for 5 minutes each while BCG and ECG were recorded simultaneously.

Postprocessing: BCG Data During Activities

Data segments containing identifiable BCG were isolated from segments that were overwhelmed by motion artifacts using a variance-based method. This method was used because the signal voltage undergoes a large variation when there is movement compared with when the participant was sitting still. A moving windowed variance (Var_{mov}) with a window size of 1 second was computed for the BCG signal, and after trying different thresholds between $mean(Var_{mov})$ and $\frac{1}{4} mean(Var_{mov})$, a threshold value equal to $\frac{1}{2} mean(Var_{mov})$ was found to be the most appropriate in distinguishing signal segments with motion artifact. All signal segments (windows) with variance above this threshold had too many motion artifacts and were discarded. Of the data that had identifiable BCG, only signal segments with a duration of 5 seconds or longer were kept to ensure that enough consecutive heartbeats were obtained to calculate heartbeats as slow as 40 beats per minute (ie, a bottom threshold that is lower than anyone's resting heart rate would be).

Figure 3 shows 5 minutes of BCG data obtained from a participant during the study and the moving windowed variance applied to the signal. It can be observed that the selected moving variance function is able to detect noisy segments (with motion artifacts) in the BCG data, as they have significantly large variance. This method was applied to BCG recordings of all participants for four activities; the *sitting as still as possible* activity was excluded, as all participants were still during this activity; therefore, most of the data contained a signal that could be directly analyzed.

Figure 3. Five minutes of ballistocardiography data obtained from a participant (top). The moving windowed variance function applied to the signal. Signal segments above the threshold were discarded (bottom). BCG: ballistocardiography; Var: variance.
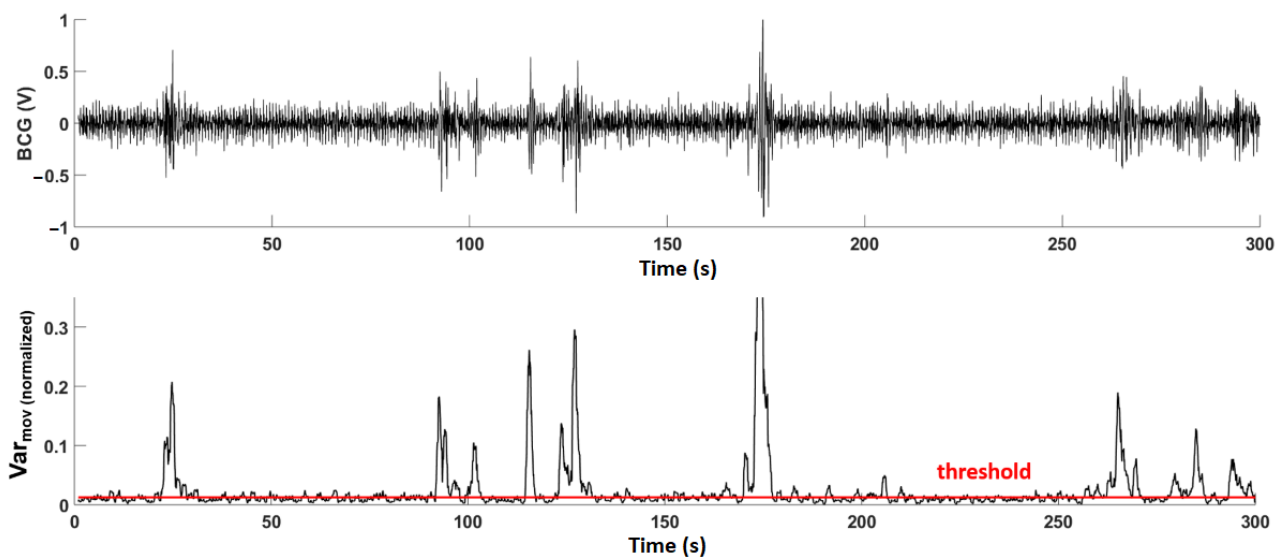

Postprocessing: BCG J-Peaks Detection for Heart Rate Calculation

Similar to the R-peaks in an ECG signal, the largest signal amplitude in the BCG during a heartbeat is referred to as the J-peak. A count of these J-peaks can be used to estimate heart rate; however, as J-peaks do not stand out as much from the rest of the signal as R-peaks do in ECG, it can be difficult to detect them (Figure 4). Most J-peak detection methods reported in the literature have extracted heartbeat segments in the BCG signal by using ECG R-peaks as reference [30-32].

Figure 4. Electrocardiography (top) and ballistocardiography (bottom) recordings obtained simultaneously from a participant. BCG: ballistocardiography; ECG: electrocardiography.
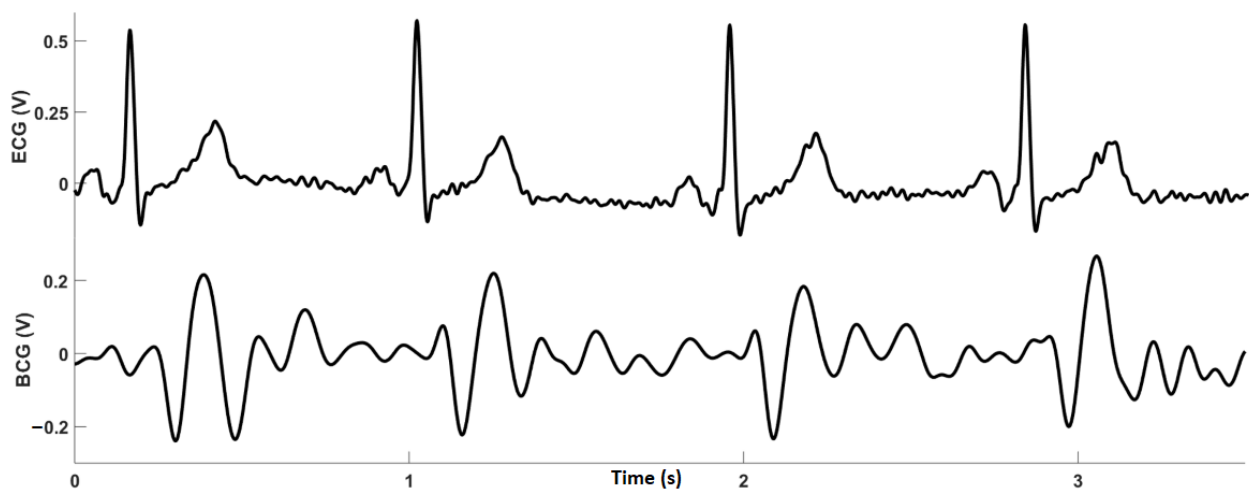
J-Peak Detection Using Continuous Wavelet Transform

As the aim of this study was to calculate heart rate information solely from the BCG acquired through the seat cushion, methods that do not require ECG had to be considered, such as beat-to-beat heart rate estimation methods [33,34]. An algorithm based on the continuous wavelet transform (CWT) was developed, as wavelet analysis has been performed extensively on heart rate signals [35-38]. CWT is a method that helps in analyzing local variations in frequency in a time series by decomposing the signal into time-frequency space. It provides essential information about the dominant frequencies and how they locate in time. Although the Fourier transform provides accurate information about the frequency content of a signal, it does not provide information about how these frequencies are located in time. The windowed Fourier transform can provide some localized frequency information, but it is not efficient for signals with abrupt changes, such as in the case of BCG [39]. The CWT is an efficient tool in this instance, as it can help identify when (or at what scale of the analyzing wavelet) dominant frequencies are present in the BCG signal. Therefore, the CWT can be used to identify the locations of the heartbeat segments in a BCG signal.

The CWT can be described as follows: Let x_n be a discrete-time signal with a length of N (n=0, 1, 2, 3, ..., $N-1$), where all n points have the same time spacing δt. The CWT of x_n, denoted by $W_n(s)$, is defined as

where Ψ^* is the complex conjugate of $\Psi(n)$, which is the analyzing wavelet function, and s is the scaling factor. The equation mentioned earlier shows that the wavelet transform is obtained by the convolution of x_n with scaled and translated versions of $\Psi(n)$ [40], depending on the parameter s. The analyzing wavelet $\Psi(n)$ has two important properties, that is, it is limited in time and has zero mean [41]. The choice of the analyzing wavelet depends on the analysis being performed; for this case, a Morlet wavelet was used because of its similarity to the BCG waveform and its wide use in biomedical analysis [42-45].

In the methods described in the literature, wavelet transforms have been used for noise cancelation, followed by template matching [35] and the use of different CWT scales for different subjects [36]. However, in this study, the same CWT scale was used for all participants to keep the algorithm autonomous.

Wavelet analysis was performed on the BCG using MATLAB to determine which scales in the CWT provided the most useful information about the time localization of heartbeat segments. A scalogram of the CWT was plotted to observe the scales that contributed the most energy during heartbeat segments. Figure 5 shows a scalogram for a BCG recording obtained during the study, describing the energy for each wavelet coefficient for each scale in time. The figure shows that scales 27-31 provide the most differentiable heartbeat information in the BCG (distinguishable by green, yellow, and red areas in the scalogram image). After testing these five scales, it was observed that scale 30 worked best for all participants, as it provided the largest magnitudes during heartbeat segments. The magnitude plot of the CWT coefficients at scale 30 (CWT_{30}) is also shown in Figure 5.

Figure 5. Ballistocardiography (BCG; top) recording with the J-peaks labeled and the continuous wavelet transform (CWT) for the recording with the 400-ms window for heartbeat extraction labeled. Scalogram for CWT of the BCG recording (bottom). BCG: ballistocardiography; CWT: continuous wavelet transform.
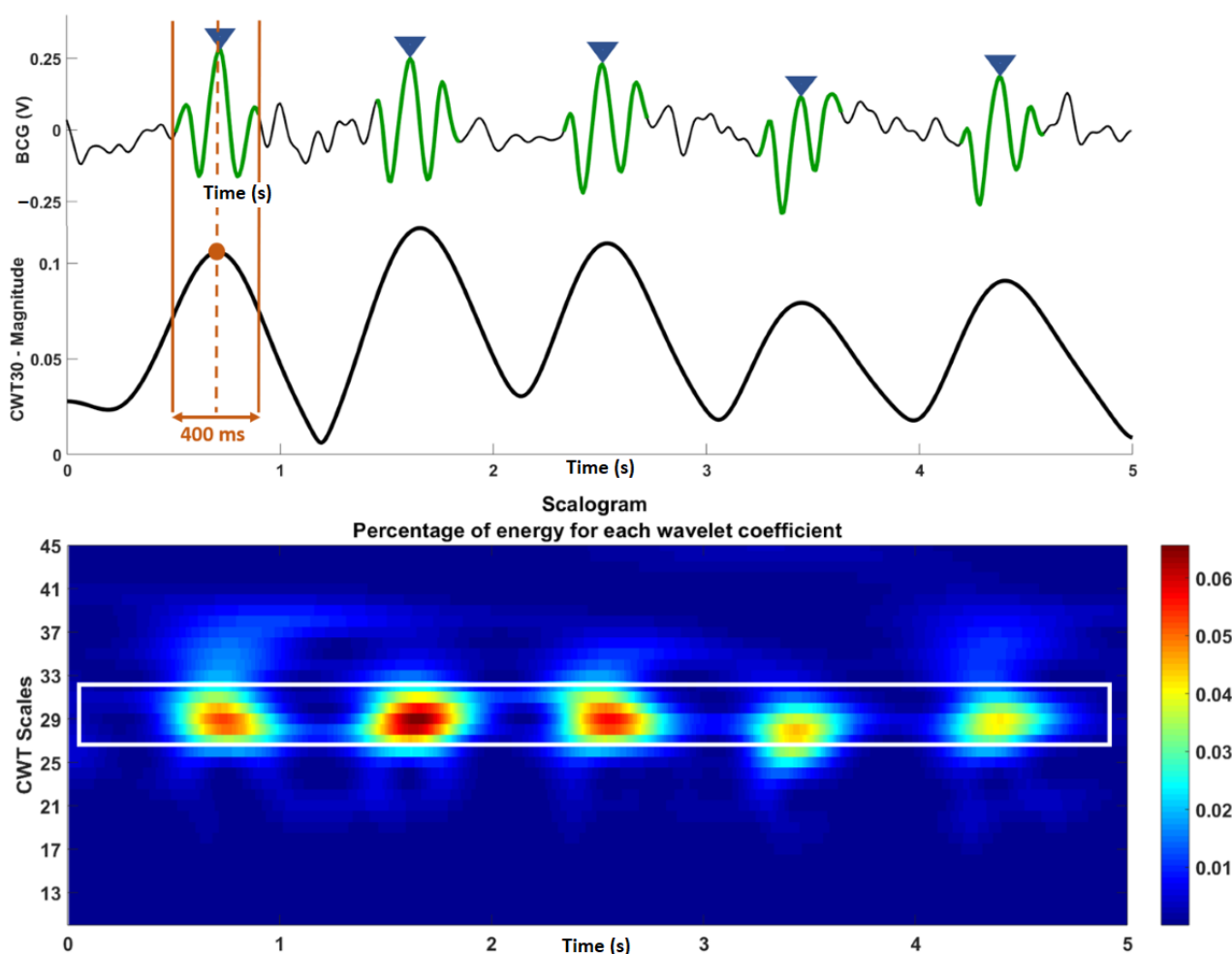
It can be observed in Figure 5 that CWT_{30} has a repetitive pattern with a series of peaks directly related to heartbeat segments in the BCG, indicating that the maximum energy in the BCG lies in the areas around these peaks (in time). Therefore, these peaks of the CWT_{30} can help identify BCG heartbeat segments. It was observed that for most participants, the typical BCG waveform was approximately 400 ms in duration; therefore, 400 ms windows (corresponding to heartbeats) from the BCG were extracted using time indices obtained from the locations of the peaks in CWT_{30}. J-peaks were then autonomously searched for only during these segments, thereby decreasing the chances of

incorrectly labeling J-peaks in the BCG. J-peaks were labeled by setting an amplitude threshold equal to the mean of all heartbeat segments. In addition, a time-based threshold was also set, where a J-peak was labeled only if it was at least 500 ms apart from the previous J-peak. This allowed the calculation of heart rates as high as 120 beats per minute, which is well within the normal resting heart rate limit [46].

The CWT analysis and J-peak detection were performed for 1 minute of BCG data obtained from the 60- to 120-second portion of the Sitting Still activity for all 20 participants. This segment was chosen because some participants spent a few seconds adjusting their posture and then remained seated still for the rest of the activity; therefore, data after the first 60 seconds were taken to be representative of the sitting still activity. The performance of the algorithm for J-peak detection was compared with the corresponding R-peaks in the ECG.

Estimating Signal-to-Noise Ratio

The signal-to-noise ratio (SNR) for the BCG was estimated using the method presented in a study by Bialasiewicz [44],

which was also used in the studies by Inan et al [30], Shao et al [47], and McCall et al [48]. The SNR is estimated using the following equation:

In the abovementioned equation, E_1 is the subensemble average of the first 10 seconds of the BCG signal, and E_2 is the same for the next 10 seconds. N is the total number of samples in the subensemble average. A subensemble average is the average of all the heartbeat segments in a BCG for a certain duration (in this case, 10 s).

Results

Participant Demographics

Table 1 gives an overview of the demographics of the study population.

Table 1. Participant demographics (N=20; 13 female and 7 male).

Participant ID	Sex	Age[a] (years)	Height[b] (cm)	Weight[c] (kg)
1	Female	41	171	61
2	Female	23	163	56
3	Male	34	168	59
4	Female	24	160	56
5	Female	23	182	72
6	Male	24	178	65
7	Male	24	183	75
8	Male	24	180	75
9	Female	27	165	56
10	Female	73	160	90
11	Female	22	160	49
12	Male	26	183	100
13	Female	27	158	65
14	Male	29	178	95
15	Male	43	173	128
16	Female	81	168	75
17	Female	75	157	65
18	Female	84	167	63
19	Female	75	178	72
20	Female	80	159	59

[a]Mean 42.9 (SD 24.2).

[b]Mean 169.5 (SD 9.1).

[c]Mean 71.8 (SD 18.8).

BCG During Activities

Figure 6 shows 15 seconds of BCG recordings for each of the five activities obtained from participant 1. Table 2 summarizes

the results for four simulated activities (the *sitting still* activity was excluded because all participants remained seated still and did not perform any voluntary movement during the recording; therefore, it had long segments of detectable data).

Figure 6. Example data obtained from participant 1 for all five activities. Circles mark J-peaks in the ballistocardiography. Dotted boxes mark noisy signal segments due to motion artifact. BCG: ballistocardiography.
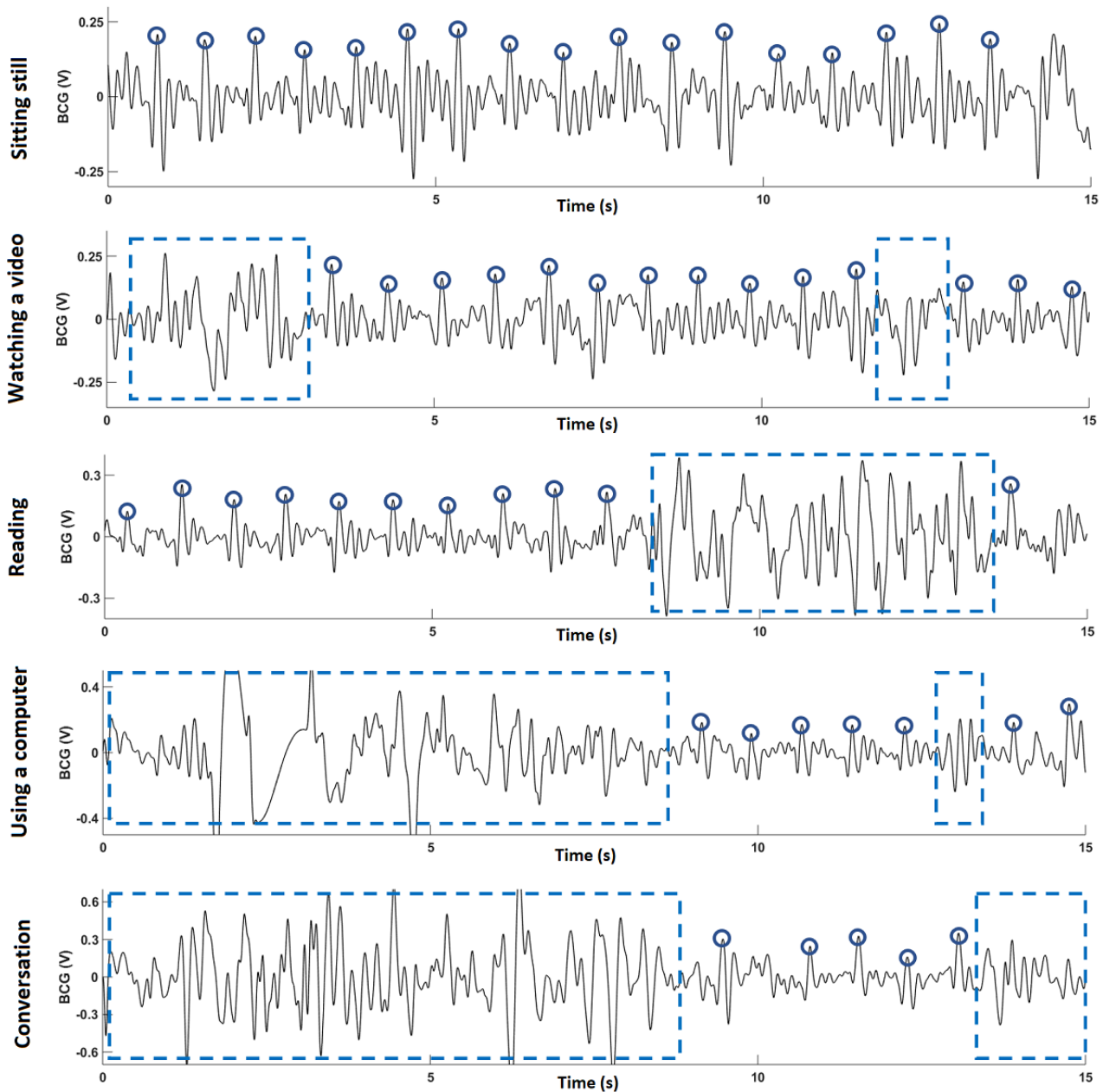
Table 2. Results for four simulated activities for 5 minutes each for 20 participants for segments ≥5 seconds.

Activity	Shortest segment (s), mean (SD)	Longest segment (s), mean (SD)	Total number of segments, mean (SD)	Total duration of segments (s), mean (SD)	Total recording containing clean ballistocardiogram data, %
Watching a video	13.1 (13.5)	78.1 (42.4)	9.3 (3.6)	264.6 (24.9)	88.2
Reading	5.9 (1.3)	38.5 (18.6)	12.5 (2.5)	177.9 (50.5)	59.3
Conversation	5.4 (0.4)	20.8 (11.1)	9.8 (3.3)	97.1 (41.3)	32.3
Using a computer	5.4 (0.6)	18.5 (11.2)	9 (3.9)	89.1 (56.1)	29.7

As shown in Figure 6, the J-peaks are readily identifiable when a person is seated still on the prototype. During the watching a video activity, all participants remained seated still for most of the time (an average of 88.2% of the time). For the reading activity, large motion artifact was observed, as turning a page while reading led to significant movement, causing the average duration containing clean BCG to be as low as 59.3%. Similar results were obtained when using a computer activity, as typing on a keyboard leads to significant movement. For the conversation activity, a large variation in time spent sitting still was observed throughout all participants because of different behaviors during a conversation, as some participants used body

gestures more often than others. On average, across the four activities, the participants remained seated still for almost one-third of the time.

CWT-Based J-Peak Detection Method

The results for the CWT-based J-peak detection algorithm for all 20 participants are summarized in Table 3; the R-peaks in the ECG are included for comparison. A true J-peak positive is a J-peak that was correctly identified by the algorithm. A false positive is a peak that was incorrectly identified as a J-peak. An undetected true J-peak positive is a true J-peak that was not detected (missed) by the algorithm. A visual analysis was conducted to compare the results of the J-peak detection algorithm with the ECG data to establish true positives, false positives, and undetected J-peaks. The sixth column in Table 3 shows the percentage of true J-peak positives compared with the corresponding ECG R-peaks. Overall, the CWT-based algorithm achieved an average accuracy of 91.4% for J-peak detection. The accuracy was more than 90% for 14 participants, whereas for 3 participants (participants 4, 15, and 20), the accuracy was less than 80%. For illustrative purposes, Figure 7, Figure 8, and Figure 9 show 7 seconds of BCG and ECG data from participants 6, 20, and 4, respectively.

Table 3. Performance analysis of the continuous wavelet transform–based J-peak detection algorithm.

| Participant ID	Total R-peaks	True J-peak positives	False J-peak positives	Undetected true J-peak positives	True J-peak positives[a], %	Signal-to-noise ratio[b], dB
1	73	72	0	1	98.6	36.3
2	84	80	2	2	95.2	33.5
3	81	77	1	3	95	43
4	69	46	19	4	66.6	19.9
5	69	61	5	3	88.4	25.7
6	77	77	0	0	100	38.2
7	74	60	8	6	81	26.6
8	67	67	0	0	100	41.2
9	76	73	1	2	96	30.7
10	73	71	1	1	97.2	34.8
11	71	67	3	1	94.3	26.4
12	73	71	1	1	97.2	28.8
13	70	67	1	2	95.7	35.5
14	60	59	0	1	98.3	43.5
15	78	60	16	2	76.9	19.6
16	58	56	2	0	96.5	27.9
17	74	71	3	0	95.9	28.8
18	62	50	11	1	80.6	25.9
19	58	57	1	0	98.2	37.4
20	63	48	15	0	76.1	30.1

[a]Mean 91.4 (SD 9.4).

[b]Mean 31.7 (SD 6.9).

Figure 7. Seven seconds of electrocardiography and ballistocardiography (BCG) recordings for participant 6. The BCG signal is clean, and the algorithm is able to detect all J-peaks correctly. BCG: ballistocardiography; CWT: continuous wavelet transform; ECG: electrocardiography.
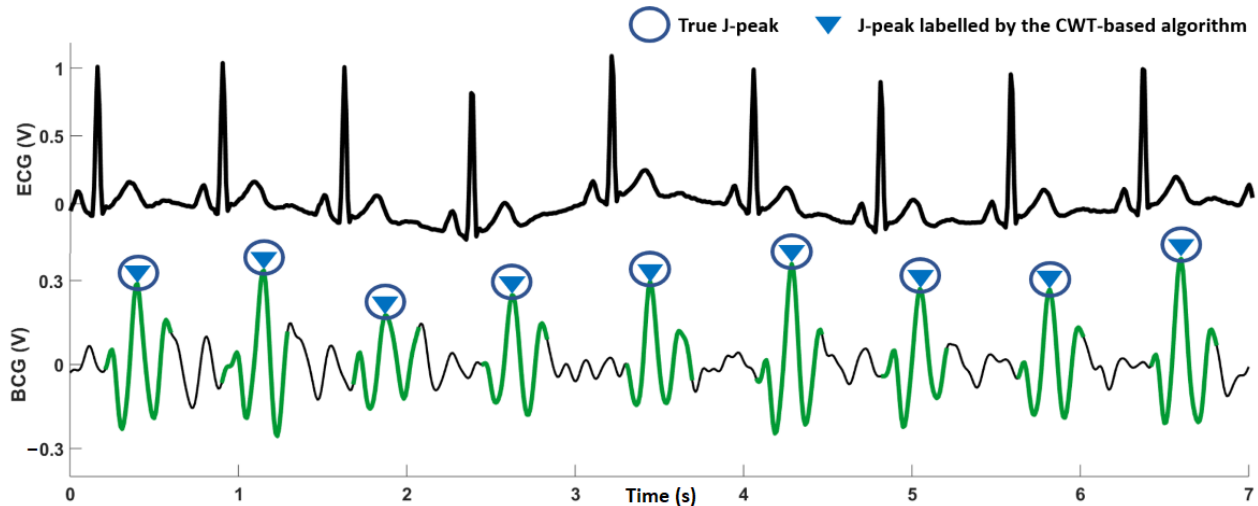
Figure 8. Seven seconds of electrocardiography and ballistocardiography recordings for participant 20. The signal visually appears to be of good quality, but J-peaks amplitudes are not significantly greater than the signal around them, causing the algorithm to label some J-peaks incorrectly. BCG: ballistocardiography; CWT: continuous wavelet transform; ECG: electrocardiography.
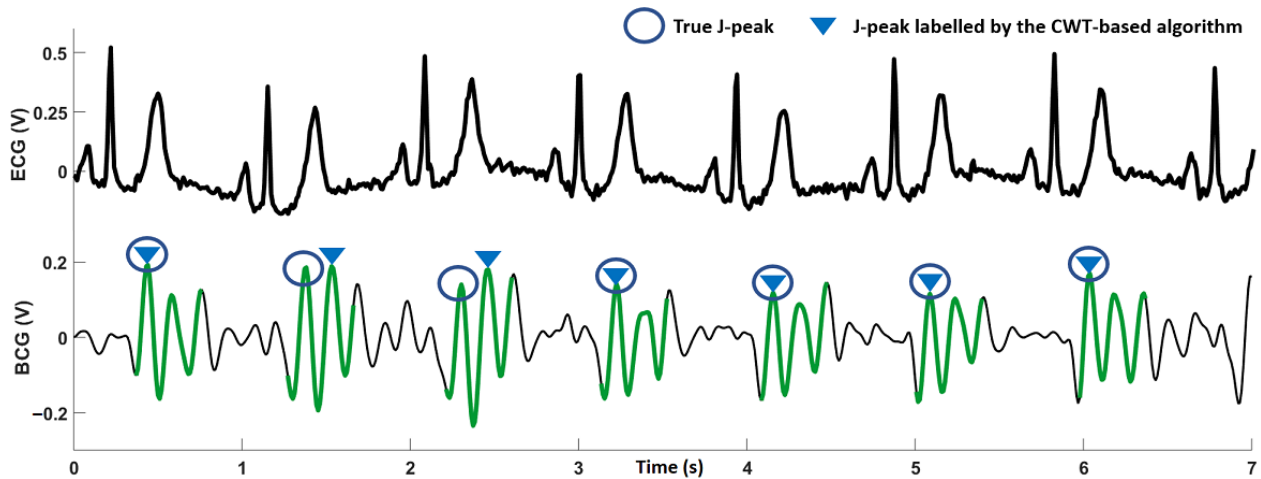
Figure 9. Seven seconds of electrocardiography and ballistocardiography recordings for participant 4. The signal is of poor quality visually, and the J-peaks are not easily distinguishable. This signal also had a very low signal-to-noise ratio. BCG: ballistocardiography; CWT: continuous wavelet transform; ECG: electrocardiography.
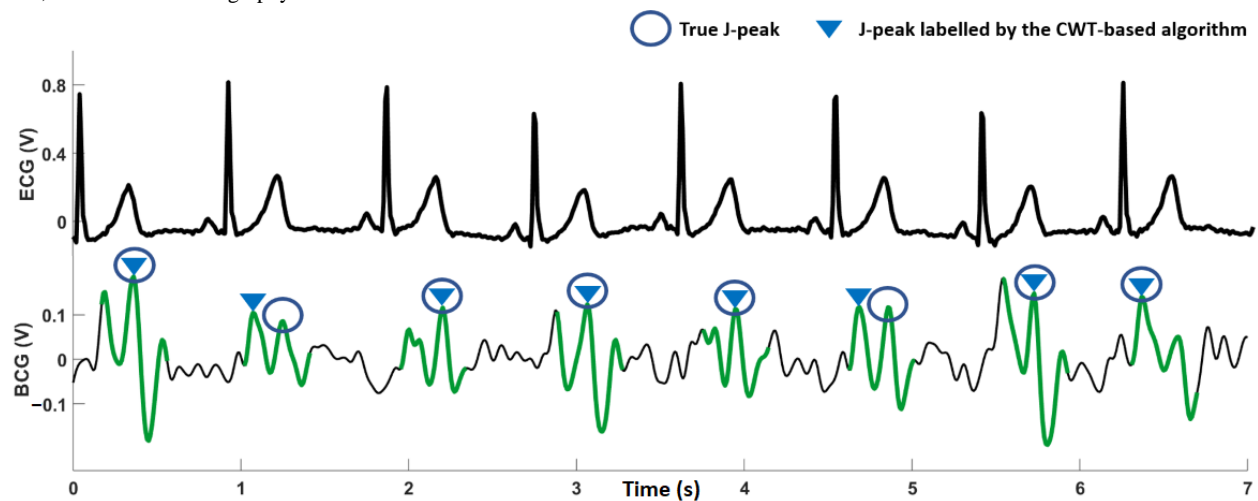
Discussion

Principal Findings

The results in Table 2 indicate that there is a substantial number of signal segments (longer than 5 s) during all activities where the person is seated still, resulting in high-quality BCG data. The presence of a large number of these clean heartbeat segments enables the extraction of heartbeat data, which suggests that the seat cushion can be an effective method for continuous monitoring of heart rate using BCG.

Visual analysis of the data in Table 1 was performed for possible correlations between BCG signal shape and age, sex, or weight; none were found.

The CWT-based algorithm performed well for the participants in this study. For example, for participant 6, the CWT-based method was able to correctly identify all J-peaks in the BCG trace, as shown in Figure 7. The amplitudes of the J-peaks are larger than the signal segments around them, which is also evident from the high SNR obtained for the BCG signal (Table 3). The BCG for participant 20 (Figure 8) shows that the signal visually appears to be of good quality, with an SNR just below average. However, the amplitudes of the J-peaks for this participant were not much larger than the other peaks in the signal around them. This caused the algorithm to label some J-peaks incorrectly and correctly identify only 76% (48/63) of true J-peak positives. As shown in Figure 9 for participant 4, it can be observed that the signal quality is poor; the J-peaks are not clearly discernible because they have low amplitudes compared with the signal around them during a heartbeat. This is corroborated by the low SNR obtained for this signal (19.9 dB). The accuracy of J-peak detection was the lowest for this participant. For participant 20, as mentioned earlier, a low J-peak detection accuracy was obtained for a relatively high SNR. This is a limitation of the algorithm, as it can generate inaccurate values of heart rate because of incorrect identification of J-peaks, even for BCG signals that are visually robust.

Excluding the three outliers, the algorithm resulted in an average accuracy of 94.66% (1136/1200). Commercially available wearable devices that use PPG as the signal to calculate heart rate have been evaluated in studies for accuracies between 79.8% to 99.1% [49] and 94.04% to 94.14% [50]. This suggests that the performance of the seat cushion prototype is comparable with that of commercially available wearable devices.

We note that the detection accuracy for the proposed algorithm would be increased by using ECG R-peaks as a reference to detect J-peaks. However, this research focused on calculating heart rate by having a person simply seated on a cushion without them having to wear or attach any sensors, which is a requirement for the acquisition of an ECG signal.

The limitations of the J-peak detection algorithm can be improved. In this study, the CWT scales were used to highlight heartbeat segments to detect J-peaks; however, it would be worthwhile to investigate whether a scale of the CWT can directly provide heart rate information, as it has a repetitive nature similar to that of the BCG (Figure 5). This would increase the algorithm speed while decreasing the computational resources. Machine learning–based approaches are another area worth exploring to detect patterns in BCG across various BCG signals and thus further improve accuracy.

Conclusions

This paper presents research on creating a seat cushion for ambient heart rate monitoring using BCG. The seat cushion was developed using off-the-shelf components and resulted in a cost-effective prototype that performed robust BCG detection. The CWT-based algorithm we developed for autonomous J-peak detection achieved 94.6% accuracy (excluding three outliers), making it a viable alternative to existing health monitoring technologies. The solution presented here is portable, unobtrusive, and can be easily integrated into a living environment for zero-effort heart rate monitoring.

Emerging research that captures ECG without requiring electrodes attached to the skin, such as coupled capacitance, could be explored to improve the robustness of detecting heart rate as well as potentially supporting measurement of other cardiac information, such as blood pressure. The system input–referred noise can be calculated to quantify noise and identify changes in the seat cushion design that could lead to cleaner BCG signals. To better exclude BCG segments involving significant physical movement, a sensor fusion approach could be explored by sensing acceleration using an accelerometer to detect this movement in real time. Developments such as these will shape the future of unobtrusive and more pervasive heart rate monitoring.

Conflicts of Interest

None declared.

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Abbreviations

AAL: ambient assisted living
BCG: ballistocardiography
CWT: continuous wavelet transform
DC: direct current
ECG: electrocardiography
PPG: photoplethysmography
SNR: signal-to-noise ratio
ZET: zero-effort technology

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Homes of Stroke Survivors Are a Challenging Environment for Rehabilitation Technologies

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Abstract

The design of digital technologies that support poststroke rehabilitation at home has been a topic of research for some time. If technology is to have a large-scale impact on rehabilitation practice, then we need to understand how to create technologies that are appropriate for the domestic environment and for the needs and motivations of those living there. This paper reflects on the research conducted in the Motivating Mobility project (UK Engineering and Physical Science Research Council: EP/F00382X/1). We conducted sensitizing studies to develop a foundational understanding of the homes of stroke survivors, participatory design sessions situated in the home, and experimental deployments of prototype rehabilitation technologies. We identified four challenges specific to the homes of stroke survivors and relevant to the deployment of rehabilitation technologies: identifying a location for rehabilitation technology, negotiating social relationships present in the home, avoiding additional stress in households at risk of existential stress, and providing for patient safety. We conclude that skilled workers may be needed to enable successful technology deployment, systematizing the mapping of the home may be beneficial, and education is a viable focus for rehabilitation technologies.

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Introduction

The design of interactive technologies to support rehabilitation from disability acquired through stroke has been a topic of research since 1991, when Dijkers et al [1] presented a novel robotic system that could guide a stroke patient through a series of reaching exercises, under the hypothesis that repeated use could support the rehabilitation of movement in the affected limb. Research has subsequently expanded to cover a broad range of robotic installations intended to support the rehabilitation of motor abilities [2] and to approaches such as the use of virtual reality content to motivate physical engagement with robotic installations and to ground motor skills relearning in practical examples [3-5]. Many of these installations have been targeted at high-throughput clinical environments where individuals might spend a relatively short period.

Most rehabilitation takes place post discharge, frequently in the home, and this phase has historically been poorly supported by health services [6]. As a result, in recent years, there has been a shift in service delivery from hospital-based rehabilitation to the community. Although rehabilitation would ideally continue

until maximum recovery has been achieved [7], the increasing demand for services and financial constraints typically means that service needs often cannot be met, potentially creating a situation in which outcomes for stroke survivors are suboptimal. A radical alternative paradigm, which has been explored through initiatives such as the Expert Patient Programme [8,9], is self-management, which has also been translated into the concept of self-care [10]. The aim of self-care is to help individuals take control of their own health and well-being, potentially supported by services designed to enable this [11].

Evidence suggests that long-term, intense, task-specific, context-specific, goal-oriented, variable, and environmentally enriched poststroke rehabilitation improves function, independence, and quality of life [12,13]. Significant advances in the performance and affordability of information and communication technologies have led to the exploration of its use to support rehabilitation that is clinician led or from a self-management or self-care perspective [14]. Examples include the use of commodity gaming technologies such as the Nintendo Wii or Logitech EyeToy to motivate significant amounts of movement [15,16], the provision of telecare technologies that allow health care practitioners to monitor and guide progress in engaging with rehabilitation activities [17], and the integration of relatively inexpensive force feedback interaction devices to help support someone in engaging in a difficult motor activity, under the hypothesis that repeated assisted completions of activity will lead to long-term improvement in the ability to conduct nonassisted completions [18].

Even at a technological level, the widespread provision of home-based technologies is a very different type of challenge to that of provision for the clinical environment. Home-based deployment of technology might naturally lend themselves to (and necessitate) technologies that are commodified, with a much lower unit price, to facilitate large-scale uptake. As a target for technology design and deployment, the home should not be thought of as a smaller-scale, lower-intensity version of a clinic. Foundational research within the fields of computer-supported cooperative work and human-computer interaction has sought to draw technology designers' attention to the home as a playful place [19,20]; as an often private place of sanctity and relaxation [21,22]; and as a space with an often complex and nonhierarchical social structure, far removed from the more rigid social structures that might be found in the workplace [23]; hence, in a rehabilitation technology context, it is very different in nature from the more rigid and streamlined nature of the clinical environment. There is an explicit recognition within these fields that the home is inherently a challenging environment for the deployment of digital technologies (eg, see the discussion in the study by Tolmie et al [24]).

Given that brain injuries can lead to profound and varied disabilities and hence inherently raise the difficulty of living in a space [25], the homes of stroke survivors are likely to raise additional challenges specific to the disruption that stroke can cause and which rehabilitation technology designers or deployers should attend to in their work. There may be a danger that rehabilitation technology, if not carefully designed to have a place in the homes of stroke survivors, will simply become another burden, likely to be engaged with infrequently and hence ineffective at supporting rehabilitation. Some practical examples of such barriers have been provided in studies by Axelrod et al [26] and Threapleton et al [27]. To become widespread, integration of interactive rehabilitation technologies into home-based therapeutic practice is likely to require a rich understanding of the challenges that this environment presents for technology development work.

As a contribution to this developing area of inquiry, this paper draws on the work conducted through *Motivating Mobility: Interactive Systems to promote Physical Activity and Leisure for people with limited mobility*, a 3-year research study funded by the UK Engineering and Physical Sciences Research Council. Motivating Mobility was a collaboration among researchers with expertise in psychology, physiotherapy, technology design, and technology deployment.

In Motivating Mobility, we engaged in three phases of work selected to provide a rich understanding of the home and how rehabilitation technology targeted at upper-limb disabilities might find a place in it. This paper integrates results from published and unpublished Motivating Mobility studies to identify challenges in the deployment of rehabilitation technologies into the home environment and implications of these challenges for health care practices.

Research Approach

Work in the Motivating Mobility study was situated within an emerging approach known as Research through Design, characterized effectively by Zimmerman et al [28], which positions the technology design process as a vehicle to generate knowledge about a setting. Research through Design typically supports the generation of knowledge by loosening financial or temporal constraints that might constrain a more commercially oriented technology design process, and knowledge is generated through reflection on the design process, the information that it draws on, and the decisions that are made within it. Research through Design has been applied in health research, including the work by Thieme et al [29], who reported on lessons learned through the design and integration of bespoke-designed digital artifacts into a secure mental health service.

As a piece of Research through Design, work in Motivating Mobility was structured into three phases. Phase 1 consisted of sensitizing studies that provided initial insights into the nature of the home environment to ground the work of the project. Phase 2 consisted of situated design case studies in which the research team visited the homes of 4 stroke survivors and worked collaboratively to identify technologies that might support rehabilitation and find an effective place in their homes. In phase 3, prototype implementations of technology were deployed into 4 homes, usage was captured through electronic logs, and interviews were conducted to understand how technologies were or were not appropriated. Detailed methods and findings are presented in studies by Egglestone et al [25], Axelrod et al [26], and Balaam et al [30,31]. Ethical approval was obtained in advance from the University of Sussex Research Ethics Committee, and informed consent was obtained in writing before participation in any of the studies that have informed

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this paper. Participants in design case studies had the right to opt out of the use of photographic material in research publications.

In this paper, we have reexamined the material collected by Motivating Mobility studies to present emergent findings that represent the totality of what we have learned through this work. Our focus was on what we have learned about the challenges of the domestic environment for rehabilitation technology design and deployment.

Challenges for Domestic Rehabilitation Technologies

Challenge 1: Identifying a Location for a Rehabilitation Technology

Early in Motivating Mobility, a photographic study of the homes of stroke survivors was conducted [26]. Although this can only present a snapshot of the lives of the recruited participants (Figure 1), it does provide graphical evidence for phenomena that are likely to be widely recognizable, such as rooms repurposed because of disability (eg, from a lounge to a bedroom) and surfaces cluttered with possessions because of the difficulty of conducting organizing tasks owing to the acquired disability. Through focus groups conducted with stroke survivors, we learned of participants who had needed to downsize to a smaller property, sometimes through loss of income. Such changes can be deeply distressing.

Figure 1. Selected image from photographic sensitizing study. First published in the study by Axelrod et al [26].

One implication is that finding a physical space to place digital technologies may be more difficult in the homes of stroke survivors. This does not preclude the integration of technology; we found that participants were often willing to make changes to their homes to incorporate technologies that they believed to have benefits. This suggests that finding an appropriate location is a necessary part of the technology deployment process. It may also implicate work to persuade residents of the benefits of the technology versus the effort of integrating it into their space.

The complexity of finding an appropriate location for a rehabilitation technology may be enhanced by long-term residency in a home, frequently measured in decades, and by the nature of the home as an ongoing project to create a pleasing and stimulating environment [32]. In one of our design case studies, a participant described their home as a 30-year project

with every element selected through hours of thought and maintained with love and care. Adding an obtrusive digital technology to such a controlled environment requires careful negotiation and ultimately risking the technology to be unacceptable to the user and hence potentially rejected for deployment. A study by Threapleton et al [27] has raised the possibility of bulky prototype equipment harming recruitment rates to research studies because of its impact on the domestic environment.

Further complications might arise from the changed and often heightened emotional reaction to the home, which can be caused by stroke. One example can be seen in an *emotional map* (Figure 2), captured in a sensitizing study, along with an interview explaining its meaning to the contributor [26]. In Figure 2, the red dots indicate physical spaces in the home that provoke anxiety. Red dots in the kitchen were placed there by the participant to indicate residual anxiety caused by this being the location in which the stroke occurred, even though the interview was several years poststroke.

Figure 2. Emotion map of the home of a stroke survivor. First published in the study by Axelrod et al [26].
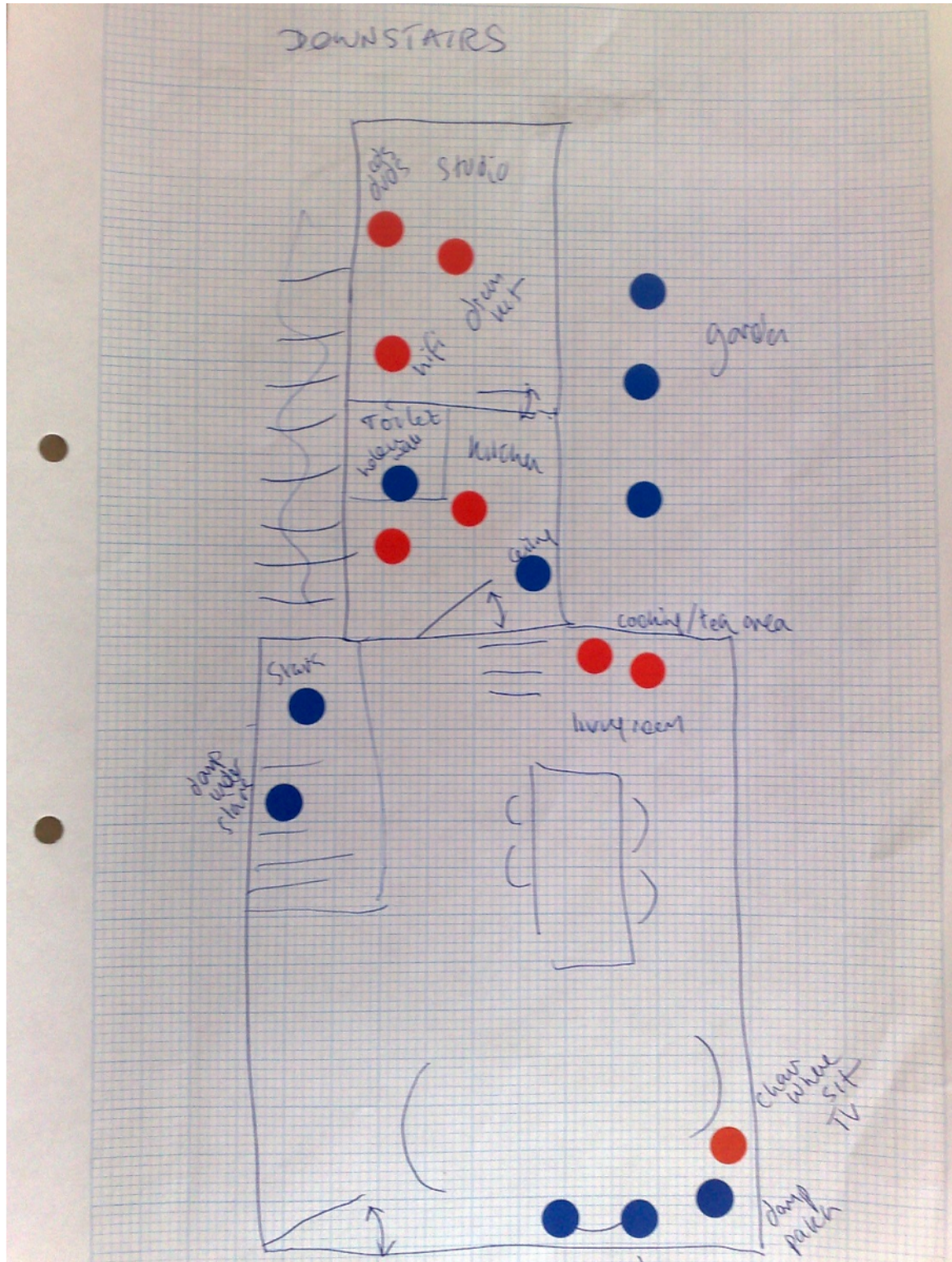
Other examples of heightened emotional reactions to the home include the following:

- A participant who had slept in a spare room for many years poststroke as she had experienced a stroke in her bedroom and had since been unable to reenter this because of the acquired emotional load associated with it.
- Participants distressed by locations associated with practical activities that had become difficult because of the acquired disability (eg, kitchens or utility rooms).

Technology deployment work may need to take into account these heightened reactions.

A substantial body of literature describes integrating elements of the domestic environment directly into rehabilitation technologies. A study by Pridmore et al [33] has described a mixed-reality kitchen environment in which users are encouraged to perform repeated exercises involving the manipulation of tracked physical kitchen artifacts such as kettles as part of relearning practical skills. Although we do not argue

that such designs are inappropriate, we would suggest that the often profound emotional changes caused by stroke might make certain locations challenging for technology deployments. Such locations may provide a rich resource for meaningful interactions if handled sensitively and may provide a route toward long-term improvements in quality of life. A technology that supports effective reengagement with a location that induces anxiety might provide substantial benefits to its user. However, if handled naively, for example, if a rehabilitation technology is placed in a difficult location without careful consideration, then they risk underusage or no usage at all of the technology or of creating negative associations of the technology.

Given the challenges described earlier, finding an appropriate place in the home for technology quickly became a central question for our research. In our design case studies, we addressed this through an initial design session where we discussed issues of space and place with our participants. This often led to a specific first proposal for where a technology might be placed, which was then further discussed in subsequent design sessions with a participant.

One notable phenomenon was that our participants sometimes already inhabited a *safe* or *stimulating* space for a substantial proportion of their day, which had been specifically designed to support their well-being. The tactics that we observed in creating these spaces included the use of a comfortable armchair with accompanying photographs, entertainment systems, and necessary physical support (such as armrests), placed in a space in the home that was less likely to induce anxiety. The motivation for creating such spaces seemed to account for and ameliorate the negative effects of the difficulties in mobility acquired through stroke.

In two of our design case studies, we worked with participants to explore a tactic of appropriating these spaces for the purpose of introducing technology (Figure 3). This involved integrating digital technologies with ergonomic elements to enable the technology to be positioned in the space. Discussions with participants suggested that a possible negative outcome of this approach might be a perceived reduction in the support that the space provided for well-being; this is then a danger which should be seen in light of the discussion around situated anxiety provided earlier.

Figure 3. Technology added to a "stimulating space".

Challenge 2: Negotiating Social Relationships

Through sensitizing studies, we learned of the active role that others sharing a home, such as partners, can take in the rehabilitation process. Participants told us of partners who had

learned a great deal about stroke and rehabilitation theory to provide more expert support for ongoing rehabilitation efforts. They also told us of partners who had made substantial modifications to the home to support well-being. To learn about the potential role of coresidents in relation to technology, we

invited partners to all participatory design sessions and scheduled these sessions to allow for the provision of input from partners wherever possible. For one design case study, with a stroke survivor in her 30s, parents were also invited, as they played a significant and active role in her care. All prototype deployments were in shared environments, and we explicitly included coresidents in the follow-up interview process.

In addition to opportunities, we observed that the presence of others in the same household could create contention over the usage of space. In the design case study illustrated in Figure 3, we used a television as an output device for a piece of situated technology because of its proximity to a stimulating space; however, this introduced a contention around the usage of the television, which was seen to substantially reduce engagement with our technology.

One notable example of the way in which a partner might shape an interaction with a technology was provided in a design case study that we called the *Rehab Reader* [30]. The study used a tablet PC attached to a commodity squeeze sensor. Various electronic books were loaded onto the PC, and the sensor was configured so that a squeeze allowed for progressing through the book, one paragraph at a time. In designing this technology, our intention was for repetitive exercise to be conducted as a side effect of a meaningful and enjoyable activity, and hence for significant quantities of exercise to be conducted—quantity of exercise is currently believed to be a key determinant of the effectiveness of motor rehabilitation. Our participant Irene (not her real name) had lost the ability to read books because of the eyesight damage caused by stroke, and the flexibility of a digital device allowed us to present text in a size with which she could engage. As such, it gave renewed access to a hobby that she had previously valued. A photograph of the prototype implementation of the Rehab Reader is provided in Figure 4.

Figure 4. The Rehab Reader. First published in the study by Balaam et al [30]
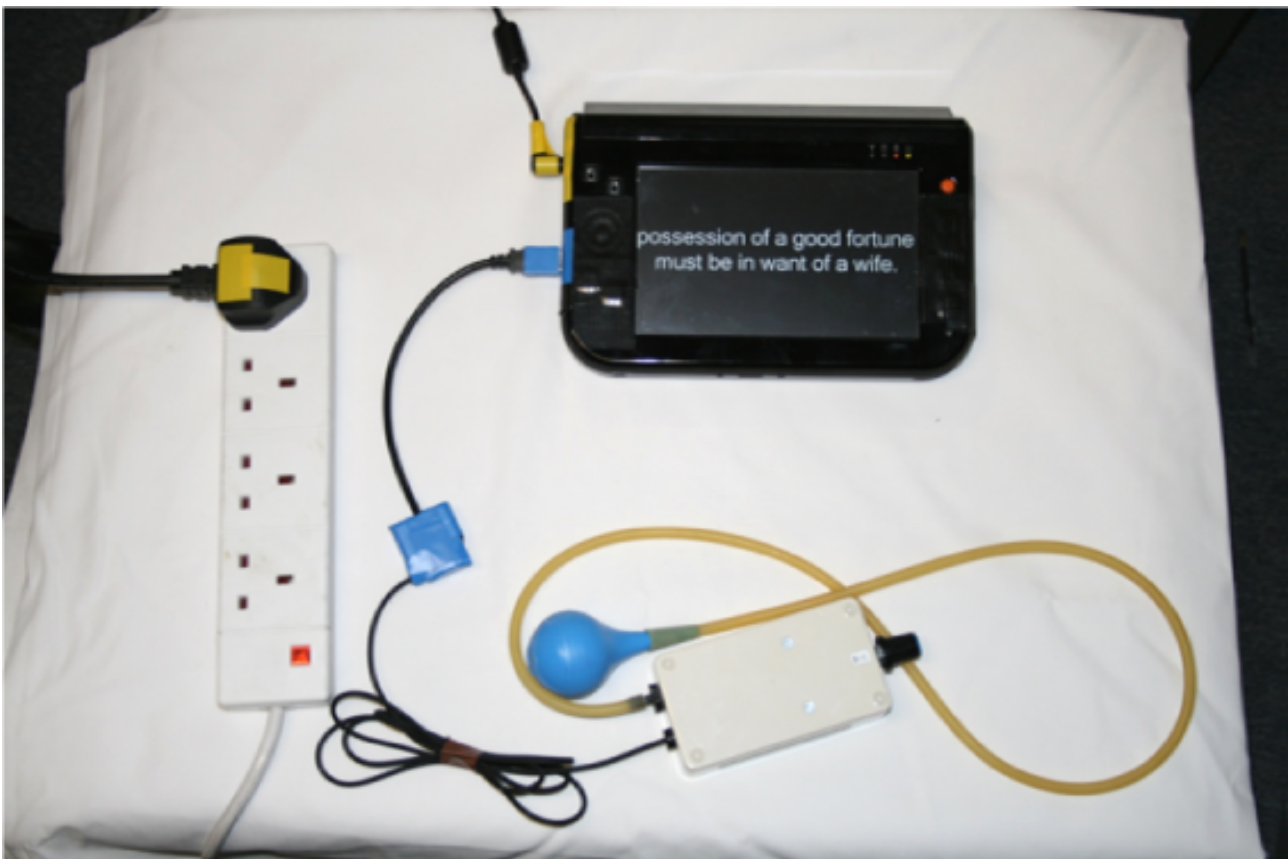
A prototype was deployed for a period of 7 months, and a total of 6621 grasp and release exercises were conducted during this period. Substantial grasp and release recovery was noted in the hand used to control the device. However, a contention emerged between Irene and her partner about the meaning of the device, and hence how it should be used. Irene saw the prototype as a leisure device, with exercise occurring as a side effect. Her partner saw it as an exercise device, similar in nature to how he saw a Nintendo Wii owned by a couple. Irene's partner pressured her to use it at fixed and regular times during the day, so as to perform a reliable amount of exercise. She wanted to use it when she felt like it, and this contention in meaning caused arguments within the couple. It is possible that this contributed to the overuse of the device, as described in challenge 4. Although this is a very specific scenario, we present it to draw attention to the importance of understanding the social nature of interaction with rehabilitation technologies. Others in a social setting are key actors who need to be understood as part of a rehabilitation technology deployment and who can play a role in relation to it, which ranges from supportive to disruptive. As such, their engagement may need to be managed.

One of our least successful prototype deployments involved a novel children's toy specifically designed to allow a mother

who had experienced a stroke in her 30s to perform rehabilitation motor exercise while playing with her young child, a key person on the social side of her existence (Figure 5). The tactic here, discussed in great detail with our participant before construction of the prototype, was essentially to use play with the child as a motivator for engagement. However, the outcome of this choice was that engagement was tied to the sustained interest of the child, and when the child got rapidly bored with the toy, then this motivation, and hence any kind of physical exercise, was ended. This is a case study that suggests some degree of caution when attempting to appropriate the social context into technology design because of the introduction of a dependency on an (essentially unpredictable) individual.

Figure 5. The Ball FUNnel—prototype of a child's toy.

Challenge 3: Avoiding Additional Stress in Households at Risk of Existential Stress

We learned through our sensitizing studies of the almost intolerable levels of existential stress that could be experienced in the homes of stroke survivors [25]. Stress might be caused by the need to make rapid changes to the organization of the home, with partners picking up domestic duties that they might be unprepared for. Difficulties are often accentuated by their own health conditions. Stroke frequently had a substantial negative impact on the social lives of both members of a couple; hence, stress was increased through the loss of social interaction. It could also be accentuated by the need to move to a smaller residence for financial reasons and the sometimes poor quality of social care provided by the local government. Existential stress was universal across participants and at the margins of what could be coped with.

A household with continuing high levels of stress around their everyday existence may be a difficult environment to deploy new technologies, especially if those technologies require additional effort to learn about, engage with, or maintain in a working state. Potentially, rehabilitation technologies that do not take into account or which increase the already high levels of stress may be more likely to fail. In Motivating Mobility, we adopted a tactic of not building technologies that depended upon network connections, in the belief that having to maintain the functionality of a network connection would likely lead to excessive stress and hence lack of use of the technology. We note that our work was done in a period when domestic technology was frequently discussed as being unstable and requiring skilled work to maintain (refer to Tolmie et al [24] for a contemporaneous ethnographic study of the work to keep networking working).

A second technological contributor to domestic stress might include the clutter of cabling, chargers, displays, and interaction devices that make up a technology deployment. Technological clutter might be thought of as particularly problematic if domestic residents are already struggling to keep on top of basic domestic tasks such as cleaning. Much of our participatory design work focused on identifying technologies that were as self-contained as possible, with as little clutter as could be achieved. This involved working with participants to find appropriate spaces in their homes for necessary components such as chargers and creating devices that were engineered to require as little expert maintenance as possible. Producing technologies that did not add to clutter sometimes involved

substantial design and engineering work. However, none of our prototype technologies were rejected due to the clutter that they created, so we feel that this effort added substantial value.

Challenge 4: Providing for Patient Safety

To support the design of interventions that were effective, design case studies were conducted as an active collaboration between interaction designers familiar with the domestic environment, software engineers, and physical therapists familiar with stroke treatment. An open question was the implications for future health care practice of creating effective domestic rehabilitation technologies; in this context, the research therapists working on the project modeled how a practicing therapist might respond in the future and allowed us to learn, on a small scale, what a technologically augmented therapist role may look like.

In practice, therapeutic intervention in design case studies has two principal roles: identifying exercises that might provide rehabilitation benefits if conducted regularly and monitoring deployments for effectiveness and safety. The latter involved regular contact between a technology user and a therapist, conducted either in person or by telephone, as appropriate. The therapist talked about the usage of technologies and any manifestations of physical problems. In one case, this process led to a modification to a prototype implementation of a piece of technology that had already been deployed, in order to correct an ergonomic problem caused by it being used in a different location than the one planned, meaning that it was causing discomfort to the user, with usage potentially detrimental to rehabilitation.

The most heavily used of our prototypes was the Rehab Reader, described in detail earlier. Regaining the ability to read books provided such a benefit to the participants that they used it for many hours per week. Early in the intervention, they reported to their appointed therapist experiencing some pain in the eye affected by stroke and were advised to reduce their usage while this had a chance to adjust. The therapist also visited to provide alternate physical interaction devices to support the avoidance of repetitive strain injuries, observed the usage, and offered guidance on appropriate and inappropriate physical positioning of the device in order to avoid encouraging movements that were not of a high-quality nature.

It is conceivable that some of the work of a physical therapist might be encoded in rehabilitation technologies, especially given the recent advances in the capabilities of Artificial Intelligence systems. However, what the above examples highlight is that any deployment of a rehabilitation technology is likely to need some engagement from an experienced professional, not only to assess an environment but also to potentially monitor progress and ameliorate any dangers of the rehabilitation process.

The distributed nature of the domestic environment then raises a challenge for the provision at scale of sufficient domestic visits to support safe and effective use of technologies, and these challenges might be particularly difficult to resolve in areas that are geographically isolated (such as rural communities) [34]. How to address the challenge of providing sufficient in-person support for rehabilitation technology deployment is an open question and one that would need to be addressed by health

services as part of the long-term work of integrating interactive technologies into the rehabilitation process.

Discussion

Overview

We have described four challenges that affect the design and deployment of effective home-based rehabilitation technologies for stroke. Our aim is to support effective deployment work in the future and therefore the successful uptake of rehabilitation technologies by health services, as a possible route toward recovery from disability acquired through brain injury. The following are three implications arising from these challenges. They were selected to provide insight into how rehabilitation technology deployments can be supported on a larger scale.

Skilled Workers May Be Needed to Enable Successful Technology Deployments

Although our interest is in rehabilitation technology, much of the complexity we have observed relates to what might be described as human factors around the technology [35], for example, the interactions between people and others in relation to the technology and the interactions between people and the technology itself. For example, the complexity of finding a place for a rehabilitation technology in a home where routines have been disrupted by a brain injury, where traumatic effects of the brain injury persist, and where space is jointly managed by multiple residents likely needs, in many cases, a skilled worker to negotiate; however, some potential users of technology may be able to negotiate these challenges by themselves.

If deployment work is to be done as part of health care systems, and as domestic rehabilitation technologies are a relatively new phenomenon, we might speculate that existing health care professions are, as a whole, unlikely to have the skills or knowledge required to immediately engage in effective deployment work and to negotiate all the challenging human factors identified earlier. In some cases, it seems likely that existing professions may be able to adapt; during deployment studies, we found that a team of physiotherapists were capable of monitoring usage and suggesting alterations to support successful and safe engagement, and we might expect a reasonable match with skills and knowledge present in professions such as occupational therapy.

Regardless of whether rehabilitation technology deployments are supported by health care workers drawn from existing professions or by a new type of health care worker, it seems clear that new tools and potentially new forms of training might be needed to prepare such workers to perform the challenging work of selecting, deploying, and supporting rehabilitation technologies, and provision may be a requirement for the large-scale integration of rehabilitation technologies into real-world health care practice.

Systematizing the Mapping of the Home May Be Beneficial

One mechanism for supporting health care workers to perform technology deployment work may be evidence-based tools to

systematize the mapping of the home and its routines, so as to enable a more rapid understanding of the complexities of this environment than that achieved by our study team. Identifying what features to map in the home of a stroke survivor and collecting mapping information took a significant amount of effort and discussion during our design case studies among a group of researchers with a substantial body of expertise in technology design and deployment. This level of effort would be impractical to repeat on a larger scale, but a strength of the Research through Design approach is that it allows for lessons learned through design-oriented research endeavors to be considered as a primary output of the research process, so as to support the work of others engaging in a similar space.

Our work suggests the importance of considering prior usage of the home (ie, before a stroke occurred); current and anticipated or hoped for future usage of the home; changes in emotional response due to stroke; any spaces purposefully created to support the well-being of a stroke survivor; social usage of a space that might have an impact on the technology integration process; and the availability of utilities necessary to support technologies, principally power sockets but potentially also access to a network. The latter can be affected by structural features such as thick boundary walls or the location of domestic routers. Tolmie et al [24] provided an account of the challenge of deploying network-enabled technologies into domestic networking environments.

If rehabilitation technologies are to be deployed on a wide scale across thousands of homes, then we would argue that mapping exercises, although vital, need to be completed quickly and efficiently. This seems to be an ideal candidate for the creation of standardized materials that systematize the mapping process and allow for the collection of information known to be useful in supporting technology deployment work. This would not exclude human judgment in the final decisions made around rehabilitation technology deployments; however, it would provide for a good foundation of knowledge to be collected to ensure that key decisions around place could be taken efficiently, hopefully increasing the scalability of the process of deploying rehabilitation technologies.

How these standard measures might be made available to people doing technology deployment work, and how deployment specialists might be supported in quickly collecting and analyzing collected information, is a question for further investigation. However, we might imagine the creation of computer interfaces to support the collection of data in the field, as has been done in other areas involving specialist visits to particular locations, such as in the railway maintenance industry [36].

Education Is a Viable Focus for Rehabilitation Technologies

Much of the technology rehabilitation literature is built around the design and deployment of technologies that encourage rehabilitation by showing people what to do in terms of exercises and by helping them do it, often in a repetitive manner. However, work on Motivating Mobility suggests that teaching people how to understand and conceptualize their rehabilitation is an important role for technology and might boost outcomes. This is very clear in the narrative presented in relation to challenge 3, where 2 partners had such a profound difference of view about how to use a technology. It was also embedded in a broad range of discussions with participants, who often described being motivated to do rehabilitation exercises but not knowing what was appropriate or safe to do and hence not engaging in them.

Providing education about rehabilitation, in this case, from common mental health problems such as anxiety and depression, has been a core approach in the category of health technologies known as Computerized Cognitive Behavioral Therapy; examples of these technologies have been proven to work in large clinical trials [37]. We might speculate about the possible efficacy of deploying technologies that provide education in the principles of rehabilitation.

Conclusions

The design of interactive technologies to support rehabilitation from disability acquired through brain injury has been a topic of research since 1991, and hundreds of technology prototypes have been piloted and reported in the literature, with the domestic environment being a focus of research. We have conducted research work intended to support an understanding of how domestic rehabilitation technologies might be integrated into health care practice and considered a range of human factors at play in this process.

We suggest that for large-scale deployments to become a practical reality, the preparation of health care professionals needs to be considered, and health care professionals need to be provided with appropriate tools (such as systematized, evidence-based methods to allow for the mapping of deployment environments).

Deployments may also need to consider the provision of education for the recipients of technology (including both brain injury survivors and others in their social context), as a lack of knowledge of rehabilitation and how it can occur may be a barrier to engagement with the deployed technology.

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Mawson), the University of Oxford (Nour Shublaq, Penny Probert Smith), the University of Nottingham (Stefan Rennick-Egglestone, Tom Rodden), and the University of Dundee (Thomas Nind, Ian Ricketts).

Conflicts of Interest

None declared.

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<u>Original Paper</u>

Integrating Behavior of Children with Profound Intellectual, Multiple, or Severe Motor Disabilities With Location and Environment Data Sensors for Independent Communication and Mobility: App Development and Pilot Testing

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Abstract

Background: Children with profound intellectual and multiple disabilities (PIMD) or severe motor and intellectual disabilities (SMID) only communicate through movements, vocalizations, body postures, muscle tensions, or facial expressions on a pre- or protosymbolic level. Yet, to the best of our knowledge, there are few systems developed to specifically aid in categorizing and interpreting behaviors of children with PIMD or SMID to facilitate independent communication and mobility. Further, environmental data such as weather variables were found to have associations with human affects and behaviors among typically developing children; however, studies involving children with neurological functioning impairments that affect communication or those who have physical and/or motor disabilities are unexpectedly scarce.

Objective: This paper describes the design and development of the ChildSIDE app, which collects and transmits data associated with children's behaviors, and linked location and environment information collected from data sources (GPS, iBeacon device, ALPS Sensor, and OpenWeatherMap application programming interface [API]) to the database. The aims of this study were to measure and compare the server/API performance of the app in detecting and transmitting environment data from the data sources to the database, and to categorize the movements associated with each behavior data as the basis for future development and analyses.

Methods: This study utilized a cross-sectional observational design by performing multiple single-subject face-to-face and video-recorded sessions among purposively sampled child-caregiver dyads (children diagnosed with PIMD/SMID, or severe or profound intellectual disability and their primary caregivers) from September 2019 to February 2020. To measure the server/API performance of the app in detecting and transmitting data from data sources to the database, frequency distribution and percentages of 31 location and environment data parameters were computed and compared. To categorize which body parts or movements were involved in each behavior, the interrater agreement κ statistic was used.

Results: The study comprised 150 sessions involving 20 child-caregiver dyads. The app collected 371 individual behavior data, 327 of which had associated location and environment data from data collection sources. The analyses revealed that ChildSIDE had a server/API performance >93% in detecting and transmitting outdoor location (GPS) and environment data (ALPS sensors, OpenWeatherMap API), whereas the performance with iBeacon data was lower (82.3%). Behaviors were manifested mainly through hand (22.8%) and body movements (27.7%), and vocalizations (21.6%).

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Conclusions: The ChildSIDE app is an effective tool in collecting the behavior data of children with PIMD/SMID. The app showed high server/API performance in detecting outdoor location and environment data from sensors and an online API to the database with a performance rate above 93%. The results of the analysis and categorization of behaviors suggest a need for a system that uses motion capture and trajectory analyses for developing machine- or deep-learning algorithms to predict the needs of children with PIMD/SMID in the future.

Introduction

Background

Children with profound intellectual and multiple disabilities (PIMD) or severe motor and intellectual disabilities (SMID), as the name implies, have an estimated intelligence quotient of less than 25, which is equivalent to a maximum developmental age of 24 months [1,2]. These children often have difficulty in communication, especially understanding spoken or verbal language and symbolic interaction with objects [1,3]. The severe or profound motor disabilities are characterized by restricted or absence of hand, arm, and leg functions, resulting in limited or lack of ability to move independently [1,4]. In some cases, children with PIMD/SMID also have sensory impairments and chronic health conditions, which include but are not limited to epilepsy, visual impairments, constipation, spasticity, deformations, incontinence, and reflux [5,6]. Despite the severe challenges associated with these conditions, it is important to facilitate the ability of these children to communicate with people and interact with the environment independently.

Owing to their profound intellectual and neuromotor disabilities, one of the most challenging aspects of supporting children with PIMD/SMID is communication. Several augmented alternative communication apps have been developed that focus on helping children with speech disabilities, including a voice output communication aid (VOCA). With the help of mobile phones, VOCA apps such as Drop Talk and Voice4U have been helping children with speech disabilities communicate with other people. Their main function is to produce a voice when a user clicks a specific icon, symbol, or picture (display) that corresponds to a word or phrase. These displays can be combined (interface) to make sentences that can match a specific situation. Although VOCA offers a promising support approach for children with speech disabilities, selecting displays and choosing interfaces that best fit a specific situation are quite difficult tasks for children with speech and intellectual disabilities, because of their inability to determine which interface they should switch to in each situation and location due to their cognitive disability [1].

Prior Work

In 2017, Karita [7] developed Friendly VOCA, a user-friendly VOCA iOS mobile app that enables children and individuals with speech and/or intellectual disabilities to communicate with other people independently. Unlike other available VOCAs,

Friendly VOCA has the ability to automatically switch displays or interfaces that match the user's location at a specific time [7]. To achieve this, Friendly VOCA uses GPS technology to identify the user's current outdoor location in terms of map coordinates (latitude and longitude). However, to address the inability of GPS to identify indoor locations (eg, inside a store or a room) and elevated surfaces (eg, building floors), iBeacon was utilized. iBeacon is a system developed by Apple Inc that is based on Bluetooth low energy (BLE) proximity sensing, which transmits a universally unique identifier and radio signal strength indication (RSSI) to a user's app. These two combined systems have helped Friendly VOCA to switch interfaces, which are displayed automatically depending on the user's location at a specific time. Both the GPS and iBeacon systems have been tested, and experiments revealed that they can automatically show appropriate interfaces and displays that correspond to users' locations with 100% and 71% accuracy, respectively [7].

Script Theory and Location Data

Grounded in Schank and Abelson's [8] script theory, Friendly VOCA's concept of automatically switching displays or interfaces that match the user's location is based on the notion of "scripts." Scripts are the organized set or body of our basic background knowledge or "schema" that we must have to understand how we respond or behave appropriately to a particular situation or location [8]. This theory was used to structure the schema of Friendly VOCA on specific scripts in the form of varied displays and interfaces tailored to a specific situation (eg, class or playtime), location (eg, classroom, playground, home), and time (eg, morning, lunch breaks, evening) using the GPS and iBeacon systems [7].

Although the use of scripts greatly matches the intention of Friendly VOCA, it may also present possible misunderstandings or incorrect inferences due to many variations of situations or locations (eg, type of restaurant), where a general script may not be applicable (eg, different scripts in fast food and fine dining restaurants). Similarly, Friendly VOCA's set of displays and interfaces may not perfectly cater to all children with speech and/or intellectual disabilities since each child has personalized needs that are beyond the abilities that Friendly VOCA can currently provide. Most importantly, it also neglects the specific needs of children with PIMD/SMID. Since Friendly VOCA requires the user to choose and click an icon or symbol to produce a voice output, apparent understanding of symbolic interaction (interpreting symbols or icons) or verbal language (comprehending voice outputs) is required, which may seem

difficult for these children due to their severe or profound intellectual disabilities [1]. For example, children with PIMD/SMID may not understand that a symbol or a picture showing a hand with its index finger pointing to a face means "I," "I am," or "me," let alone understand the meaning of the voice output that corresponds to the symbol. Moreover, clicking an icon or symbol can also be physically demanding for some children with profound neuromotor dysfunctions [1].

Relation of Environment Data With Children's Behavior and Affect

Environment data such as weather variables, including humidity, wind speed, precipitation, decreased visibility, and less hours of daylight, were found to have associations with human affects and behaviors such as physical activities among typically developing children [9-12]. Yet, similar studies involving children with neurological functioning impairments that affect communication or those who have physical or motor disabilities are unexpectedly scarce. VanBurskirk and Simpson [13] investigated the relationship between meteorological data (ie, barometric pressure, humidity, outdoor temperature, and moon illumination) with classroom-collected behavioral data of three children with autistic disorders who had significant behavior problems, including screaming, falling to the floor, head-butting, biting, kicking, hitting, and elopement. In contrast with the results of similar investigations among typically developing children, there was a weak relationship found between the behavior patterns demonstrated by the children with autism and meteorological parameters [13]. Notably, the selection of weather variables was only based on previous studies among typically developing children, since related studies on children with autism had not been performed. Most importantly, given the fact that the study was in its initial stage with clear methodological limitations, the authors stressed that the results must be interpreted with caution and should be further investigated, which might yield different results among children with more nuanced behavior [13].

Categorizing the Behaviors of Children With PIMD/SMID

Children with PIMD/SMID only communicate through movements, sounds, body postures, muscle tensions, or facial expressions on a presymbolic (nonsymbolic) or protosymbolic (limited information) level with no shared meaning, which hinders expressing their needs [14-17]. These behaviors can also be minute and refined, which may be difficult for caregivers and teachers to perceive and interpret their needs [14]. Surprisingly, to our knowledge, prior to the studies of Tanaka et al [18], Motoda et al [19], and Ashida and Ishikura [14,20], scarcely any study had examined the behaviors of children with PIMD/SMID to enable perception and interpretation. In 2013, Ashida and Ishikura [14] introduced six major categories based on the body parts movements involved in each expressive behavior of children with PIMD/SMID: eye movement, facial expression, vocalization, hand movement, body posture, body movement, and noncommunicative behaviors (others). They then used these categories to analyze the expressive behaviors of two children in 2015 [20]. They found that one child had many active movements of the arms, legs, and eyes, and

expressed their needs and emotions by changing gaze and smiling, whereas the expressions of the other child were limited to the movements of the head, neck, mouth, and eyes [20]. This suggests that to predict the needs of children with PIMD/SMID, interventions that focus on interpreting their behaviors, whether they involve head, face, or upper limb movements, can be developed. However, to realize this goal, it is first necessary to collect data on the children's behaviors associated with their needs. Yet, to the best of our knowledge, there is hardly any technology specifically developed for this purpose.

Mobile-Based Data Collection

The smartphone is now widely used as a data collection tool in psychological studies [21]. Its use has also advanced field experiment methodology such as broadening the scope reach, control randomization, and ability to collect a wide variety of data over time through the use of mobile apps [22]. Smartphone-based data collection through the use of apps provides real-time data, and is an efficient and accurate method with minimal errors and inconsistencies [23,24]. Apps, through a user interface, can also combine data available in smartphones (eg, GPS) or other mobile-sensing devices (usually using Bluetooth technology) to facilitate collection (frontend), which can be transmitted through the portal server and stored in a database (eg, MySQL, Google Firebase) (backend), and extracted for data processing during or after interventions [21,24]. Integrating location and sensor data can provide more fine-grained studies of behavior expression across situations and behavior inference [21,25]. Data collected from mobile apps and sensors are usually used to extract useful features to build a predictive model with machine-learning algorithms [26]. Thus, we developed ChildSIDE, a mobile app that collects behavioral data from children with PIMD/SMID as interpreted by their caregivers. Similar to Friendly VOCA and grounded in the notion of scripts, the ChildSIDE app also collects location and environment data through the use of location and environment (weather) data-sensing technologies and an online application programming interface (API). By not only collecting and analyzing children's behaviors but also collecting and analyzing location and environment data associated with each behavior, ChildSIDE could help to infer their intentions and needs in the future.

Goals and Hypotheses of This Study

This paper describes the design and development of the ChildSIDE app. The app was pilot-tested among purposively recruited children with PIMD/SMID and their caregivers, and its server/API performance was investigated in terms of detecting and transmitting location and environment data to the app database. Another aim of this study was to identify which movements were associated with the children's behaviors by categorizing the movements using the table of expressions proposed by Ashida and Ishikura [14]. This will help in identifying the method or design of the system that will be further developed in the future. This study is exploratory in the context of testing the app's server/API performance in detecting and transmitting environmental data using the sensors, API, and outdoor location (GPS), but not the use of the iBeacon system for indoor location due to the relatively low server/API

performance rate of iBeacon based on a previous experiment [7]. According to previous literature, we hypothesized that the children's behavior will mainly involve head, face, or upper limb movements.

Methods

App Design, Development, and Interface

ChildSIDE, a mobile app, was developed to collect: (a) caregivers' interpretations of the behaviors of children with PIMD/SMID, (b) location, and (c) environment data. The app was developed on the Android (OS Android 6.0) mobile platform (HUAWEI P9 lite; Kirin 650 Octa Core, 4×2.0 GHz and 4×1.7 GHz) using Eclipse Android Studio (version 4.0.1), an integrated development programming environment software, and Java 1.80_242 (OPEN JDK) programming language in Windows 10 Pro (1909) [27,28]. The design of ChildSIDE was based on internet-of-things systems for a human-computer interaction interface and its name originates from the main goal of being "beside" its target population, children ("Child"), by aiding independent communication and mobility. "SIDE" is also an acronym for "Sampling Information and Data of children's expressive behaviors and the Environment," which is explicitly derived from its main function of collecting children's behaviors with associated location and environment data. The completed app used in the pilot-testing sessions was installed on two Huawei Nova lite mobile phone (OS EMUI 8.0 based on Android 8.0) with a HUAWEI Kirin 659 Octa Core CPU (4×2.36 GHz + 4×1.7 GHz) [29].

ChildSIDE has two interfaces (Figure 1): a behavior settings interface (a) and a behavior list interface (b). The behavior settings interface allows the user to add a behavior. Users should click the "Add row" button to add a new row, and then a new row will appear in the list above it (2). The user can then enter the category code, the behavior's name, and a category name in the settings interface below this new row (3). The assigned codes correspond to the order of behaviors the user wants to appear in the behavior list interface (b). If the user wants to put the most common behavior at the top of the list, the code should be 0, and the second most common behavior is coded "1," which follows the behavior that was coded 0, continuing in this manner. To save the information, users should click the "update" button (4), and then the new behavior with its corresponding code and category name will appear in the list above on the setting interface (5). The "x" button (6) on the upper right corner of the interface should be clicked to go to the behavior list interface (b). The behavior list interface shows the behavior name on the top row and the category name in a space below. When a user clicks a behavior name (7), the app automatically sends the behavior and category name with its associated location and environment data to the database. To add or edit a behavior, the user needs to click the gear button (8) on the upper right corner of the interface to go to the behavior settings (a). When adding a new behavior to an already existing category, users need to enter the name of the category; otherwise, a new category will be created. Categorizing the behaviors will make it easier for the user to locate or update them subsequently.

Figure 1. ChildSIDE user interface and guide. (a) Behavior settings, (b) behavior list.
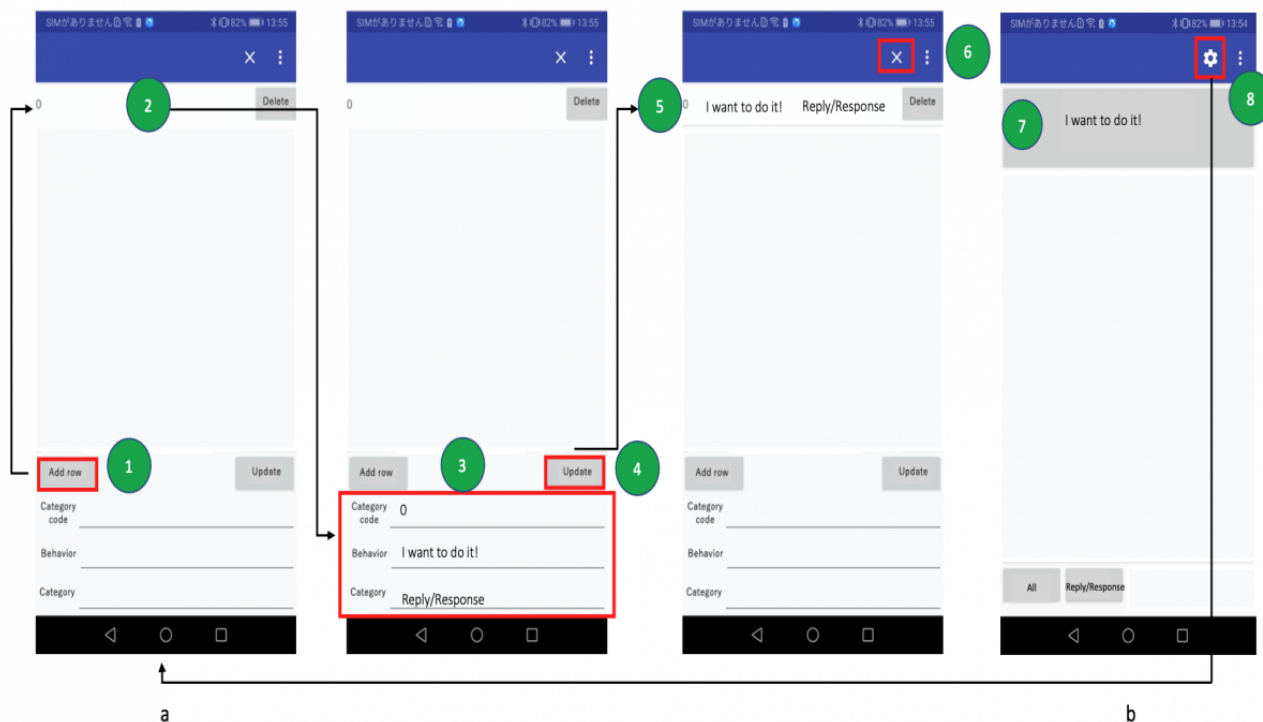
Location and Weather Data Sources

Figure 2 shows how the ChildSIDE app collects data from the data sources (iBeacon, GPS, ALPS Sensors, and OpenWeatherMap API) and transmits the data to the Google Firebase database. The Android's built-in time stamps and GPS (GPS/AGPS/Glonass) (a) were used to identify the user's current outdoor location in terms of map coordinates (latitude and longitude) [29].

iBeacon (Figure 2, b) (BVMCN1101AA B), from module BVMCN5103BK manufactured by Braveridge [30], has a 2402 to 2480 MHz frequency range, –20 to +4 dBm transmission power (terminal output), is AA battery-powered, and operates on 2.2 volts [30]. iBeacon is based on BLE proximity sensing that provides proximity-based app services, and coarse-grained indoor location positioning and navigation [31]. iBeacon has widespread applications that range from advertisement (providing product information), education (interactive activities for museum visitors), and tracking (luggage at the airport or patients in emergency rooms) to an evacuation guide system during emergency situations [31]. It transmits proximity measurements based on RSSI and MAC address (6 bytes: F5:B0:E2:A2:AE:69), and uses an iBeacon name to a close mobile device to identify the user's specific indoor location [32]. The RSSI is the strength of the beacon's signal relevant to the receiving device that determines the distance between them, which ranges from –26 to –100 (in inches) [33]. The transmission accuracy between the mobile device and iBeacon can be categorized as immediate (0 to 0.5 meters), near (0.5 to 2 or 3 meters), or far (2 or 3 meters to 30 meters) [32,33]. The Bluetooth LE model of Braveridge BVMCN1101AA B is certified by the Bluetooth special interest group, Japan Radio Law (Japan Quality Assurance Association), and is US Federal Communications Commission (FCC) Part 15-compatible and Harmonized European Standard EN300 328 (ETSI Technical Committee electromagnetic compatibility and radiospectrum matters)-compatible [30].

The IoT Smart Module Sensor Network Module Evaluation kit consists of a multifunction Bluetooth sensor (ALPS Sensor; Figure 2, c) module (Mouser and manufacturer number: 688-UGWZ3AA001A Sensor Network Kit W/BLE Mod Sensors) developed by ALPS Alpine [34]. It has a 2.4 GHz frequency, operates with a 3.3 volt supply, and has –93 dBm Bluetooth receiver sensitivity [34]. It includes multiple sensors for pressure, temperature, humidity, ultraviolet, ambient light, and 6-axis (Accel + Geomag); it also has a built-in microcontroller unit or processor (memory and input/output

peripherals on a single chip) for realizing efficient power management and an ultracompact module realized with high-density mounting technology [34]. The kit is used to monitor work environments, and in fitness and health care [34]. It has also been used to acquire and transmit 11 motion and environment data: temperature (°C) and relative humidity (RH%) geomagnetic sensor (electric compass; 6-axis Accel+Geomag; ranges: g1, g2, g3, and resolutions μT1, μT2, μT3); ultraviolet or ambient light (mW/cm^2 and Lx), and atmospheric pressure (hPa) [34].

Weather data (atmospheric pressure, humidity, sunrise and sunset time) were obtained from OpenWeatherMap API (Figure 2, d), an online service that provides weather data that matches the user's current location [35]. OpenWeatherMap API uses a numerical weather prediction model (90% and 100% reliability, and 1% inaccuracy) from several data sources (global: NOAA GFS 0.25 and 0.5 grid sizes, NOAA CFS, ECMWF ERA; weather stations: METAR stations, users' stations, companies' stations; and weather radar data and satellite data) in 371 national capitals and major cities [35]. The API has 15 parameters: country name, location name (region or city), weather, sunset time, sunrise time, current time, minimum temperature (°C), maximum temperature (°C), atmospheric pressure (hPa), main temperature (°C), humidity (%), weather description, cloudiness (%), wind direction (degrees), and wind speed (meters/second) [35]. When a user clicks a behavior, the app automatically sends the behavior and category name with its associated GPS and iBeacon location data, and environment data from the OpenWeatherMap API and the ALPS sensors to the Google Firebase database (Figure 2, e), a third-party service provider that allows the data to be stored in real time and synchronized among mobile platforms [36].

As previously mentioned, weather variables, in particular humidity, solar radiation, wind speed, visibility, hours of daylight, barometric pressure, temperature, and moon illumination, were found to have association with the emotions and behaviors of typically developing children [9], yet little is known about these effects among children with neurological or physical impairments, specifically among children with PIMD/SMID. Thus, since the majority of these studies, including this study, were exploratory and had no specific inclusion criteria on what weather parameters should be investigated, all weather parameters of ALPS Sensors and OpenWeatherMap API were included. Most importantly, most of the weather variables investigated in previous studies are similar to those collected by ALPS sensors and OpenWeatherMap API.

Figure 2. Data flow from the data sources (iBeacon, GPS, ALPS Sensors, and OpenWeatherMap API) detected and transmitted by ChildSIDE app to the Google Firebase database. API: application programming interface; RSSI: radio signal strength indication.
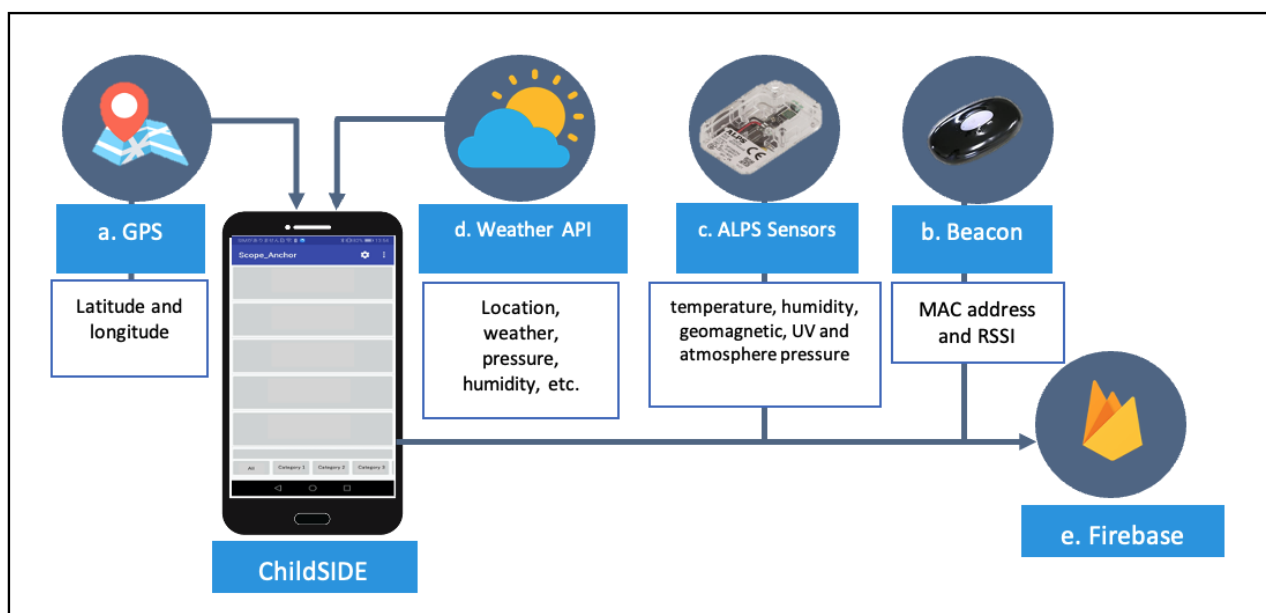
Study Design, Sampling, and Participant Inclusion Criteria

For pilot testing, we utilized a cross-sectional observational study design by performing multiple single-subject face-to-face and video-recorded sessions. Studies that used a single-subject design among children with special education needs showed more powerful results than those that used a group research design [37]. The app was pilot-tested among purposively sampled child-caregiver dyads recruited at a special needs school from September 24, 2019 to February 25, 2020.

The children included in this study met the following criteria: diagnosed with PIMD/SMID or severe or profound intellectual disability, with or without comorbid sensory impairments and/or chronic health conditions, which include but are not limited to epilepsy, visual impairments, constipation, spasticity, deformations, incontinence, and reflux, and with a chronological or mental age of 18 years and below at the time of the study. Caregivers were either the primary (immediate family members) or secondary (nonfamily, including teachers, supporters) caregivers who had been living or supporting the children for 3 years or more. This criterion was set to ensure that caregivers were familiar and have a working schema about the children's behaviors.

Ethical Considerations

This study was part of a project that was written, performed, and approved as per international ethical guidelines (Declaration of Helsinki [38] and the International Council for Harmonization Good Clinical Practice guidelines, approval number: R2-18) [39]. The parents or caregivers of all participants provided their consent for the child's participation in this study by signing a written informed consent form. They were also informed that their participation in the study was voluntary and that they may stop their participation at any time. All data that contain participant information or identity were coded and blurred, respectively, and are stored in a password-protected network server database and computer for their protection and privacy.

Intervention

Experimental Setup

A video-based recording method was used in all sessions for interrater analyses and categorizing of behaviors. This method has been reported to have higher interrater reliability than traditional observational methods, and allows researchers to collect, analyze, and validate data retrospectively [40]. One videotape recorder in a tripod placed 2 meters from the participants was used to capture the child's facial expressions, and upper and lower limb movements (Figure 3a), and all exchanges of responses between the child and their caregiver (Figure 3b). Before the sessions, one iBeacon device and one ALPS sensor were installed in each location (there were a total of 18 different locations that included classrooms, music room, playrooms, and others). They were installed either on a shelf, blackboard, bulletin board, or on an air conditioning unit with an approximately 2-meter distance (estimated mean distance 2.18 meters, SD 0.09, mean error 0.184, root mean square error 0.411) from the ChildSIDE app (Figure 4). For more information on the location (room and specific location installation), sampling frequency, estimated mean distance, SD, mean error, and root mean square error of each iBeacon device used in the sessions, please refer to Tables S1 to S3 in Multimedia Appendix 1.

Figure 3. Intervention setup. (a) Videotape recorder (VTR) focusing on facial, and upper and lower limbs movements. (b) Intervention setup in a classroom setting: 2-meter distance from the VTR to the child with profound intellectual and multiple disabilities (PIMD) or severe motor and intellectual disabilities (SMID) and caregiver, and the location where the iBeacon and ALPS sensors were placed.
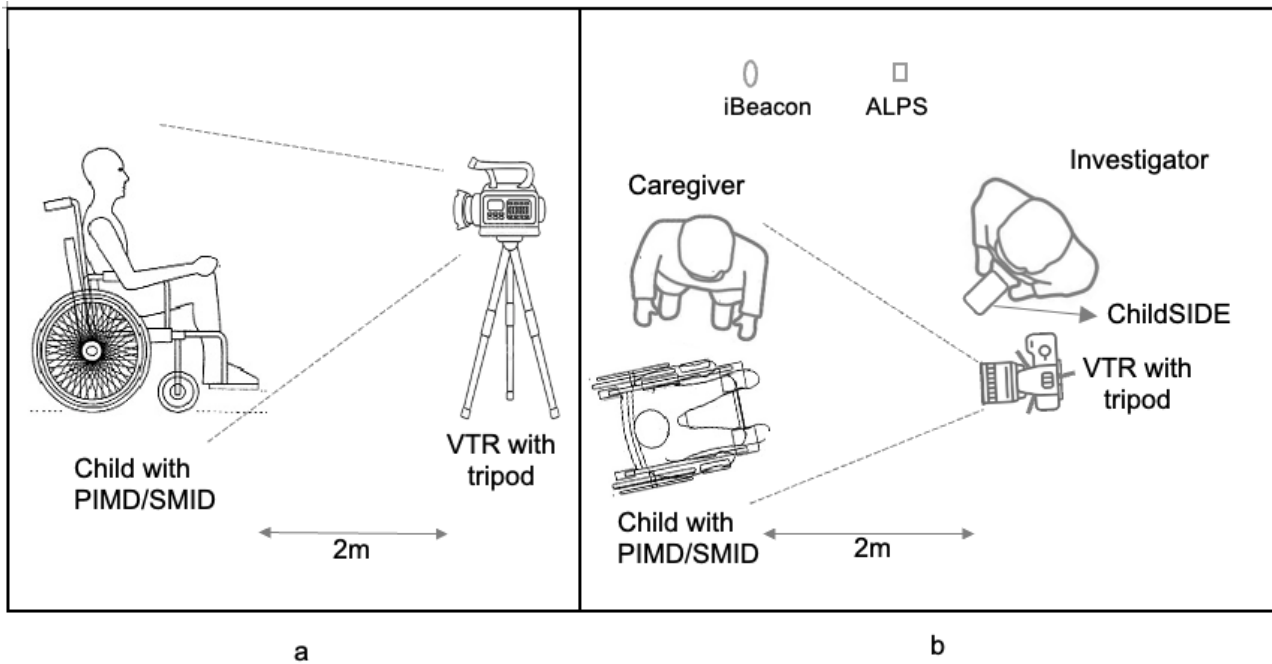
Figure 4. A sample experimental setup showing how the radio signal strength indication of iBeacon is detected by the ChildSIDE app with an actual distance of 2 meters.
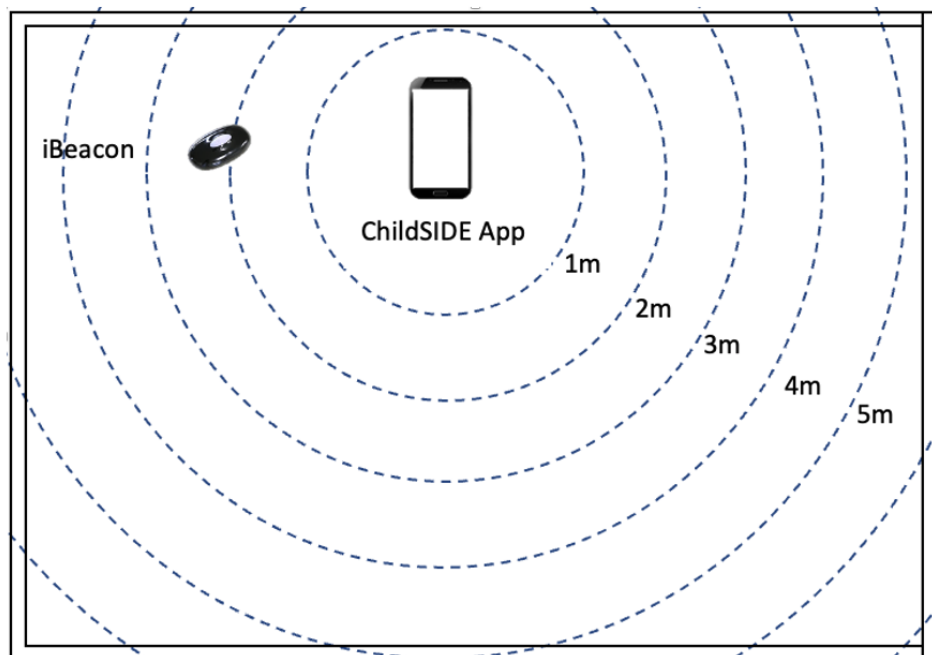
Sessions

Multiple single-subject face-to-face sessions were performed; the duration of each session depended on the child's availability and the willingness of their caregivers to participate and be recorded. The sessions were divided into three batches (batch session 1, elementary; batch session 2, junior high school; batch session 3, high school). The three batches of sessions were performed within 16 days with an average of 4.2 sessions per day (SD 1.95). In total, there were 105 sessions performed that ranged from as few as 1 session and as many as 15 sessions per child (with an average of 5 sessions per child). Initially, we performed 90 sessions (recording time range 0.37-32 minutes, mean 19 minutes, SD 11.3 minutes among 19 children). When

another child was recruited, we still performed 15 additional sessions (recording time range 6 to 54 minutes, mean 28 minutes, SD 13.8 minutes) among the participants.

All sessions were recorded in the locations where the children usually spend time to ensure they can behave normally and interact with their caregivers even in the presence of other children, caregivers, and an investigator. The sessions did not interfere with the academic lessons where children interact more with the main teacher or supporter. Initially, the investigator identified the behaviors under investigation based on the categories and description of the body parts and movements involved in the behavior of children with PIMD/SMID. However, since our aim was to collect behaviors linked to the children's specific needs, the investigator frequently had to add new behaviors as required, especially when a child exhibited a certain reaction (eg, vocalization, gesture) and when the caregiver responded by confirming the child's need (eg, want to go to the toilet) verbally or by actions (eg, assist the child to the toilet). The sessions targeted their behavior during morning greetings, lunchtime, and break time when they would always interact more with their caregivers who attended to their needs.

To control for the confounding effect of the presence of an investigator or the intervention, the investigator was trained and was instructed to strictly prevent interacting with the participants or interfering with the sessions. All sessions were performed by only one trained investigator with the expectation that the participants will be familiar and comfortable with the session procedures and with the investigator to ensure collecting fairly consistent and valid behavior data from the participants.

Statistical and Data Analysis

Server/API Performance

To measure server/API performance of ChildSIDE in detecting and sending data from data sources to the database, frequency distribution and percentages of the 31 location, motion, and environment data types from each data source were computed, including 3 from iBeacon, 2 from GPS, 11 from ALPS sensors, and 13 from OpenWeatherMap API. The behavior data without any associated data from any data source were deleted. Each transmission to the app database was scored "1" and errors (ie, app failed to detect signals from sensors or vice versa) were scored "0." Since each data source has multiple data types, the mean scores were computed and used for comparison to the total number of behavior data with associated location and environment data.

Interrater Agreement

To categorize the body parts or movements (minor categories) involved in each behavior using the table of expressions in children with PIMD/SMID (Table 1) [14], two raters watched the video recordings independently and analyzed each behavior recorded by the app. Each rater provided a score of "1" in each minor category to which a behavior belongs; otherwise, a score of "0" was given. For example, "Goodbye" can be expressed by waving the hands and producing sound; thus, this behavior was given a score of 1 for the minor category "moving" under the major category hand movement (Table 1, d.3) and a score of 1 for the major category vocalization (Table 1, c). To test the agreement between the two raters in each behavior per minor and major category, κ statistics were computed. To identify the κ coefficients in each major category, each category was given a score of 1 when there was at least one minor category with a score of at least 1. The level of agreement was assessed as follows: $\kappa=0$, less than chance; $\kappa=1.01$-0.20, slight; $\kappa=0.21$-0.40, fair; $\kappa=0.41$-0.60, moderate; $\kappa=0.61$-0.80, substantial; and $\kappa=0.81$-0.99, almost perfect agreement.

Interrater agreement between the two raters in each major and minor category was assessed according to κ coefficients with a significance level of $P<.01$ [41]. The two raters also counted the number of times (frequency) each movement (minor category) was displayed for each behavior. Lastly, the raters reanalyzed their responses, and once a consensus was reached, a final categorization of behaviors was created based on the table of expressions in children with PIMD/SMID. All statistical analyses (χ^2 and κ) were performed using the "stats" (version 4.0.1) and "irr" (version 0.84.1) packages of R (version 4.0.2) statistical computing software.

Table 1. Category table of expressions in children with profound intellectual and multiple disabilities or severe motor and intellectual disabilities [14].

| Categories	Criteria
a. Eye movement	
1. Gazing	Gaze at people and things (in the case of people, look at their faces)
2. Eye tracking	Eye movements that follow the movements of people and things in a linear fashion
3. Changing line of sight	Change of line of sight, movement of line of sight; gaze rolls and moves; point-like movement that is distinct from "a.2. eye tracking." The momentary glare can also be evaluated. Movements that cannot be evaluated as gaze/tracking
4. Opening or closing the eyelids	Not an involuntary blink; their reaction when told to open or close their eyes
b. Facial expression	
1. Smiling	Smile
2. Facial expression (other than smile)	Something that is not expressionless; changes in facial expressions (eg, surprise, frowning, sticking out tongue)
3. Concentrating and listening	Focusing on picture books, music, and voices etc
c. Vocalization	Producing sound
d. Hand movement	
1. Pointing	Hand pointing or pointing finger toward an object
2. Reaching	The action of reaching or chasing after reaching the target, not by pointing the hand or finger
3. Moving	Grab, hit, beckon, push, raise hands, dispel, etc
e. Body movement	
1. Approaching	Head or upper body (or the whole body) is brought close to a person or an object
2. Contacting	Touching people and things with the hands and body; excludes cases that are touched by accident
3. Movement of a part of the body	Head and neck movements, upper body movements, upper and lower limb movements (eg, shake, bend, move mouth, flutter legs); excluding "d.1. pointing," "d.2. reaching," "d.3. moving," and distinguished from "f.1. stereotyped behavior"
f. Noncommunicative behaviors (others)	
1. Stereotypical behavior	The same behavior or movement is repeated without purpose; behavior that occurs in a certain repetition (eg, finger sucking, shaking hands, rocking), excluded from shaking things in "d.3. moving"
2. Injurious behavior to self and others	Hitting someone, biting finger, etc
3. Others	Difficult to classify other than the above categories

Results

Participants Profile and Session Outcomes

A total of 19 of 22 child-caregiver dyads (3 dyads were excluded owing to unavailability) were assessed for eligibility. The children were aged from 8 to 16 years (equivalent of 3rd grade to 1st year of high school), 13 (68%) were males, 15 (79%) had PIMD/SMID diagnoses, and 4 (21%) had severe or profound intellectual disabilities.

Figure 5 shows the participant, session, and data flow using the CONSORT diagram. In the 16-day collection period, 90 sessions were performed wherein 308 individual behavior data were collected. The daily average data collected was 20 (SD 12.2) and the average number of data collected per session was 5.2 (SD 2.2). Seven of these were identified as test data, which were

excluded, bringing the total number to 301. From the 19 child-caregiver dyads, one child-caregiver dyad (8-year-old male with PIMD/SMID) was added, leading to the addition of 15 additional sessions and 63 individual behavior data, bringing the total to 20 child-caregiver dyads, 150 sessions, and 364 individual behavior data collected. Of the 364 individual behavior data, 37 without any associated data from any data source were deleted. In total, 327 data entries with associated data from iBeacon, GPS, ALPS, Sensor, or OpenWeatherMap API data sources were used to compare frequency percentages. In the interrater agreement assessment used for categorizing the behavior data, 35 individual behavior data that were not detected by the app were also deleted. From the total 292 individual behavior data (see Multimedia Appendix 2 for more information on the individual behavior data), one had no score from the two raters, subjecting only the remaining 291 to interrater agreement (κ) statistical analysis.

Figure 5. CONSORT diagram of participant, session and data flow from enrollment, allocation, and analysis.
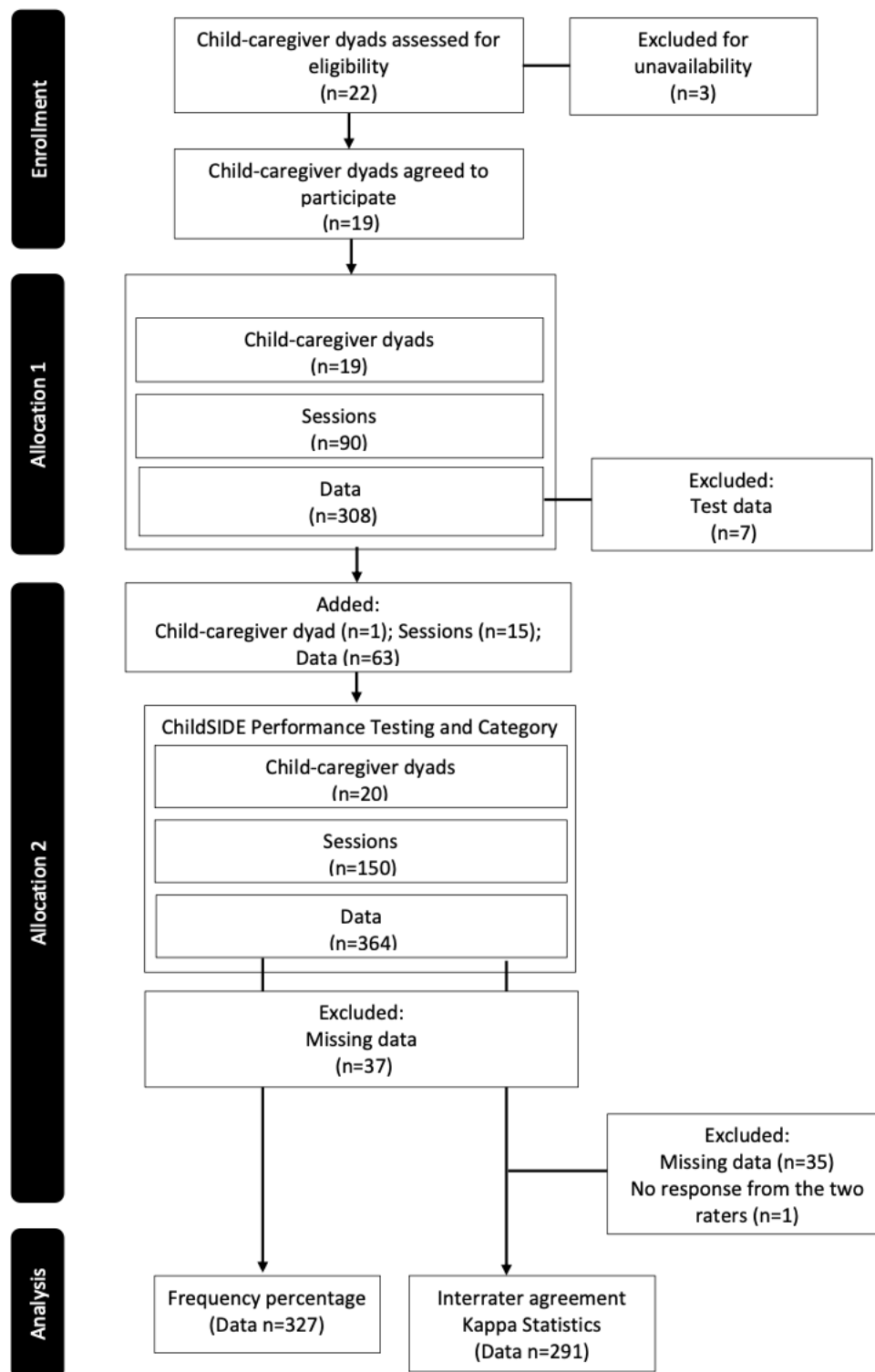
iBeacon, GPS, ALPS Sensor, and OpenWeatherMap API data

The app was able to detect and transmit 269 (82.3%) MAC addresses, 269 (82.3%) RSSI, and 269 (82.3%) iBeacon names (Figure 6). Ultraviolet or ambient light sensors range (S1 in Figure 6) and resolution (S8 in Figure 6) had the relatively lowest scores at 213 (65.1%) and 266 (81.3%), respectively, among the ALPS sensors. The scores for the 6-axis

(Accel+Geomag) sensor ranges (S2, S3, and S4 in Figure 6) and resolutions (S5, S6, and S7 in Figure 6) ranged from 318 (97.2%) to 321 (98.2%). Among the ALPS sensors, 100% of the pressure sensor range (S9 in Figure 6), temperature and humidity sensor range (S10 in Figure 6), and resolution (S11) data were detected and transmitted by the app to the database. Among the OpenWeatherMap API parameters, wind direction (A14 in Figure 6) had a relatively lower score of 288 (88.1%) compared with that of the other parameters (A1 to A13 and A15

in Figure 6) that had scores of 312 (95.4%). In general, iBeacon had the relatively lowest mean score (269, 82.3%) among the data sources: GPS (327, 100%), ALPS Sensors (305, 93.4%), and OpenWeatherMap API (310, 94.9%). This means that the ChildSIDE app shows a server/API performance ranging from 82% to 100% in detecting and transmitting location and environment data to the database.

Figure 6. Frequency percentages of transmitted data and errors in each data type, and mean scores (black dots) in each data source detected and transmitted by the ChildSIDE app to the database. iB1: MAC address; iB2: radio signal strength indication; iB3: iBeacon name; GPS1: longitude; GPS2: latitude; S1: ultraviolet (UV) range (mW/cm2); S2, S3, S4: 6-axis (Accel+Geomag) sensor ranges [g]; S5, S6, S7: 6-axis (Accel+Geomag) sensor resolutions [μT]; S8: UV resolution [Lx]; S9: pressure sensor range (hPa); S10: temperature and humidity sensor range ($^{\circ}$C); S11: temperature and humidity sensor resolution (%RH); A1: country name; A2: location name (region or city); A3: weather; A4: sunset time; A5: sunrise time; A6: current time; A7: minimum temperature ($^{\circ}$C); A8: maximum temperature ($^{\circ}$C); A9: atmospheric pressure (hPa); A10: main temperature ($^{\circ}$C); A11: humidity (%); A12: weather description; A13: cloudiness (%); A14: wind direction (degrees); A15: wind speed (meters/second).
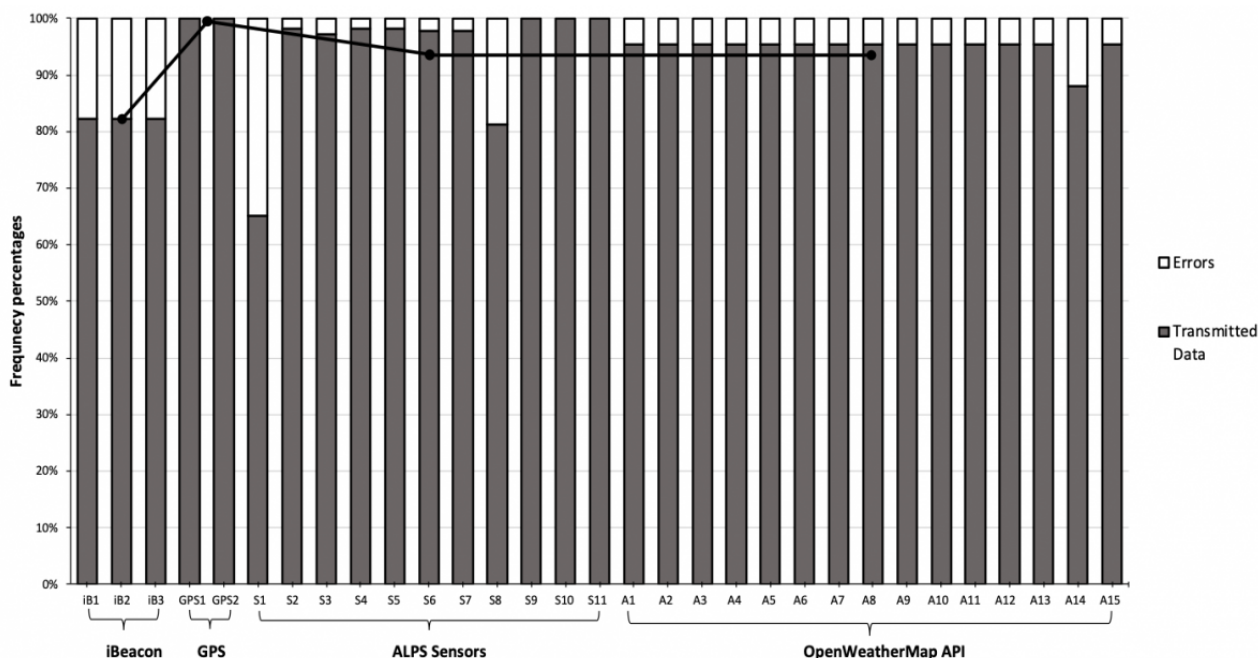
Behavior Categories

Table 2 shows the levels of agreement based on the κ coefficients and range between the two raters in identifying the body parts or movements (minor categories) involved in each behavior. The κ statistics revealed that the levels of agreement between the two raters in 14 out of 16 minor categories ranged from fair (κ=0.21-0.40) to almost perfect (κ=0.81-0.99) with statistical significance (P<.001).

The minor categories with the highest and lowest κ coefficients were pointing and stereotypical behaviors with κ coefficients of 0.88 and 0.21, respectively. Only one rater scored a need under the concentrating and listening category, and the behaviors

that fell under the injurious to self and others category differed between the two raters. Further, although the two raters had an almost perfect level of agreement (P<.001) in vocalization (0.95) and hand movement (0.88), and substantial level of agreement in eye movement (0.83), facial expression (0.70), and body movement (0.78), noncommunicative behaviors (others) only had a κ coefficient of 0.40, representing a fair interrater agreement level. From these results, we were able to identify 676 body parts or movements involved in 291 individual behavior data. Of these 676, children's behaviors comprised 27.7% body movement, 22.8% hand movement, 21.6% vocalization, 15.4% eye movement, 9% facial expression, and 3.6% other expressions.

Table 2. Interrater agreement and frequency distribution of the major and minor categories of the table of expressions in children with profound intellectual and multiple disabilities or severe motor and intellectual disabilities [14].

Categories	Interrater agreement			Frequency distribution (N=676), n (%)
	κ	κ range[a]	*P* value	
a. Eye movement	0.83	5	<.001	104 (15.4)
1. Gazing	0.64	4	<.001	38 (5.6)
2. Eye tracking	0.50	3	<.001	13 (1.9)
3. Changing line of sight	0.53	3	<.001	46 (6.8)
4. Opening or closing the eyelids	0.74	4	<.001	7 (1.0)
b. Facial expression	0.70	4	<.001	61 (9.0)
1. Smiling	0.69	4	<.001	36 (5.3)
2. Facial expression (other than smile)	0.34	2	<.001	24 (3.6)
3. Concentrating and listening[b]	N/A[c]	N/A	N/A	1 (0.1)
c. Vocalization	0.95	5	<.001	146 (21.6)
d. Hand movement	0.88	5	<.001	154 (22.8)
1. Pointing	0.88	5	<.001	29 (4.3)
2. Reaching	0.69	4	<.001	25 (3.7)
3. Moving	0.79	4	<.001	100 (14.8)
e. Body movement	0.78	4	<.001	187 (27.7)
1. Approaching	0.44	3	<.001	16 (2.4)
2. Contacting	0.76	2	<.001	35 (5.2)
3. Movement of part of the body	0.64	2	<.001	136 (20.1)
f. Noncommunicative behaviors (others)	0.40	3	<.001	24 (3.6)
1. Stereotypical behavior	0.21	2	<.001	16 (2.4)
2. Injurious behavior to self and others[d]	–0.0003	N/A	.95	2 (0.3)
3. Others	0.44	4	<0.001	6 (0.9)

[a]κ ranges for qualitative interpretation: 0, less than chance; 1, 1.01-0.20; 2, 0.21-0.40; 3, 0.41-0.60; 4, 0.61-0.80; 5, 0.81-0.99 [41].

[b]One score from one rater.

[c]N/A: not applicable.

[d]Needs did not match.

Discussion

Principal Results

With the use of location and environmental sensing technologies, we were able to develop ChildSIDE, a mobile app that collects caregivers' interpretation of the expressive behaviors of children with PIMD/SMID, along with location and environment data. The app was also able to detect and transmit data to the database with above 93% server/API performance, except for iBeacon for which the app had the relatively lowest performance rate of 82.3%. Further, interrater agreement (κ) analysis showed an almost perfect level of agreement between two raters, and we were able to identify and categorize 676 body parts or movements involved in 291 individual behavior data. These analyses showed that expressive behaviors of children with PIMD/SMID were manifested mainly through body and hand movements, and vocalizations.

App Server/API Performance

Among the location and environment data-sensing technologies that were used, the app had relatively the lowest performance in detecting and transmitting iBeacon data. Although relatively higher, a previous study on the use of the iBeacon system in Friendly VOCA showed the same result [7]. This trend emphasizes the possible problem with the placement of iBeacon devices and not the mobile apps developed. That is, our intervention setup may be problematic, since we placed the iBeacon device approximately 2 meters from the app. Dalkilic et al [32] tested the accuracy of iBeacon devices in sending signals to an app, and found that when iBeacon was close to a mobile phone, the app has difficulty in detecting exactly where the signal is coming from. The authors further explained that the electromagnetic fields or waves generated by mobile phones interfere with those coming from the iBeacon device, resulting in low location accuracy [32]. Their experiments also revealed that when iBeacon devices were placed further away from

mobile phones (if there is no radio interference from other iBeacon devices, laptops, or mobile phones), up to 8 meters, the app gave more accurate distance estimations [32]. Aside from this explanation, we also considered that placing iBeacon devices in adjacent rooms led to the difficulty for the app to detect and therefore transmit the iBeacon data to the app database. Thus, we checked if the iBeacon data detected and transmitted by the app to the database originated from the iBeacon installed in the same room. We found that the iBeacon data detected and transmitted by the app to the database were approximately the same (96% similarity) as the data from the iBeacon installed in the same room as the app. This finding is similar to that of Dalkilic et al [32], who examined the effect of walls by placing one iBeacon device and a mobile phone in one room and another iBeacon in an adjacent room. They found that the wall between the two rooms blocked the signals from the iBeacon that was not in the same room as the app [32].

iBeacon RSSI

Although we acknowledge and plan to address the problems in our intervention setup, specifically with respect to the placement of the iBeacon device relative to its distance from the app, we also assumed that the problem may have been related to the signal strength of the iBeacon device that we used, which was different from that used in our previous work. Paek et al [31] tested three iBeacon devices, and found that the variation in the signal was much too high, and the RSSI values and corresponding signal propagation model varied significantly across iBeacon vendors and mobile platforms. To address this variability, we plan to test different iBeacon devices from different vendors, and choose the best product that fits our mobile platform and the goal of our study in the future. Most importantly, we will also consider an iBeacon device (BLE) company that conforms to the regulations and technical standards of Japan Radio Law (Japan Quality Assurance Association), with US FCC Part 15 and Harmonized European Standard EN300 328 compatibility [30].

Future Developments

The Friendly VOCA and ChildSIDE apps are part of a holistic system that will enable children to have independent communication and mobility. This initial study confirms that children's behaviors were manifested mainly through hand and body movements, which provide the structure of an inference smart environment system that can predict children's needs through speech or movement patterns. Part of our future work plan is to develop models that will make use of the behavior data that were collected in this study, and to construct machine- or deep-learning algorithms to predict children's needs. Once developed, the model will be used to analyze new behavior data that will be collected using an optical motion camera, as a recently developed technology to capture human movements [42]. The outputs will be analyzed using movement trajectory software, a powerful tool in motor behavior studies [43]. That is, the ChildSIDE app will be connected to the optical motion camera using a common database to enable the continuous and seamless transmission of data. The predictive models will then be passed through the database to our previously developed Friendly VOCA that will produce the specific sound or voice.

This will allow smart speakers to respond to the children's needs either by sending voice commands to home gadgets and appliances (eg, television, lights, or air conditioning system) or to inform the caregivers of the need for support and assistance.

In the future, we will make use of the ChildSIDE app and the optical motion camera in collecting new behavior data to build an automatic and individualized predictive model for each child with PIMD/SMID, or other neurological or physical or motor impairments, resulting in clear provision of an individual-centered, holistic, and smart environment inference system. With this goal in mind, an equally important and interesting line of study in the future is to test its application among adults or older populations with PIMD/SMID or other conditions for communication or delivering rehabilitation interventions.

Although this study was limited to and focused on testing the app's performance in detecting and transmitting environmental data to the database, it is also noteworthy to consider that weather variables such as humidity and solar radiation were identified as predictors of changes in the emotional and behavioral states of children [9]. Our future work, as part of the inference system that we will develop, will also explore the possibility of whether movements, behaviors, and consequently the needs of children with PIMD/SMID can be predicted using the environmental data (location and weather variables) that were collected in this study.

At present, we only rely on the interpretations of the children's close caregivers (eg, parents, teachers, therapists) because the children are highly dependent on them for pervasive support in everyday tasks, 24 hours a day [1,4]. These caregivers are more capable of discerning and interpreting the mostly unique behaviors of each child than other people. Thus, we are expecting that our system will help people who are not as close to the children to easily communicate with them and be part of their communication group.

Strengths and Limitations

One of the main strengths of this study was the inclusion of a relatively high number of children with PIMD/SMID, or severe or profound intellectual disabilities (n=20) compared with similar previous studies, which only had a maximum of two children assessed. This enabled us to perform 105 multiple face-to-face and video-recorded sessions, and collect 371 individual behavior data, which were analyzed and categorized. With the use of the app, this study contributes to the emerging body of evidence in categorizing the expressive behaviors of children with PIMD/SMID, which can be of great help in designing and planning interventions.

Despite these strengths, several limitations of this study may affect the generalizability of our findings. We were able to perform multiple sessions among our target population; however, we only performed these sessions in a school setting. This limits our study in providing a more diverse perspective on children's behaviors, as they have distinctive behaviors and needs at home and toward their immediate family members who they are more familiar with. This will be taken into consideration in our plans of testing the app at home and other locations,

which will help to measure the ability of the app in detecting and transmitting behavior, location, and environment data to the app database in a different setting. Most importantly, we also acknowledge that although we strictly adhered to the session protocol, the potential confounding effect of the presence of the investigator or the intervention may have affected the validity of the behavior data collected from the children.

Our findings are also limited to children with PIMD/SMID who are attending special needs schools. Since some children with similar needs attend regular schools or are in health care facilities, we will consider including these settings in our future interventions. Another limitation of our study was the method used to measure the performance rate of the app in detecting and transmitting location and environment data from iBeacon, GPS, ALPS sensors, and OpenWeatherMap API data sources. Although it is ideal to measure the app's server/API performance by comparing it with other apps that use similar location and environment data-sensing technologies, to the best of our knowledge, no other app has been developed with the same goals and functions as the ChildSIDE app to date. Consequently, we had no other means of measuring this function other than counting the data transmitted and detected by the app to the database.

Our findings on the movements involved in the behaviors of the children with PIMD/SMID were limited to the children recruited in our study and may not represent the population in general; thus, they must be interpreted with caution. Lastly, we consider a potential language limitation on the translation of our data from Japanese to English. Although the data were translated by a bilingual translator, we still consider that there were words in Japanese that did not have an English equivalent or were difficult to translate in English in the same context. This also leads to the limitations on the generalizability of our findings and conclusions, which may only represent children with PIMD/SMID in the Japanese population and could differ in other countries.

Conclusions

This study confirms that the ChildSIDE app is an effective tool in collecting the behavior of children with PIMD or SMID along with associated GPS location and environment data, as revealed by its high server/API performance rates. However, the app had difficulty in detecting and transmitting short-distance indoor location sensor data from iBeacon devices. This study also adds to the emerging body of evidence for the possibility of categorizing and interpreting the expressive behaviors of children with PIMD/SMID. This emphasizes the need to develop a system that uses motion-capture technology and to develop algorithms using machine or deep learning as part of an individual-centered, holistic, and smart environment inference system to predict the needs of children with PIMD/SMID in the future.

Authors' Contributions

VH: validation, formal analysis, writing-original draft, writing-review and editing, and visualization. TK: conceptualization, methodology, funding acquisition, project administration, supervision, writing-review and editing, and resources. YF, YY: methodology, validation, formal analysis, investigation, data curation, and writing-review and editing. YW: validation, formal analysis, data curation, and writing-review and editing. SS, EO, TS: conceptualization, software, resources, project administration, and writing-review and editing.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Location, frequency, estimated mean (SD) distance, mean error, and root mean square error (RMSE) to the iBeacon and the ChildSIDE app.
[DOCX File , 18 KB - rehab_v8i2e28020_app1.docx]

Multimedia Appendix 2
Behavior data collected by ChildSIDE app.
[DOCX File , 16 KB - rehab_v8i2e28020_app2.docx]

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Abbreviations

API: application programming interface
BLE: Bluetooth low energy
FCC: Federal Communications Commission
PIMD: profound intellectual and multiple disabilities
RSSI: radio signal strength indication
SMID: severe motor and intellectual disabilities
VOCA: voice output communication aid

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Effectiveness of Distance Technology in Promoting Physical Activity in Cardiovascular Disease Rehabilitation: Cluster Randomized Controlled Trial, A Pilot Study

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Abstract

Background: Physical activity is beneficial for cardiovascular rehabilitation. Digitalization suggests using technology in the promotion of physical activity and lifestyle changes. The effectiveness of distance technology interventions has previously been found to be similar to that of conventional treatment, but the added value of the technology has not been frequently studied.

Objective: The aim of this pilot study was to investigate whether additional distance technology intervention is more effective in promoting physical activity than non-technology–based treatment in 12 months of cardiac rehabilitation.

Methods: The cardiovascular disease rehabilitation intervention consisted of three 5-day inpatient periods in a rehabilitation center and two 6-month self-exercise periods at home in between. Participants were recruited from among cardiac patients who attended the rehabilitation program and were cluster-randomized into unblinded groups: conventional rehabilitation control clusters (n=3) and similar rehabilitation with additional distance technology experimental group clusters (n=3). Experimental groups used Fitbit Charge HR for self-monitoring, and they set goals and reported their activity using Movendos mCoach, through which they received monthly automated and in-person feedback. Physical activity outcomes for all participants were measured using the Fitbit Zip accelerometer and the International Physical Activity Questionnaire.

Results: During the first 6 months, the experimental group (n=29) engaged in light physical activity more often than the control group (n=30; mean difference [MD] 324.2 minutes per week, 95% CI 77.4 to 571.0; P=.01). There were no group differences in the duration of moderate to vigorous physical activity (MD 12.6 minutes per week, 95% CI –90.5 to 115.7; P=.82) or steps per day (MD 1084.0, 95% CI –585.0 to 2752.9; P=.20). During the following 6 months, no differences between the groups were observed in light physical activity (MD –87.9 minutes per week, 95% CI –379.2 to 203.3; P=.54), moderate to vigorous physical activity (MD 70.9 minutes per week, 95% CI –75.7 to 217.6; P=.33), or steps per day (MD 867.1, 95% CI –2099.6 to 3833.9; P=.55).

Conclusions: The use of additional distance technology increased the duration of light physical activity at the beginning of cardiac rehabilitation (for the first 6 months), but statistically significant differences were not observed between the two groups for moderate or vigorous physical activity or steps per day for both 6-month self-exercise periods.

Trial Registration: ISRCTN Registry ISRCTN61225589; https://doi.org/10.1186/ISRCTN61225589

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Introduction

Cardiovascular rehabilitation (CR) aims to reduce cardiovascular risks, encourage healthy behaviors and adherence, reduce disability, and promote an active lifestyle. Cardiovascular disease (CVD) care is multidimensional, including nutritional counseling, risk factor management, psychosocial interventions, and the promotion of physical activity [1]. Physical activity benefits patients with CVD by reducing the risk for further cardiac events [2], and exercise-based CR has been proven to reduce overall and cardiovascular mortality [3]. In addition, light-intensity physical activity has been shown to be beneficially associated with obesity, markers of lipid and glucose metabolism and mortality [4]. However, the physical activity engagement of cardiac patients has been below the threshold with respect to gaining improvements in cardiorespiratory fitness [2].

Home-based CVD rehabilitation has been found to be as effective as center-based rehabilitation in improving clinical and health-related quality of life outcomes [5]. Digitalization has given rise to the application of distance technology toward physical activity-promoting rehabilitation [6]. Technology-based physical activity-promoting distance interventions have been shown to be as effective as comparable interventions delivered conventionally (ie, paper-based materials or in-person meetings) [7]. Compared to usual care, technology-based distance interventions are more effective in increasing physical activity, especially among patients with medical diagnoses [8-10]. Our preliminary systematic reviews showed that technology may be a promising tool for promoting physical activity in CR [8,9]. However, there is insufficient evidence on the additional value of distance technology in interventions promoting physical activity for patients with CVD.

This pilot study aimed to investigate, at the individual participant level, whether internet software and activity monitoring in addition to a 12-month conventional cardiovascular distance rehabilitation effectively promotes light or moderate to vigorous physical activity (MVPA) or an increase in steps per day, compared to similar rehabilitation regimes without distance technology. Cluster randomization was chosen to control the potential cross-contamination between experimental and control groups, since the intervention took place in standard cardiac rehabilitation group-based courses. The rehabilitation program consisted of two 6-month home-based rehabilitation periods in between three 5-day inpatient courses.

Methods

Design

This cluster randomized controlled trial pilot study (ISRCTN61225589) assessing the effect of additional distance technology-based rehabilitation on patients with CVD was conducted between September 21, 2015, and November 30, 2017. The study protocol was approved by the Ethics Committee of the Central Finland Health Care District. The 12-month CR program was executed in groups of 10 rehabilitees each, which is standard practice at the Peurunka rehabilitation center. Sample size was defined by the rehabilitation groups that began the rehabilitation during the years 2015-2016. Physical activity outcomes were measured 3 times during the intervention: at baseline, 6 months, and 12 months. Participants or caregivers were not blinded to the intervention. However, the physical activity outcome assessor (author SH) and the researchers (authors TP and AK) who performed the statistical analyses of the results were blinded to the treatment allocations of the groups.

Participants and Randomization

Participants were recruited from among patients with CVD who attended the CR program at a rehabilitation center in Finland. The eligibility criteria of the participants included age (18 years or older), diagnosed cardiovascular risk factors, angina pectoris with physical working capacity limitations, myocardial infarction, coronary artery bypass graft surgery, or coronary angioplasty. Exclusion criteria included musculoskeletal disorders, cognitive or memory impairment, or if the independent use of computer or remote technology application was not possible.

Participants had been allocated into 6 groups by officers of Social Insurance Institution of Finland, who also scheduled the inpatient periods for each group. Officers in charge of the allocation were not informed about the research project. Randomization was designed by three members of the research group (authors HK, TS and AK), and it was completed before interventions or any of the rehabilitation courses started by two members of the research group (authors HK and TS) and one person outside the research group generating the random allocation sequence.

Participants were cluster randomized in cluster pairs (1 and 2, 3 and 4, 5 and 6) by picking up numbered papers (either "A" or "B") that issued to which treatment allocation the group belonged. Pairwise randomization of clusters bypassed any systematic effect bias due to the season in which the rehabilitation was conducted. The groups of rehabilitees were randomized to control and experimental clusters, one of each starting in autumn, winter, and spring. After randomization, rehabilitation center staff individually enrolled participants who provided written consent in the intervention. Participants were assigned to the interventions by two members of the research group (authors HK and TS).

Conventional Cardiac Rehabilitation

Cardiac rehabilitation courses were arranged by the Social Insurance Institution of Finland, and in this study, the courses were held in and the data were collected from one rehabilitation center. The group-based courses were driven by a multidisciplinary team and consisted of meetings with a doctor; physiotherapist; nurse; and, optionally, a social worker, psychologist, or dietitian. The CR courses aimed to promote multidimensional self-efficacy by focusing on psychosocial factors related to coping with CVD in daily life. During the course, participants obtained information about CVD, counseling for managing daily activities with heart illness, and group discussions with peers, in addition to physiotherapy and aerobic exercise. During the inpatient periods in the rehabilitation center, participants performed health- and functioning-related tests.

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A 12-month rehabilitation course, that both groups attended, consisted of three 5-day inpatient face-to-face rehabilitation periods in the rehabilitation center (at the beginning of the study, at month 6, and at month 12). The rehabilitation program promoted adaptation to life with CVD. Promoting physical activity was one part of the content, which aimed to reduce the barriers CVD rehabilitees have with respect to exercising [11]. Participants were provided information on the health benefits of physical activity based on the American Heart Association (AHA) recommendations [12] and encouraged to exercise in accordance with their condition. The walking goal was 10,000 steps per day. Individual goal setting of total physical activity followed the Specific, Measurable, Achievable, Relevant and Time-bound goal setting framework [13]. Between inpatient periods, participants followed their designated exercise programs. Participants in the conventional cardiac rehabilitation control group received the usual rehabilitation program, which was identical to the experimental group but did not contain technology. In the control group, the instructions on how to perform exercises, goal setting, and self-monitoring were paper-based for the control group. Goals were determined using the Goal Attainment Scale [14].

Additional Distance Technology in Conventional Cardiac Rehabilitation

Participants in the additional distance technology experimental group received an additional distance technology program, which aimed to promote health and functioning-related lifestyle changes, such as physical activity and healthy nutrition. Participants set and monitored their individual goals and received instructions on how to perform exercises via the Movendos mCoach internet software [15]. The experimental group was instructed and motivated to perform physical activity self-monitoring with a wrist-worn Fitbit Charge HR [16] activity monitor. The Fitbit Charge HR displayed steps per day, energy expenditure, heart rate, and the quantity and quality of sleep. At the beginning of the intervention, the experimental group received 1.5-hours face-to-face support on the use of activity monitoring technologies from an information technology specialist, a nurse, and a psychologist. During the second inpatient period, 6 months later, the participants attended another 30-minute counselling session. In addition, the participants received a tutorial video on how to use Fitbit Charge HR and Movendos mCoach. The participants were contacted twice a month through the application. They received one automatic prompt to engage in physical activity, and the second contact was made by a physiotherapist who gave feedback of the activity recorded in the application.

Measures

Objective physical activity for all participants, in terms of steps per day, light physical activity (LPA), and MVPA were measured individually from each participant using a hip-worn Fitbit Zip (San Francisco, CA) accelerometer during the outpatient period for one week at 0, 6, and 12 months. Participants were instructed to use the device all the time while awake and not during sleep. The Fitbit Zip device automatically defines thresholds for the outcomes between LPA and MVPA. The days participants walked 1000 to 30,000 steps per day were included in the analysis. Subjective MVPA was measured using the International Physical Activity Questionnaire (IPAQ) [17], in which the participants recalled their activity over the last 7 days. During the inpatient periods, participant clusters were asked about the possible harms and other problems related to the use of technology and the intervention. Subjective adherence to the treatment was measured individually with a separate questionnaire (S. Hakala, unpublished data, October 2020). Adherence on using internet software was measured by analyzing the number of recordings made to the software, and the number of messages sent to the care provider during the 12-month intervention.

Statistical Analyses

Two researchers (authors AK and TP) conduced the statistical analyses using IBM SPSS Statistics for Windows, Version 25.0 [18]. Outcome analysis was blinded, analyzing outcomes from group A and group B. After all the analyses were made, the encrypted treatment allocations of both groups were revealed. Absolute scores of outcomes measured with Fitbit Zip and IPAQ were used in analysis of changes in outcomes from baseline to 6 months, and from 6 to 12 months. Linear mixed models evaluated the effectiveness of the intervention on physical activity outcome. An independent samples t test (two-tailed) or Mann-Whitney U test analyzed differences between groups. Mean difference (MD) values described the differences between groups' means, whereas positive values favored the experimental group and negative values favored the control group. In-group changes were analyzed based on tests of normality and using a paired samples t test (two-tailed) or Wilcoxon signed-rank test. Confidence intervals were reported with point estimates.

Results

Participants

The participants' mean age was 60 (SD 6.0; range 41-66) years, and 81% (48/59) of the participants were male (Table. 1). The level of physical activity in both groups was between low and moderate at baseline (see Multimedia Appendix 1). Bypass surgery was performed for 9 (15%) out of 59 participants, and angioplasty was performed for 75% (44/59) of participants either once (36/44, 61%), twice (5/44, 8%) or more (3/44, 5%). Cardiovascular operations were performed 3 to 6 months before the intervention (10/50, 20%), 6 to 12 months before the intervention (24/50, 48%), more than 12 months before the intervention (14/50, 28%), or during the intervention (2/50, 4%). The dropout rate during the intervention was 10% (6/59; Figure 1).

Figure 1. Flowchart of the cardiac rehabilitation intervention. CONSORT: Consolidated Standards of Reporting Trials.
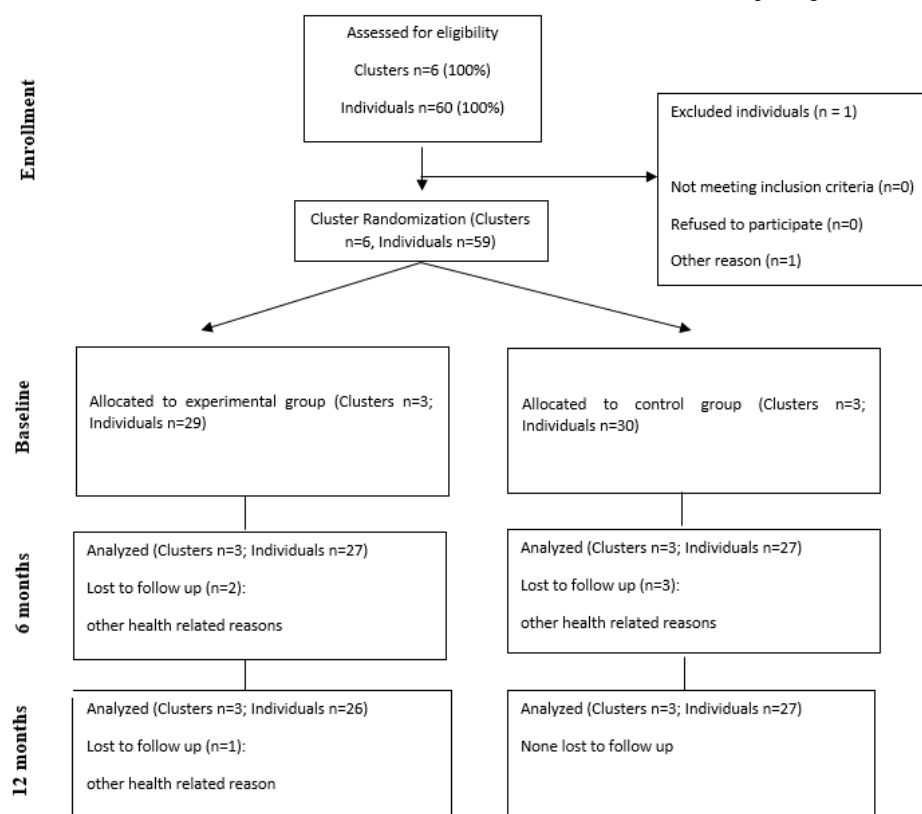
Table 1. Baseline characteristics in the conventional cardiac rehabilitation control group and the additional distance technology intervention experimental group.

Baseline characteristics	Control group (n=30) mean (SD)	Experimental group (n=29) mean (SD)	P value
Age (years), mean (SD)	59.2 (6.1)	59.7 (6.0)	.73
Female, n (%)	4 (13)	7 (24)	.36
BMI, mean (SD)	28.5 (4.3)	29.0 (5.2)	.69
6 minutes walking test (meters), mean (SD)	661.5 (83.7)	610.0 (68.1)	.40
Steps per day, mean (SD)	7269 (2565)	6614 (3859)	.48
LPA[a] (min/week), mean (SD)	177 (55)	150 (58)	.10
MVPA[b] (min/week) , mean (SD)	176 (130)	184 (165)	.85
Uses a computer, n (%)	23 (77)	26 (90)	.28
Uses a smartphone, n (%)	22 (73)	22 (76)	.87
Owns self-monitoring devices for PA[c], n (%)	11 (37)	13 (45)	.58

[a]LPA: light intensity physical activity.

[b]MVPA: moderate to vigorous physical activity.

[c]PA: physical activity.

Physical Activity Changes From 0 to 6 Months

The experimental group had a greater increase in the minutes per week of LPA measured with the Fitbit Zip accelerometer compared to the control group (MD 324.2 min, 95% CI 77.4 to 571.0; *P*=.01; Figure 2), but there were no statistically significant differences between groups in the minutes per week of MVPA (MD 12.6 min, 95% CI –90.5 to 115.7; *P*=.82) or in steps per day (MD 1084.0 steps, 95% CI –585.0 to 2752.9; *P*=.20; Figures 3 and 4). Likewise, there were no statistically significant differences between groups with respect to the duration of MVPA measured by the IPAQ (MD 34.0 min, 95% CI –327.3 to 395.3; *P*=.85).

Figure 2. Light physical activity measured with the accelerometer at baseline, 6 months, and 12 months.
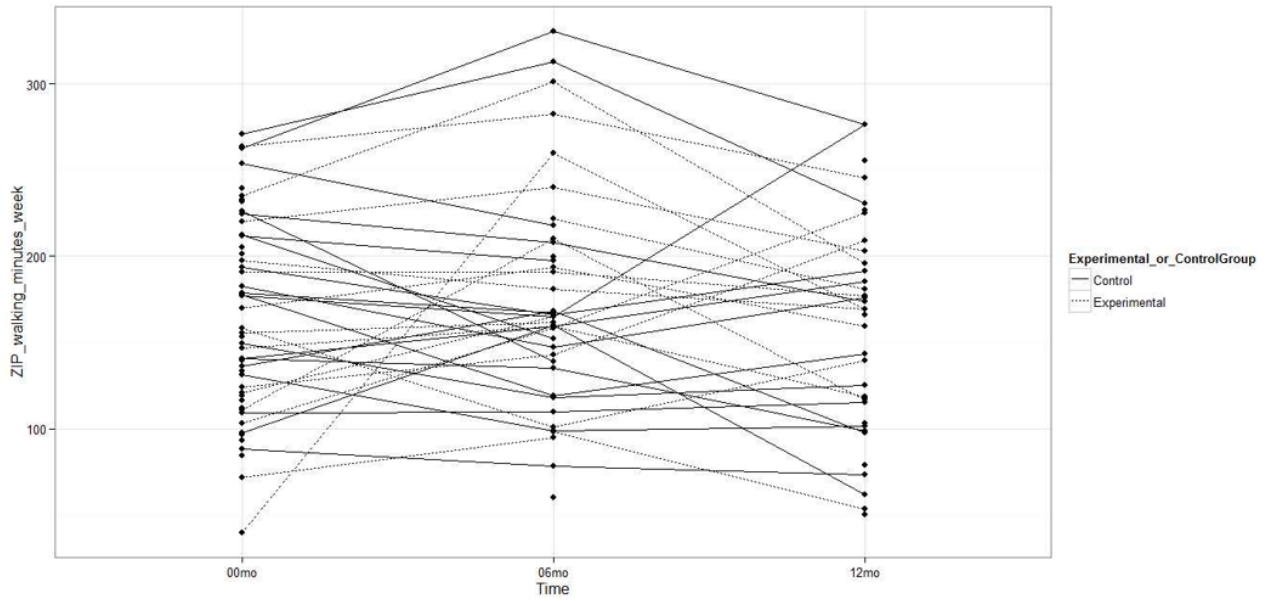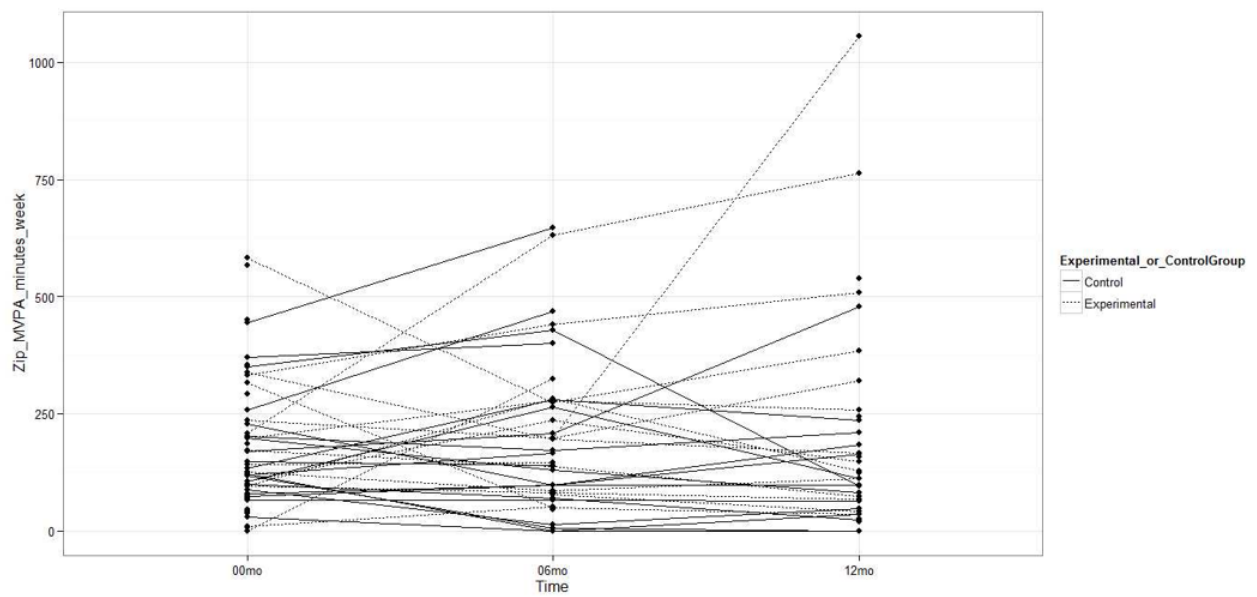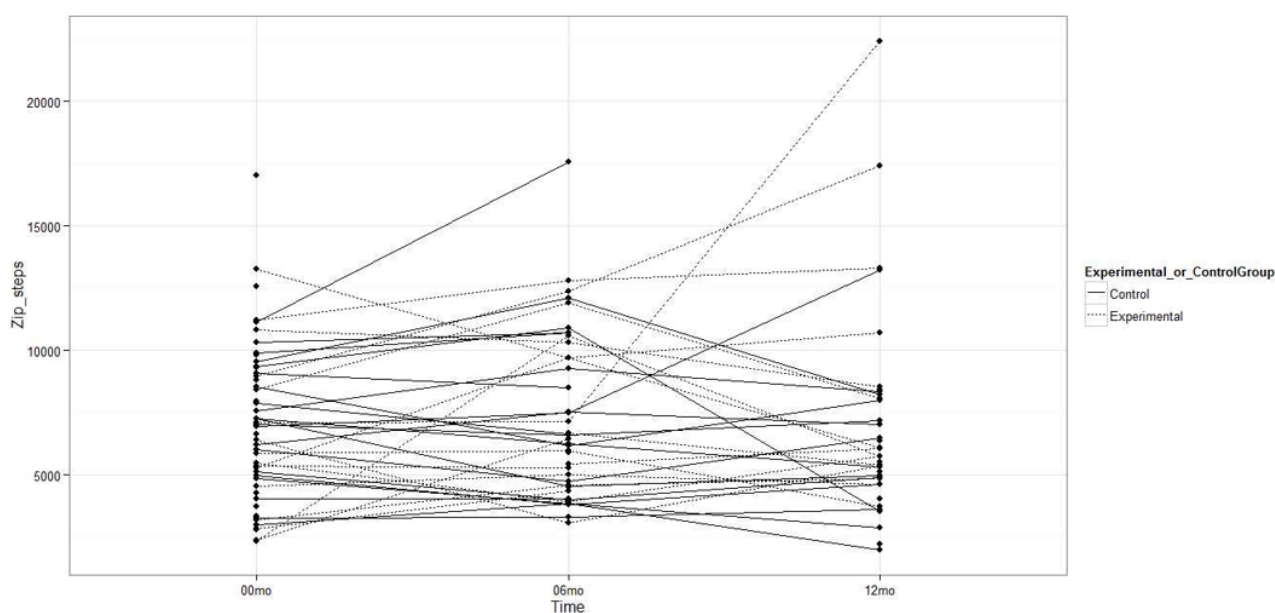

Figure 3. Moderate to vigorous physical activity measured with the accelerometer at baseline, 6 months, and 12 months.

Figure 4. Steps per day measured with the accelerometer at baseline, 6 months, and 12 months.

Physical Activity Changes From 6 to 12 Months

No statistically significant differences were observed between the experimental and control groups in the accelerometer-measured LPA minutes per week (MD –87.9 min, 95% CI –379.2 to 203.3; P=.54; Figure 2), MVPA minutes per week (MD 70.9 min, 95% CI –75.7 to 217.6; P=.33), or steps per day (MD 867.1 steps, 95% CI –2099.6 to 3833.9; P=.55; Figures 3 and 4). As such, there were no differences between groups in the MVPA minutes per week measured with the IPAQ (MD –292.2 min, 95% CI –755.6 to 171.2; P=.21).

Adherence and Side Effects of the Treatment

During the 12-month intervention, participants in the experimental group made an average of 98 (SD 167; range 0-716) recordings regarding their physical activity in Movendos mCoach and sent an average of 6.4 (SD 6; range 0-26) messages to the care provider. The results from a subjective questionnaire indicated that on a scale from 1 to 7, in which 1 indicated "totally agree" and 7 indicated "totally disagree," the participants almost or somewhat agreed they had actively used the Fitbit Charge HR (mean 2.4, SD 2.0). Participants somewhat disagreed that they had actively used Movendos mCoach (mean 4.9, SD 2.2). In total, 14% (4/29) of participants reported developing eczema as a result of the wristband of the Fitbit Charge HR. No other harms were reported.

Discussion

In this 12-month cluster randomized trial, additional distance technology-based intervention effectively increased LPA during the first 6-month period of cardiac rehabilitation and maintained the achieved level of physical activity from 6 to 12 months. The novelty of this pilot study was the significant finding that distance technology brings added value in increasing LPA compared to similar rehabilitation interventions without technology. Previous studies have shown that distance

technology-based physical activity interventions are approximately as effective as comparable conventional care in increasing physical activity [7], which is in line with this study, as no differences between groups were observed in MVPA or steps per day.

Recommendations on physical activity for special populations differ from those addressed to healthy people [19]. Adherence to physical activity recommendations has been low in both males and females with a history of cardiac events and previous studies adduced the difficulties in prescribing appropriate exercise regimens and achieving patient adherence in CVD rehabilitation [20]. Patients with CVD must overcome various barriers to exercise, such as having minor injuries, lack of time, or fatigue [11]. Although they would benefit from high-frequency training, improving their maximum aerobic capacity and muscle function, the fear of exercising is highly disruptive for 20% of cardiac patients [21]. The AHA recommends performing LPA given its recently studied health impacts [12]. LPA has been found to be favorable for multiple health-related outcomes, such as BMI, waist circumference, C-reactive protein, insulin resistance [4] and blood plasma glucose [22]. Obtaining a sufficient level of LPA is important, especially in the subacute phase of CVD rehabilitation, providing a basis for more intensive and independent exercising during the next phase of the rehabilitation (ie, intensive outpatient therapy). Our results illustrating substantial increases in LPA of 324 minutes per week in the experimental versus control group during the first 6 months are also clinically valuable.

We chose to use cluster randomization for practical and ethical reasons. In cluster randomization all the rehabilitees from the same group are enrolled to the same treatment allocation. As the intervention was executed in groups of participants, following the standard practice in cardiac inpatient rehabilitation, cluster randomization controlled the cross-contamination of experimental and control groups.

Pairwise randomization of clusters matched for the possible seasonal influences to be similar in both groups. This was reasonable, as the weather conditions vary between seasons in Finland. Since no differences between the groups at baseline were observed in most prognostic factors related to the results, randomization was shown to be successful.

This study used Fitbit Zip to measure physical activity, as it was considered suitable for research purposes at the time of planning the intervention. It is reasonable to assume the rapid acceleration of technology brought forth more accurate devices for measuring physical activity, which provides a basis for evaluating previously used versus newly developed technologies, including their accuracy, as more studies are conducted. Problems with the accuracy of Fitbit Zip occur mainly with more intensive activities, which subacute phase cardiac rehabilitees are not normally engaging in, and with resting time, which was not investigated in this study. During normal walking, Fitbit Zip records measurements with greater accuracy when placed in the torso region [23]. In this study, Fitbit Zip was placed on the hip; although wrist-worn accelerometers have been found to be more comfortable to wear [24], the long durations of the self-exercising periods require devices with greater memory capacities, which hip-worn accelerometers have. Physical activity was measured with both the objective accelerometer and subjective questionnaire. However, objective physical activity could have been measured with periods longer than 1 week to avoid the loss of data.

The strength of this study is the comparative design of both experimental and control interventions. The distance technology intervention was also well-tolerated by the participants, which may have resulted from intensive counselling on the use of technology and available practical support during the intervention. The intervention did not cause side effects or harm participants. The rehabilitation center is well-experienced in managing cardiac rehabilitation programs, and the intervention was designed with a multi-professional and interdisciplinary research group.

The limitations of this study relate to the sample size, which could have been larger. Nevertheless, we were able to focus on improving the adherence to the intervention with in-person counselling sessions at the beginning and in the middle of the intervention. For instance, to ensure the correct use of the Fitbit HR Charge and Movendos mCoach, a tutorial video was made for the participants in the experimental group. Clear instructions on how to use technology have been found to be important among older people [25]. Despite the tutorial video and the in-person consultations, the participants faced multiple technical challenges or sometimes forgot to use the device. In the future, the use of technology could improve with better compatibility between the activity monitor and computer or the implementation of less expensive, more advanced smartphones. In addition, future studies should investigate whether a more intensive use of technology could promote physical activity at different intensity levels and for longer periods of time. Likewise, the diversity of the participants pertaining to technology use and the ability to adapt to new technologies should be taken into account at the individual level [26]. Qualitative research is essential to further explain findings from CVD-related physical activity studies, develop effective physical activity motivation and encouragement methods, and thereby enhance patient management. Special focus should be given to increasing MVPA by improving the types of physical activity intervention.

In conclusion, our findings indicate additional distance technology in cardiac rehabilitation may be effective in promoting LPA; however, technology provided no added value compared to conventional rehabilitation alone in MVPA or in steps per day. In the future, more studies are needed first to determine effective methods for promoting physical activity among different populations and, then to resolve which types of technology would best serve this purpose. However, the rapid acceleration of technology development requires significant investments in the research field.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Physical activity changes during the 12 months of cardiac rehabilitation.
[PNG File , 41 KB - rehab_v8i2e20299_app1.png]

Multimedia Appendix 2
CONSORT EHEALTH-checklist (V 1.6.1).
[PDF File (Adobe PDF File), 1161 KB - rehab_v8i2e20299_app2.pdf]

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Abbreviations

AHA: American Heart Association
CR: cardiovascular rehabilitation
CVD: cardiovascular disease
IPAQ: International Physical Activity Questionnaire
LPA: light physical activity
MD: mean difference
MVPA: moderate to vigorous physical activity

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Original Paper

Adapting a Person's Home in 3D Using a Mobile App (MapIt): Participatory Design Framework Investigating the App's Acceptability

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Abstract

Background: Home adaptation processes enhancing occupational engagement rely on identifying environmental barriers, generally during time-consuming home visits performed by occupational therapists (OTs). Relevance of a 3D model to the OT's work has been attested, but a convenient and consumer-available technology to map the home environment in 3D is currently lacking. For instance, such a technology would support the exploration of home adaptations for a person with disability, with or without an OT visit.

Objective: The aim of this study was to document the development and acceptability of a 3D mapping eHealth technology, optimizing its contribution to the OT's work when conducting assessments in which home representations are essential to fit a person's needs.

Methods: A user-centered perspective, embedded in a participatory design framework where users are considered as research partners (not as just study participants), is reported. OTs, engineers, clinicians, researchers, and students, as well as the relatives of older adults contributed by providing ongoing feedback (eg, demonstrations, brainstorming, usability testing, questionnaires, prototyping). System acceptability, as per the Nielsen model, is documented by deductively integrating the data.

Results: A total of 24 stakeholders contributed significantly to MapIt technology's co-design over a span of 4 years. Fueled by the objective to enhance MapIt's acceptability, 11 iterations lead to a mobile app to scan a room and produce its 3D model in less than 5 minutes. The app is available for smartphones and paired with computer software. Scanning, visualization, and automatic measurements are done on a smartphone equipped with a motion sensor and a camera with depth perception, and the computer software facilitates visualization, while allowing custom measurement of architectural elements directly on the 3D model. Stakeholders' perception was favorable regarding MapIt's acceptability, testifying to its usefulness (ie, usability and utility). Residual usability issues as well as concerns about accessibility and scan rendering still need to be addressed to foster its integration to a clinical context.

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Conclusions: MapIt allows to scan a room quickly and simply, providing a 3D model from images taken in real-world settings and to remotely but jointly explore home adaptations to enhance a person's occupational engagement.

Introduction

When the physical environment interferes with a person's ability to do the things they want, need, or like, occupational therapists (OTs) look for potential home adaptations to enhance this person's home and community participation. Indeed, a mismatch between a person's capacities and the built environment might result in personal care assistance or institutionalization, increasing the financial burden for both families and health care system [1]. Carnemolla and Bridge [2] have shown an increase in health-related quality of life and well-being following a home modification process. A systematic review performed by Stark and her colleagues [3] indicates that home modifications resulted in improved function, increased ability to provide care, and decreased falls for people with a broad range of impairments.

Essential components of the home modification process for stakeholders are to jointly identify environmental barriers faced by a person to target changes and mitigate them, to add assistive technology use, and to transform occupational engagement. To do so, occupation-based intervention in the home by OTs is valued rather than relying on interviews in a remote location [4], but home visits are challenging. They are costly and time-consuming [5-7]. Moreover, OTs have reported that home visits can be stressful and anxiety provoking for some patients because it might be viewed as a "test" that they could fail [6].

Nevertheless, visual data about the architectural elements and the home design are essential for people engaged in a home adaptation process. Previous studies have investigated photography [8,9], video recording [10], and videoconference [11,12] as a substitute to a home visit but have shown mixed success. Relevance of a 3D representation for a home adaptation process has been attested by older adults [13] and OTs [14]. Some authors have reported experimenting with 3D representations for home adaptation: photogrammetry, which is a 3D construction from 2D pictures tools [15] or 3D virtual reality space design [13,14]. However, to our knowledge, available 3D drawing tools do not allow the visualization of a person's "real" home (eg, Idapt Planning [16], OT Draw [17], Google SketchUp [18], Sweet Home 3D [19]). Some technologies create 3D scans of real-world settings but they involve either high-tech equipment [20] or remote processing of data and added sensor equipment [21].

Therefore, a convenient and consumer-available technology to map the home environment in 3D and explore adaptations with a person having disabilities without an OT visit is currently missing. This study reports on the user-centered design within an overarching participatory design process of such an eHealth technology, and on its acceptability to promote engagement of individuals facing architectural barriers in their home.
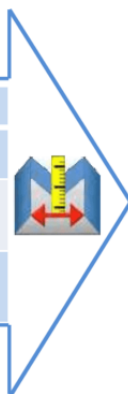
Methods

Framework

The choice of method to conduct MapIt's design focuses on understanding the aspects influencing the *acceptability* of technologies [22]. It refers to the evaluation of practical and social aspects such as reliability, cost, compatibility, and usefulness (ie, usability and utility) [22,23]. Therefore, by incorporating a *user-centered perspective* [24], a *participatory design* approach was conducted, led by researchers and where users are seen as partners (not as just study participants) [25,26]. A user-centered design approach focuses on meeting the users' needs by involving them throughout a technology's development process [24]. It is an iterative process where the prototype is tested by users and improved according to test results, thereby fostering technology acceptance [22]. The participatory approach pushes the users' involvement a step further by integrating some of them in the design team and having them participate in decision making during concept generation and development phases [25], to further improve the technology's acceptability. Still, additional users, in this case clinicians, patients, and relatives, are involved during testing rounds to give a fresh look on the design. They provide the more naïve feedback valued by a user-centered design and broaden perspectives on acceptability.

Design Process

Figure 1 summarizes MapIt's ongoing design process. Overall, the study was divided into 4 main phases: (1) exploration, (2) pretest, (3) first testing round, and (4) second testing round. The prototype exploration phase involved the design team envisioning the possibility to create 3D models of the home environment by using part of an existing technology. Indeed, as shown in the "Results" section, this study did not start from a blank slate. The pretest phase involved the design team creating and testing a first prototype, as well as establishing a user-centered testing protocol. Thereafter, the first and second testing rounds involved additional users to conduct multiple tests and iterations of the technology. Although the first and second testing rounds were tailored to the user-centered design approach, all 4 phases were part of a participatory design approach, as some users were part of the design team.

Figure 1. MapIt's design process (Notes: The numbered iterations of the prototype are placed chronologically and associated to the corresponding study phase. Some version numbers are skipped to match app and software version numbers; Version 0.4.2 of the app has not yet been tested).

Dates	2016		2018					2019			2020
	Oct 20	Nov 22	May 28	June 22	Sept 06	Sept 12	Nov 12	March 12	May 28	June 17	March 05
Iterations	RTAB-Map	Virtual repository	App v 0.1.0	App v 0.2.0	App v 0.3.0	Software v 0.3.0	Software v 0.4.0	Software v 0.4.1	App v 0.4.1	Software v 0.4.2	App v 0.4.2
Rounds of testing	-	-	Pretest	First testing round (June 07 to November 26)				-	Second testing round (June 06 to October 21)		-

The following sections describe the methods starting with Real-Time Appearance-Based Mapping (RTAB-Map; Figure 2) and a virtual repository (Figure 3), leading to an app's visualization interface (version 0.4.1; Figure 4) and a software interface (version 0.4.2; Figure 5). An overview of the scanning process is available in video format [27,28].

Figure 2. Map of a hotel bathroom to explore RTAB-Map's possibilities.
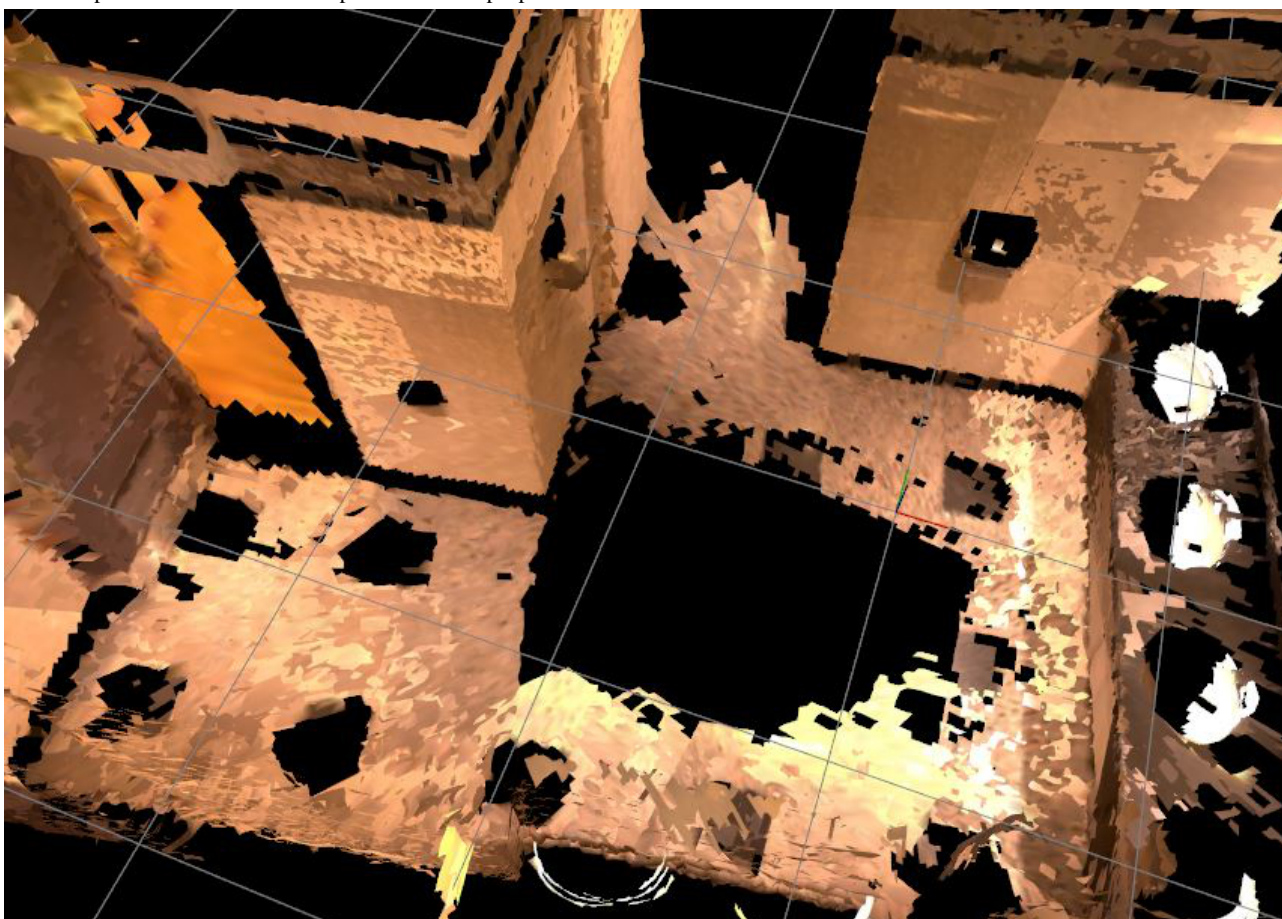
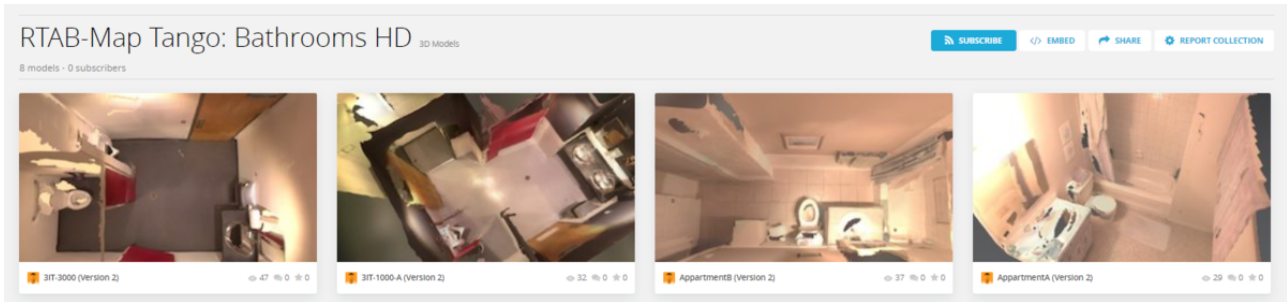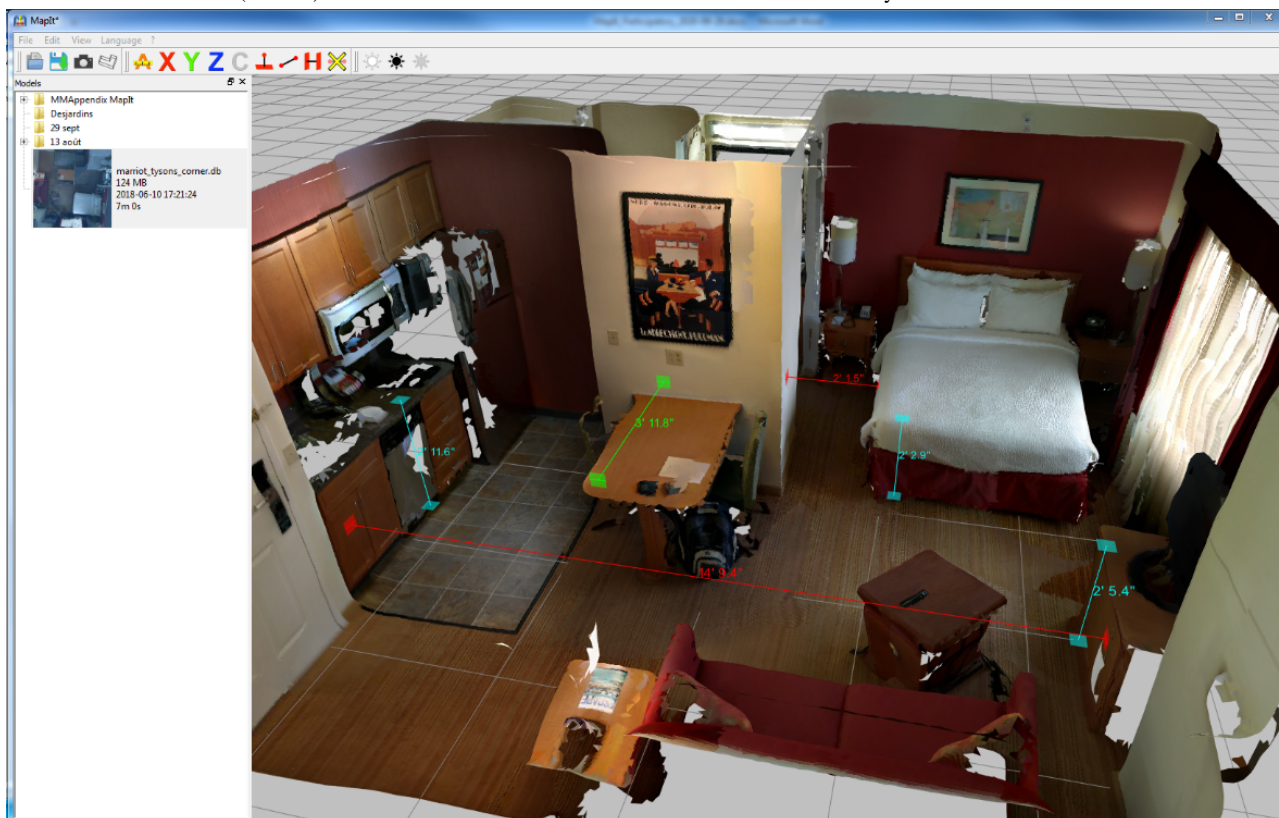**Figure 3.** Excerpt from virtual repository on Sketchfab [28].

Figure 4. Phone app interface (V 0.4.1) when visualizing a scan. On the left, no automatic measurements were applied while on the right, automatic measurements are applied.

Figure 5. Software interface (V 0.4.2) with custom measurements taken at different locations directly from the 3D model.

Stakeholders

Exploration

An informal team of 4 OTs (having 7, 15, 20, and 36 years of experiences as clinicians, 3 of them having become researchers) and 2 engineers (1 researcher and 1 postdoctoral fellow) was spontaneously formed at a scientific meeting where the idea sprouted (ie, to develop a convenient and consumer-available technology to map the home environment in 3D). While they did not have a predefined goal of addressing OTs' home visit challenges prior to this meeting, they envisioned to explore a solution when they saw a demonstration of RTAB-Map [29,30], an existing technology allowing robots to construct a map of the environment and localize their position for autonomous navigation.

Pretest

At the pretest phase, an additional clinical OT and a research professional were hired to join the team. Both women had complementary expertise. The former had 25 years of experience practicing and teaching the home adaptation process, whereas the latter had mechanical engineering and cognitive ergonomics training with 4 years of experience in participatory design as a research assistant. They were supported by 2 students (1 doctoral student with a master's in design and 1 student with a bachelor's in psychology backgrounds), contributing to the first and second testing rounds.

First Testing Round

Prototyping involved additional clinical OTs during the first testing round (not part of the design team). As it was assumed that all OTs had the right to be involved in the creation of MapIt

(democracy in cocreation being one of the guiding principles of participatory design [31]), a systematic sampling strategy was established with the regulatory board of OTs in Quebec. Members (N_{2018}=5464 [32]) received an advertisement by email to participate in the design if they had (1) indicated a professional address in the health region where the study was conducted in 2018; (2) provided an electronic address, and (3) agreed to make their names available for research (≈80% of members). Therefore, 251 members of Quebec's regulatory board of OTs were solicited (4.6%; personal communication with the board's general secretary).

Second Testing Round

A purposeful sample was retained for the second testing round with OTs not previously involved. OTs were asked to invite their patients and patients' relatives to provide input. Notably, when OTs could not visit the patient's home and scan the desired rooms, patients or relatives could be referred to the designer. The designer could then organize scanning at the patient's home with them or a relative and bring the 3D model back to their OT. In these circumstances patients or relatives were considered stakeholders.

Tools and Techniques

Overview

Tools and techniques were iteratively selected to reach the study's ultimate goal of improving the health and well-being of people engaged in a home adaptation process, by providing an acceptable technology to support this process. To reach this goal, design tools and techniques aimed to capture explicit, observable, tacit, and latent needs and knowledge (ie, what

people say, do, make, test, and dream) [25,33]. The co-principal investigators (an OT and an engineer) favored a consensual leadership, promoting interdisciplinarity and encouraging creativity and mutual learning throughout the design process moving from an existing technology (RTAB-Map for robots) to one that facilitates a home adaptation process (MapIt for OTs). To gather information from the stakeholders and their context, feedback was collected throughout, allowing to continuously include their perspectives in the design process.

The different tools and techniques, the purpose they served, and also the stakeholders who created, participated in, or benefited from each tool or technique are presented in chronological order of the study's 4 phases.

Exploration

MapIt is based on the RTAB-Map technology designed to help autonomous robots navigate wide indoor spaces occupied by dynamic and unstructured elements. It allows robots to construct a map of the environment and localize their position, a problem known as SLAM (Simultaneous Localization and Mapping) [29]. One of SLAM's key attributes is the capacity to recognize an already-visited location. This is known as loop-closure detection and helps to correct errors in the map generated by sensor inaccuracy. This detection happens in real time thanks to a memory management system which limits the number of areas to compare [30]. RTAB-Map is distributed as open-source software [34]. It is included in the ROS (Robot Operating System) distribution [35], and is largely used in the robotics community.

Demonstrations were occasions where the RTAB-Map technology and the virtual repository were shown by the software developer to the members of the design team who had the opportunity to share impressions. The technology used to support RTAB-Map was the *Project Tango tablet* (Google) while the virtual repository was made with *Sketchfab*. Formal and informal gatherings of the design team named *workshops* took place. They were places to express creativity freely, mutually probing and answering questions. During this phase, the workshops served to envision and create a first prototype of MapIt.

Pretest

Overall, *prototypes* were meant to explore and imagine [26] using MapIt as a new tool for people engaged in a home adaptation process. The first prototype used during the pretest was version 0.1.0 of the MapIt smartphone app made for the *ASUS Zenfone AR*. In this phase, *demonstrations* related to version 0.1.0 of the MapIt app and were done by the software developer to the rest of the design team. *Usability testing* [23] during the pretest aimed to resolve main usability issues before testing with other stakeholders. It involved an OT researcher and a clinical OT, both members of the design team, who were thinking out loud [36] while using the prototype. During this test, *field notes* were taken by another member of the design team to document usability comments as well as interactions of the user with the app (eg, unnoticed errors, difficulties). Afterward, the clinician received an ASUS Zenfone AR with MapIt installed for a trial period of 60 working days to further

test the first prototype in a clinical context. The clinician kept a *diary* to document information regarding the use of the app. Open-ended introduction and follow-up *interviews* in person or by phone between the clinician and another member of the design team allowed the collection of data regarding usability as well as barriers and facilitators to MapIt's use in a clinical context. To keep track of ideas and observations, *logbooks* were kept by members of the design team while conducting the pretest and modifying the technology. In this phase, *workshops* served to discuss and improve the app prototype as well as establish a protocol for testing with other stakeholders.

First and Second Testing Rounds

Iterations of the MapIt *prototype* were made during the testing rounds. Versions 0.2.0-0.4.2 of the MapIt app (made for the *ASUS Zenfone AR*) and versions 0.3.0-0.4.2 of the software (made for *Mac OS X* and *Windows*) were developed. *Demonstrations* were related to each specific version of MapIt and were first done by the software developer to the rest of the design team. Before testing, a demonstration was done by the member of the design team conducting the test (clinical OT or research professional) to the participant (clinical OTs and relatives of their patients; not a part of the design team). This demonstration allowed to share impressions, explore learnability of the prototype, and prepare for testing. Participants also received an introduction to the technology [27] as well as to 3D scanning best practices [37] in a *video* format. After the demonstration and videos, a *usability test* [23] was officially conducted and the participant was encouraged to think out loud [36] while scanning a room with the MapIt app. While relatives only tested the app, OTs also tested the software because it was added at their request, helping them take measurements and better visualize the space. While usability tests were recorded and transcribed in the first testing round, *field notes*, taken by the person conducting the test, were added in the second testing round to accelerate the analysis process. *Questionnaires* were used to gather information from the participants and their context to better understand their perspective.

Participants were characterized using questions about their use of technology and sociodemographics. In the second testing round, the Post-Study System Usability Questionnaire (PSSUQ) [38] was added to measure perceived user satisfaction regarding the app and the software. Based on a Likert scale (1=Strongly disagree; 7=Strongly agree) with 19 items grouped into 3 subscales (system usefulness, information quality, and interface quality), 3 subscores and a total score have been calculated. Questionnaires were used to gather information from the participants and their context to better understand their perspective.

After the test session, clinical OTs received an ASUS Zenfone AR with MapIt installed, for a trial period of at least of 40 working days to further experiment with the prototype in a clinical context. Four ASUS Zenfone AR phones were available simultaneously. During this period, OTs were given a *diary* template (Multimedia Appendix 1) to document information regarding their use of the MapIt app and software.

Interviews were conducted by a member of the design team to have a more in-depth understanding of the OTs' perspective.

In-person semistructured interviews were conducted in the work settings at the beginning and at the end of a trial period as well as open-ended follow-up phone interviews. They were audio recorded and transcribed and the interview guides were iteratively modified (Multimedia Appendix 2).

Workshops were conducted with design team members to discuss and improve the app prototype following test results. During these workshops, emerging themes and conclusions were compiled and reviewed to improve the prototype. To keep track of ideas and observations, *logbooks* were kept by members of the design team while conducting tests, coding interviews, and modifying the technology. A *website* was created to access installation links, file prototype modifications, and provide access to information about the use of the app and software [39]. It was accessed by the design team members as well as by the OT participants and modified by the software developer.

Data Analysis

Stakeholders' characteristics (first and second rounds of testing) or satisfaction from the PSSUQ (second round of testing) was analyzed with mean and standard deviation (continuous variables) or frequency and percentage (categorical variables). To appreciate acceptability of the MapIt app and software, in the pretest and both rounds of testing, 2 or 3 members of the design team used deductive data thematic condensation with the acceptability theoretical framework [22,23] to analyze logbooks, field notes, interview transcripts, and diary texts (both available on the first and second testing rounds only). This data thematic condensation was done in Microsoft Excel, Microsoft Word, and N-Vivo 10 (QSR International). After each iteration, emerging themes were validated with stakeholders during workshops. Improvements to the prototype were made based on those themes. These modifications were then tested and evaluated in the next iteration as suggested by the user-centered iterative design process for eHealth [24]. Triangulation was achieved by drafting and editing the manuscript with coauthors.

Research Ethics

The research protocol established for testing rounds was submitted for ethics approval, prior to involving clinicians, patients, or relatives who were not part of the research team. The study was approved by the Ethics review board of the *Centres intégrés [universitaires] de santé et services sociaux (CI[U]SSS) de l'Estrie-Centre hospitalier universitaire de Sherbrooke (CHUS)* (#2019-2827).

Results

Stakeholders

A total of 24 stakeholders contributed to designing MapIt, 10 being part of the team described above. The other 14 were either clinicians or relatives testing MapIt in a clinical context during first or second testing rounds.

Four OTs working in homecare settings responded to the advertisement sent by the regulatory board and were recruited (participation rate: 4/251, 1.6%) for the first testing round. Because they were all working in similar clinical settings (ie, homecare), to multiply perspectives in the second testing round,

an OTs' clinical supervisor in a geriatric health center organized a short in-person presentation of the project by the coprincipal investigator. After this, 3 OTs working in inpatient care and 2 OTs working in the day hospital signified their interest to participate by email and were recruited for the second testing round. Overall, those 8 females and 1 male were aged between 25 and 41 (mean 34 [SD 4.8] years) and had between 2 and 19 years (mean 12 [SD 5.1]) of clinical experience in occupational therapy. Seven hold a bachelor's degree while the 2 others had completed graduate studies. Every OT owned and used a smartphone, had internet at home, and used it every day.

The relatives who provided feedback in the second testing round were 4 males and 1 female aged between 54 and 73 (mean 67 [SD 9.4] years). They had either a high-school (n=1), professional (n=2), or graduate (n=2) diploma. All of them had used and owned information and communication technology devices but only 3 of the relatives had used a smartphone. Two of the consenting patients, 1 male and 1 female, were present in their home on the day of the scan but chose not to use MapIt due to unfamiliarity with technology. The designer did the scans herself and no questionnaire was submitted to the patients.

MapIt's Design

As shown in Figure 1, designing of the MapIt technology involved 10 complete and 1 incomplete (app version 0.4.2 not tested) iterations. More specifically, regarding usability issues, an estimated 100 were identified and around 80 were addressed in different versions of the app and software prototypes. Examples of changes made to the prototypes between iterations to address these issues are presented in Multimedia Appendices 3 and 4. The general approach to the different iterations is explained in the following sections.

Exploration

RTAB-Map

During the demonstration of RTAB-Map, OTs practicing in clinical and research fields had the opportunity to observe the construction of a map on a Project Tango tablet operated by an engineer. OTs gathered informally and suggested mapping a bathroom in the hotel to explore the possibility of using such a technology to promote occupational engagement of individuals facing architectural barriers in their home. Results were judged sufficiently promising (Figure 2).

Virtual Repository

A virtual repository (Figure 3) was created to assess the feasibility of conducting a participatory design study. The designer of RTAB-Map used a Project Tango tablet to create a repository of 10 bathroom scans and 3D models (RTAB-Map preliminary version on Tango tablet [40]; MapIt version 0.1.0 [28]). These models could be downloaded and examined using, for instance, MeshLab [41] or online on Sketchfab [42]. Certain types of lighting (see HouseB for example [28,40]) create significant increased camera exposure time, resulting in very bright images (almost white) and colorless patches in the 3D model. Nonetheless, it was confirmed that 3D representations of a person's home environment could be generated. The repository supported a research grant application to move ahead.

Pretest: Smartphone App Version 0.1.0

During the pretest, the feasibility of a smartphone app was explored. A mobile app was designed for the ASUS Zenfone AR smartphone equipped with a motion sensor and a depth perceiving camera.

During their first test with MapIt, both OTs from the design team chose to scan bathrooms. Subsequently, the clinical OT received an ASUS Zenfone AR with the app. She took 3 different bathroom scans of and took part in 2 interviews with another member of the design team.

First and Second Testing Rounds: Smartphone App and Software Versions 0.2.0-0.4.2

During the first testing round, homecare OTs took a scan of their patient's home on 47 occasions (35 bathrooms, 6 bedrooms, 1 dining room, 1 trailer home, 3 exterior accesses, 1 indoor staircase). During the second testing round, OTs working in inpatient care and in the day hospital did a scan of a bathroom or kitchen in their workplace in order to test the technology. Two of them also scanned bathrooms and bedrooms in their home to further explore the technology. Because OTs in the second testing round could not visit patients at home, they gave a consenting patient's contact number to the designer who organized the scans in each patient's home on 7 occasions. Five of these patients were hospitalized and, in each case, one of their relatives agreed to scan with MapIt (scans done by relatives: 5 bathrooms and 1 bedroom). The mean time taken by stakeholders to scan 1 room is 3 minutes and 41 seconds (range 1 minute and 6 seconds to 10 minutes and 13 seconds; SD 1 minute and 53 seconds).

In the first testing round with 4 homecare OTs, 12 semistructured interviews (mean 36 minutes; range 11-61 minutes [SD 15 minutes]) and 12 open-ended follow-up interviews (mean 12 minutes; range 3-23 minutes [SD 7 minutes]) were conducted. In the second testing round with 5 OTs working in a geriatric health center, 5 semistructured interviews (mean 37 minutes; range 27-41 minutes [SD 6 minutes]) and 15 open-ended follow-up interviews (mean 9 minutes; range 3-21 minutes [SD 5 minutes]) were carried out. The first testing round involved more recorded interviews because each usability test was included in the first interview, whereas only field notes were taken during usability tests in the second testing round. This decision was taken by the team as a way to accelerate detection of usability issues.

Including the first and second testing rounds, 14 usability tests were done either in an institution (OTs; n=9) or in a home (relatives; n=5). A total of 8 workshops happened either through formal team meeting (n=5) or scientific gathering in conferences (n=3), notably to ensure a constant focus on the context and stakeholders' needs. For instance, in response to OTs' comments, a computer software was designed to allow taking custom measurements on the scan and better viewing of the image. Usability tests and interviews therefore included the software from the moment the first version was released (December 9, 2018) to the end of testing (October 21, 2019).

MapIt's Acceptability

Stakeholders were generally satisfied with MapIt. Figure 6 presents the mean PSSUQ scores for the OTs' and the relatives' satisfaction regarding the app and the OTs' satisfaction regarding the software during the second testing round. OTs and relatives "agree" with the app and the software's system usefulness and interface quality. Information quality has lower mean scores while still being above "somewhat agree." Stakeholders mentioned that information quality scores would have been lower had the interviewer not have helped them when they encountered a difficulty.

Figure 6. PSSUQ results in the second testing round (mean overall and subscale scores); error bars show standard error.
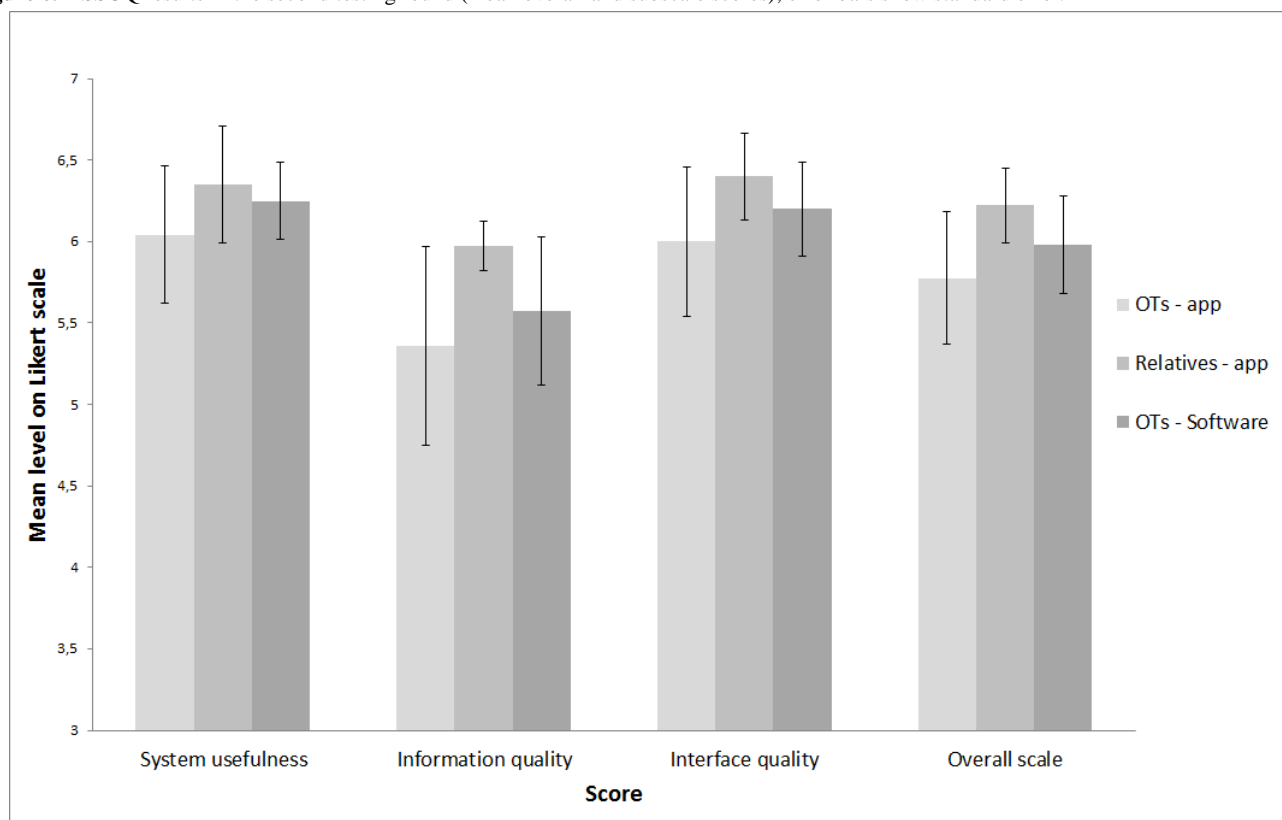
System acceptability, as per the Nielsen model, documented by deductively integrating the data is presented in Multimedia Appendix 5. Four identified themes (ie, utility, usability, accessibility, and scan rendering) and 14 subthemes, accompanied by their respective definition, are presented. Some citations extracted from field notes, interview transcripts, logbooks, and diaries are also presented to help understand MapIt's acceptability as perceived by stakeholders.

MapIt's perceived *utility* is to offer a more global view and better understanding of the patient's environment, to take measurements, facilitate recommendations, and give a visual support to explain those recommendations. Future utilities suggested were to be able to test different home adaptations by modifying the scan, import assistive device models in the scan, and create visual reports.

The main *usability* issues outlined by stakeholders were ease of use, learnability, and efficiency. The app was easy to use by a person who is familiar with smartphones but software installation needed to be simplified in future versions. The software was less intuitive than the app and it was harder to remember how to use it when trials were spaced out. The technology has been deemed efficient and the need for efficiency was underlined.

Certain *accessibility* considerations arose when talking about the implementation of MapIt in the clinical context. For instance, some patients may feel uneasy with the fact that an image of their home is available to health professionals; 2 older adults even refused scanning in their home. When the patient gives authorization but the OT cannot visit his or her home, as was the case with OTs working in the geriatric health center,

someone else must be available to scan. In this instance, the scan could be done by the patient, relatives, a government employee, or a health care professional. However, the scanning process would currently not be accessible directly to persons with major mobility or cognitive impairments. Their home would have to be scanned by someone else. Furthermore, stakeholders agreed that they would be more prone to use the technology if its access was facilitated in multiple ways: access for many stakeholders (OTs and relatives), proximity, and availability. Stakeholders also underlined the need for technical support. Comments on the cost of the technology stated that it must be kept low and, ideally, not be borne by individuals.

Stakeholders commented on the *scan rendering*. They noticed that the technology performed less well when placed in front of reflecting, dark, or single-colored surfaces. It must also be used at a certain distance from the objects scanned, which made it harder to use in small rooms. Indeed, it must be noted that image quality can be compromised by the presence of certain types of surfaces or proximity of an object. Stakeholders commented on the image quality with varying appreciation, some thinking it was good, others not. Indeed, as one familiarizes with the use of the app, the image quality of the scans produced improves. They were also concerned by the validity of measurements given by MapIt and some OTs compared them with measurements taken using a measuring tape. They argued for measurement precision, as it directly affects recommendations.

Discussion

MapIt Acceptability

The user-centered design of MapIt within a participatory approach aimed to maximize its acceptability for a home adaptation process, enabling individuals with disability to safely engage in their occupations. MapIt is a relatively easy-to-use mobile app available on a smartphone equipped with a motion sensor and a depth perceiving camera to scan a room and produce its 3D representation in less than 5 minutes. Resulting 3D models can be visualized on a computer software facilitating the measurement of architectural elements. OTs and the relatives of individuals living with disabilities found that MapIt is useful because it provides a global view and supports mutual understanding of a person's environment. To initiate and maintain adoption of MapIt in the clinical context, accessibility elements have to be considered such as who will be scanning and providing technical support, all at affordable cost for an organization. Besides residual usability issues, scan rendering is a concern.

Overall, the goal is met as MapIt produces a 3D representation of person's real home simply and rapidly. MapIt was evaluated positively as an acceptable solution, which is a crucial determinant in technology adoption according to common theories [22,23,43,44]. Compatibility has been identified previously as influencing the OT's intention to use a technology [45]. In their study, Schaper and Pervan [45] defined compatibility as the degree to which an innovation is perceived as being consistent with the existing practices, values, needs, and experiences of the health care professional.

For instance, relying on a mobile device without a complex setup, MapIt allowed OTs as well as relatives of their patients with minimal training and supervision to scan a room in a house. It even allowed taking measurements of architectural elements remotely. It provides a 3D representation from images taken in real-world settings, one of MapIt's key advantages, in addition to its ease of use. As wished by stakeholders, MapIt uses local processing to ensure the confidentiality mandatory in numerous eHealth interventions.

It is important to note that stakeholders were puzzled about evaluating an acceptable cost for MapIt. The approaches to be used for knowledge transfer and commercialization remain to be explored. Building a business model is a critical step to steer the adoption process of eHealth technologies [46]. It should be done keeping in mind that MapIt is currently dependent on 2 specific phones having Google Tango technology; all tests were conducted using the Asus Zenfone AR and Lenovo Phab2 Pro. However, MapIt could be ported to new Android phones equipped with a time-of-flight camera (eg, Huawei P30 Pro, Samsung Note10+). In the iOS ecosystem, the latest iPad Pro has the LiDAR technology (like a time-of-flight camera) required for MapIt, a technology which is also integrated into the new iPhone 12 Pro [47]. While MapIt has been designed for Android, porting it to iOS is now possible.

Feasible improvements are certainly good targets to allow jointly exploring home adaptations with MapIt. First, OTs would like

MapIt to scale up to scanning the whole house to visualize rooms' localization and design in relation to one another. Second, the tools for measuring architectural elements within MapIt have raised concerns about their ability to be trusted as much as the measuring tape. According to Kim and colleagues [15], having studied virtual reality as a substitution for a home visit, accuracy remains a critical concern for home modification specialists. Reliability and validity of measurements taken by a person on MapIt scans should be investigated. Third, adding shapes such as squares or circles to mimic adding a wheelchair in a bathroom or visualize a turning radius is relatively simple to do. Finally, further creative work should certainly aim to minimize residual usability issues such as difficulties inherent to the technology (eg, sensitivity to the type of surface, lighting, distance from object scanned, loop closure), which could be mitigated within the limits of the affordable and convenient technology chosen.

Reflection About Theory

Designing an eHealth technology such as MapIt with potential users and evaluating it in a clinical context allowed to consider its acceptability from the start, as suggested by the user-centered design [24]. However, contrary to participatory design principles, the study did not truly start at the fuzzy front-end of a co-designing process [48], exploring in detail the unmet needs of people [31] involved in improving the health and well-being through home adaptations. Indeed, to determine what was to be designed or not, a participatory design process was steered toward the team members' a priori, relying on their past research, technical, and clinical experiences. More ambiguity at the start might have led to other different solutions, whether technological or not.

Nevertheless, all study phases involved potential users, following key guiding participatory design principles such as democracy, mutual learning, and collective creativity [31]. A more targeted approach allowed us to focus on a tangible solution to increase potential success with academic grants. This approach combined a substantial number of tools and techniques into a coherent design process. Applicable results were pursued to move relatively quickly and test a solution in a clinical context.

Yet, welcoming the expression of all needs during designing (ie, explicit, observable, tacit and latent) and looking for what people say, do, make, test, and dream [25,33] poses the challenge of prioritizing the (endless) possibilities during a (non-eternal) research study. For example, the request of OTs to be able in the future to delete, add, or move architectural elements (eg, cabinets in the bathroom) on a scan must be balanced with the cost of such a technological development, in a context where other available technologies already address this need [16-21]. Interdisciplinary consensual coleadership has probably contributed to dealing efficiently with inherent tensions and encouraged open creative thinking, while focusing on getting to a clinical hands-on solution.

Study Limitations

One study limitation results from the fact that stakeholders were not left to fend for themselves if a problem occurred during

usability testing. This decision was made because the MapIt technology is not similar to any commonly used app or software. Although errors were recorded, stakeholders could ask questions and receive help from the interviewer. This did not allow to collect usability metrics relating to effectiveness (level of completion of task) and allowed limited metrics on efficiency (time to complete task) [23], but it did allow to collect impressions throughout the whole scanning and viewing tasks. In terms of usability, qualitative data were judged to be more important due to the stage of the technology development and the size of the sample. Future studies should involve testing without support of an expert.

Another limitation comes from sample size. While it includes different user groups, the sample is small which limits generalization. However, 2 rounds of testing were done, and the prototype was improved in an iterative fashion: the sample is sufficient to dig below surface value insight into usability issues [49,50]. Other stakeholders involved in the home adaptation process, such as paying authorities, builders, and interdisciplinary health care team members [51], were not solicited. Broader perspectives of stakeholders might have enhanced the participatory design even more. Still, a design team comprising OTs, engineers, clinicians, and students provided ongoing input from the start of the study, as suggested by participatory design, and input from lay OTs, older adults, and their relatives was added during testing rounds, which is coherent with a user-centered process for the development of an eHealth technology [24].

Conclusions

MapIt is an eHealth solution developed through a user-centered and participatory process perceived by stakeholders as an acceptable technology to jointly explore home adaptations overcoming environmental barriers to enhance the independence of individuals with disabilities. This mobile app mapping a room to produce a 3D representation of a "real" home with a smartphone is useful because it was relatively easy to use, contributing to OTs work by providing a global view and supporting mutual understanding of a person's environment. As with other eHealth interventions, accessibility considerations must be addressed to support adoption in the clinical context while MapIt's usability and scan rendering will be improved.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Documentation of MapIt's use.
[PDF File (Adobe PDF File), 51 KB - rehab_v8i2e24669_app1.pdf]

Multimedia Appendix 2
Interview guides.
[DOCX File , 16 KB - rehab_v8i2e24669_app2.docx]

Multimedia Appendix 3
Smartphone app prototype modifications (examples).
[PDF File (Adobe PDF File), 833 KB - rehab_v8i2e24669_app3.pdf]

Multimedia Appendix 4
Computer software prototype modifications (examples).
[PDF File (Adobe PDF File), 746 KB - rehab_v8i2e24669_app4.pdf]

Multimedia Appendix 5
Acceptability of MapIt and its contribution to the work of OTs.
[DOCX File , 19 KB - rehab_v8i2e24669_app5.docx]

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Abbreviations

OT: occupational therapist
PSSUQ: Post-Study System Usability Questionnaire
ROS: Robot Operating System
RTAB-Map: Real-Time Appearance-Based Mapping
SLAM: Simultaneous Localization and Mapping

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Original Paper

Technology Acceptance and Usability of the BrainFx SCREEN in Canadian Military Members and Veterans With Posttraumatic Stress Disorder and Mild Traumatic Brain Injury: Mixed Methods UTAUT Study

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Abstract

Background: Canadian Armed Forces service members (CAF-SMs) and veterans exhibit higher rates of injuries and illnesses, such as posttraumatic stress disorder (PTSD) and traumatic brain injury, which can cause and exacerbate cognitive dysfunction. Computerized neurocognitive assessment tools have demonstrated increased reliability and efficiency compared with traditional cognitive assessment tools. Without assessing the degree of technology acceptance and perceptions of usability to end users, it is difficult to determine whether a technology-based assessment will be used successfully in wider clinical practice. The Unified Theory of Acceptance and Use of Technology model is commonly used to address the technology acceptance and usability of applications in five domains.

Objective: This study aims to determine the technology acceptance and usability of a neurocognitive assessment tool, which was titled BrainFx SCREEN, among CAF-SMs and veterans with PTSD by using the Unified Theory of Acceptance and Use of Technology model.

Methods: This mixed methods embedded pilot study included CAF-SMs and veterans (N=21) aged 18-60 years with a diagnosis of PTSD who completed pre- and postquestionnaires on the same day the BrainFx SCREEN was used. A partial least squares structural equation model was used to analyze the questionnaire results. Qualitative data were assessed using thematic analysis.

Results: Facilitating conditions, which were the most notable predictors of behavioral intention, increased after using the BrainFx SCREEN, whereas effort expectancy decreased. Performance expectancy, effort expectancy, and social interaction were not factors that could predict behavioral intention. Participants who reported a previous mild traumatic brain injury were significantly more likely to report current symptoms of cognitive impairment. The BrainFx SCREEN is a feasible, usable, and accepted assessment tool for CAF-SMs and veterans who experience PTSD.

Conclusions: As military health care systems integrate technological innovations to improve the services and care provided, research must continue to address the acceptability and use of these novel assessments and interventions.

KEYWORDS

NCAT; PTSD; cognitive assessment; cognition; executive function; technology acceptance; UTAUT; Canadian Armed Forces; mTBI; concussion; digital health; neuropsychology; neurology; post concussive symptoms; military

Introduction

Background

Canadian Armed Forces service members (CAF-SMs) and veterans exhibit higher rates of injuries and illnesses, such as posttraumatic stress disorder (PTSD), depression, anxiety, sleep disorders, and mild traumatic brain injury (mTBI), which can cause and exacerbate cognitive dysfunction [1,2]. Numerous studies conducted in Canada, the United States, and the United Kingdom demonstrate a high prevalence of mTBI and PTSD as comorbidities specific to deployments during the War on Terror (2001-2013) [3-5]. The co-occurrence of traumatic brain injuries (TBIs) and PTSD can arise from the same or separate traumatic incidents [3].

When mTBI symptoms persist for longer than 3 months, they may be referred to as postconcussive symptoms (PCSs) [6]. In a study assessing CAF-SMs with mTBI from deployments in Iraq and Afghanistan during the War on Terror, PCS was present in 21% of those with less severe forms of mTBI and in 27% of those with more severe forms of mTBI [7]. The rates of PTSD among Canadian veterans have been estimated to be 16% [8]. Interestingly, after adjustment for confounding variables, mTBI was found to have no significant association with PCS relative to non-TBI injury [7]. Mental health conditions, such as combat-related PTSD, had a strong association with reporting three or more PCSs [5,7]. Identifying if symptoms are related to mTBI and/or a concurrent mental health diagnosis is difficult, as many of the symptoms attributed to these conditions overlap. Symptoms often described as PCS in patients with mTBI may be better explained from a psychological standpoint and may be more likely to be caused by PTSD [9]. Cognitive dysfunction is a common symptom experienced by many CAF-SMs and veterans who have experienced PTSD, mTBI, and/or a host of other comorbid conditions.

Cognitive Dysfunction and Assessment

Cognition is a broad construct that refers to information processing functions carried out by the brain [10]. Such functions include attention, memory, executive functions, comprehension, speech [11], calculation ability [12], visual perception [13], and praxis skills [14,15]. Cognition is instrumental in human development and the ability to learn, retain, and use new information in response to everyday life and is integral to effective performance across a broad range of daily occupations, such as work, educational pursuits, home management, self-regulation, health management, and leisure activities [15]. Reduced cognitive functioning can detrimentally affect a person's relationships and cause mental and emotional distress [15,16]. Within the military context, cognitive dysfunction can potentially result in decreased efficiency and effectiveness and increased risk of harm to self, the unit, and the mission [2].

Owing to the cognitive challenges and dysregulation that can be caused by PTSD, cognitive assessment and screening is important to enable clinicians to recommend treatment, referrals, and advise on a CAF-SM's or veteran's safety in activities of daily living, which may include military activities [16,17]. Reliable, valid, specific, and function-based cognitive screening and assessment practices are essential for determining the effective interventions to improve cognitive functioning [17]. Computerized neurocognitive assessment tools (NCATs) are widely used in other global militaries and have multiple benefits, including increased inter- and intrarater reliability, ease of administration, reduced time to administer, and ease of calculation and analysis of results [18]. One such tool that is being trialed within the Canadian Forces Health Services (CFHS) is the BrainFx SCREEN.

BrainFx SCREEN

The BrainFx SCREEN is a function-focused, Canadian-made screen that addresses neurofunction through a digital interface on a tablet [19]. On the basis of its more comprehensive predecessor, BrainFx 360, BrainFx SCREEN has a 10- to 15-minute duration and is administered by a health care professional trained as a Certified BrainFx Administrator (CBA) via a touch tablet to set a baseline or to determine if a further assessment or test is needed [19]. The BrainFx SCREEN has 15 tasks within seven domains of cognition, which include (1) overall skill performance, (2) sensory and physical skill performance, (3) social and behavioral skills performance, (4) foundational skills performance, (5) intermediate skills performance, (6) complex skills performance, and (7) universal skills [19]. These seven domains encompass a variety of cognitive skills, including different areas of memory, attention, visuospatial, and executive functions [19]. The BrainFx SCREEN is a new and innovative tool based on the BrainFx 360 assessment; as such, it has not been researched for validity and reliability as its predecessor has. The BrainFx SCREEN also collects a variety of demographic and health information, including level of education, presence of other comorbidities including mTBI, chronic pain, and other mental health diagnoses, current level of fatigue, presence of sleep difficulties, and presence of self-perceived neurofunctional deficits. The BrainFx 360 assessment has been subjected to reliability and validity testing, and current evidence demonstrates that this comprehensive assessment has promising validity, reliability, and sensitivity, with a focus on neurofunction [20] (Sergio L, unpublished data, 2014). The BrainFx SCREEN has undergone widespread uptake within Canada and the United States but has yet to be tested based on evidence-based models or frameworks for technology acceptance.

Technology Acceptance and Usability in Health Care and Military Contexts

Technology offers health care professionals a variety of benefits from improving effectiveness, efficiency, and potential engagement in record keeping, assessments, and interventions.

As such, the acceptance of such technologies by health care professionals, and their patients, is an important topic of interest for both practitioners and researchers [21]. Without technology acceptance and acceptable usability for the user, technological assessments and interventions may not be adopted in clinical practice despite its effectiveness. The evaluation of acceptance and usability of emerging technology is integral to advance best practices in health care [22].

Owing to some of the fundamental differences in military culture, environment, and contexts, the relationship between users and technologies, and the variables influencing this, may need to be considered separately from civilian relationships with technology. Many military organizations' approach to technology is to measure and maximize operator performance to increase system efficiency, which translates to success in military missions [23]. It is unknown if current models and frameworks of technology acceptance and usability are applicable to military populations, as the relationship between military personnel and organizations is not consumer based. It may also be presumed that the performance and functionality of technology are prioritized over comfort and esthetics [23].

Regardless of the potential differences in the relationship between the user and technology in a military context, the use of eHealth and mobile health (mHealth) innovations is becoming widespread within military and veteran populations [24,25].

This has been amplified by the recent COVID-19 pandemic when virtual health solutions have become increasingly common in all health care practices, including those in military environments. Although most studies addressing technology attitudes, beliefs, acceptance, and usability within military and veteran populations are US based, current evidence suggests that the military population is willing to use digital health and mHealth technologies [25-27]. Regardless of the context for technological innovation, adequate technology acceptance and usability is key to its uptake within that environment and culture. Before addressing the facilitators and barriers to the usability of a technological innovation, it is helpful to directly or indirectly assess technology acceptance within different user groups within their context using a framework or model.

The Unified Theory of Acceptance and Use of Technology Model

The Unified Theory of Acceptance and Use of Technology (UTAUT) model was developed based on previous theories and models for acceptance and adoption of technologies and consumer products that address the perceived technology acceptance of a user group with the goal of predicting usage behavior (Figure 1) [28]. The UTAUT has been demonstrated to explain as much as 70% of the variance in intention to use technology compared with its technology acceptance model predecessors [28].

Figure 1. The Unified Theory of Acceptance and Use of Technology model.
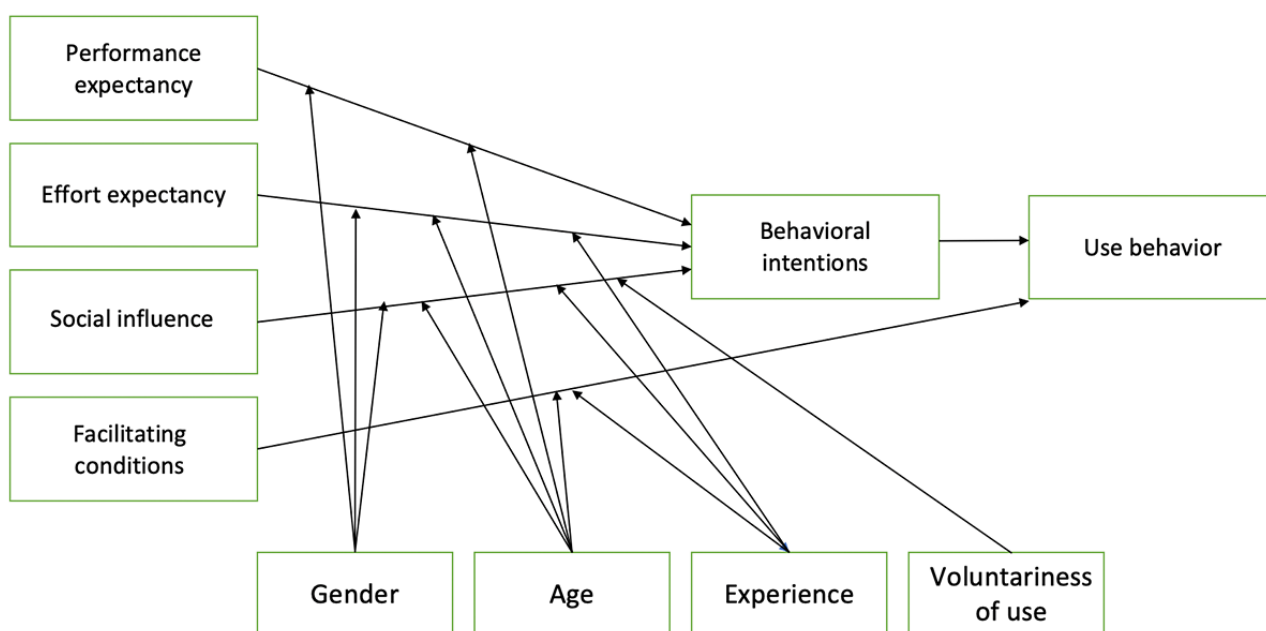
This model was developed from the point of view of the implementation of new technologies in practice within organizations on individuals rather than technology for mass consumer consumption [29,30]. The UTAUT model addresses the perceived expectations of technological acceptance of new technology in five constructs: performance expectancy (PE), effort expectancy (EE), social influence (SI; direct determinants of behavioral intention [BI]), facilitating conditions (FC), and BI, which is the direct impact on use behavior [28]. The UTAUT is a model that is commonly tested using partial least square

(PLS) structural equation modeling (SEM) and is an example of a reflexive PLS path model [28]. The exogenous latent variables (PE, EE, and SI) affect the endogenous latent variable (BI), which affects the construct of use [28]. In addition, FC can also have a direct effect on use [28]. Moderator variables, which include age, gender, experience, and voluntariness of use, also affect the interaction between the indicators and constructs [28,30].

BI is defined as the intention to use technology, and use is defined as the actual use [28]. BI predicts whether the

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technology in question will be adopted by the user in reality. The three direct determinants of BI to use technologies are PE, EE, and SI. PE is defined as the degree to which an individual believes that using the system will help the person attain gains in task performance [28]. The EE construct was defined as the degree of ease associated with the use of the system, and SI is the degree to which an individual perceives that important others believe they should use the new system [28]. FC have been defined as the degree to which an individual believes that an organizational and technical infrastructure exists to support the use of the system [28]. FC, PE, and EE are considered beliefs, or the information the person has about an object, and SI is considered the subjective norm [28]. The UTAUT has a well-established construct and content validity. Validity is more likely to be influenced by bias and other factors, including those unique to research with military populations.

The UTAUT model is most commonly used in civilian populations. As military contexts necessitate unique and varying relationships between user groups and technology, it is unknown whether the UTAUT model could be an accurate representation of technology acceptance and usability among military members and other secondary or tertiary users. The perspective of the end user and primary user, the military member, is not always measured or even considered because global effectiveness is prioritized over individual preferences [23]. Within the military context, there is an intent that technological innovations can be used effectively, efficiently, safely, and confidently in support of the mission. Military personnel are expected to use technological innovations as directed. The personal preferences of military personnel are generally not as critical as they would be in commercial industries, unless safety is compromised. As the UTAUT was originally developed for an individualistic approach to measure technology acceptance and usability, it may not be applicable to military contexts [23,28]. The literature using the UTAUT model among military populations is scarce, and the model has not been used in the CAF context. The results of existing studies using the UTAUT among military populations demonstrate varying results, making it challenging to form a hypothesis for future studies.

The UTAUT has been used in more recent years as a model and framework for addressing technology use and acceptance in health care [22]. To date, most research in health technology using the UTAUT has involved the exploration of computerized medical records, where the primary intended user is the health care professional [31]. Studies that focus on the patient as the primary intended user are beginning to emerge in the literature with specific demographics, such as older adults, youth, and cardiac populations. These studies have evaluated the technology acceptance and usability of a multitude of digital and mHealth technologies, including health apps, wearable measurement technology, and virtual access to medical records. Hypotheses regarding the effect of the latent variables on BI and use have been formed regarding health care professionals as the primary intended users. Studies focusing on the patient as the primary intended user have demonstrated variable results, making the formation of a directional hypothesis challenging.

Despite the paucity of evidence-based information regarding technology acceptance models in military contexts, the UTAUT was chosen for use in this study because of its higher potential to explain variance and the fact that it has been used in health care studies. The technology acceptance and usability of NCATs from the perspective of the patient within a health care setting warrants evaluation, as questions of feasibility must be addressed before in-context clinical investigations regarding specificity, reliability, validity, and sensitivity can take place. Without addressing acceptance and usability, technological innovations may not be adopted or sustained. Although technology acceptance and usability testing are emerging in health care settings, the combination of a military context and its effects at multiple user levels warrants further exploration. The adoption of the BrainFx SCREEN within CFHS provides an opportunity to investigate technology acceptance and usability at the primary user level of the patient.

Objective

This mixed methods pilot study aims to determine the technology acceptance and usability of a computer-based cognitive BrainFx SCREEN by CAF-SMs and veterans with combat-related posttraumatic stress disorder (crPTSD) using the UTAUT model. This study acknowledges CAF-SMs and veterans with crPTSD and/or mTBI as the primary intended users. Potential rejection of the BrainFx SCREEN by the CAF-SMs would provide important information and direction to CFHS on the way forward in addressing cognitive assessment with the BrainFx SCREEN as a tool. It was hypothesized that PE and FC would be the most influential variables for BI and use, respectively. It is also hypothesized that SI would have the least influence on BI.

Research Model

Figure 2 shows the research model used in this study. The moderator variables of *experience* were removed because the BrainFx SCREEN is not meant to be used continuously or practiced with the goal of improving performance when used as an assessment tool. As the user is asked to complete the assessment by their clinician and is not a tool designed for regular use, the moderator of *voluntariness of use* was removed for the research model. Age and gender are the two moderator variables that remained in the original research model used in this study.

Figure 2. The Unified Theory of Acceptance and Use of Technology model with age and gender as the moderator variables.
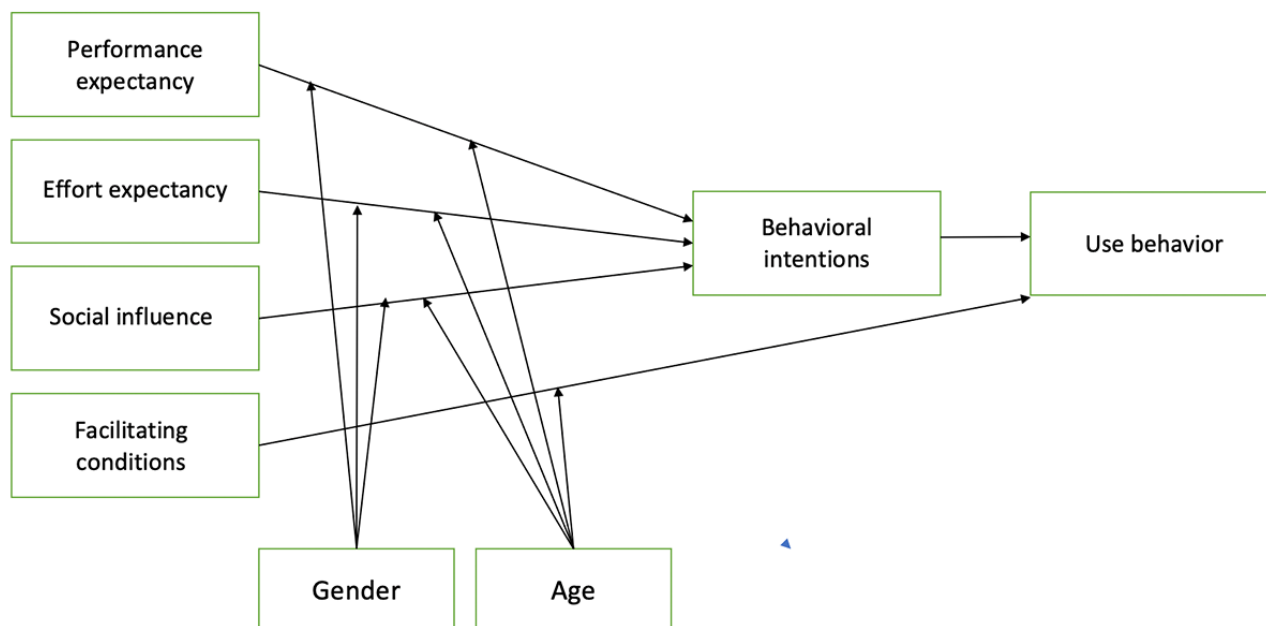
Methods

Study Design

This study of the technology acceptance of the BrainFx SCREEN was a mixed methods embedded study design with a quantitative prequasi-experimental or postquasi-experimental approach as the primary method of data collection and a qualitative thematic analysis secondary to this. This study was embedded in a larger clinical trial, which undertook a mixed methods, staggered entry randomized controlled trial (RCT) [32].

Sample Size

The target sample size was set at a minimum of 32 CAF-SMs and/or veterans with crPTSD who would participate in the study to account for a 10% dropout rate, which would still allow for power at 24 participants. With four latent variables, for 80% significance at a 5% significance level, the sample size required for this study was 18 (R^2=0.50 [33]).

Recruitment and Sampling

Recruitment of regular and reserve CAF-SMs and veterans was conducted by word of mouth among potential participants and mental health service providers as convenience and snowball sampling. Service providers supporting CAF-SMs and veterans, after being informed of the study via word of mouth and institutional email, informed the patients who met the study inclusion and exclusion criteria. Potential participants who showed interest in participation were provided with a *Permission to Share Contact Information with the Research Team* form by their service provider. The completed forms were forwarded to the research team. The researchers then contacted the potential participants via phone or email with a request for them to meet with the research team to learn more about the study and be evaluated to confirm eligibility to participate. Voluntary verbal and written informed consents were obtained from all CAF-SMs and veterans participating in the study. In addition, the BrainFx

SCREEN has an additional digital informed consent form that is required before partaking in the screen.

Inclusion and Exclusion Criteria

Participants included regular and reserve CAF-SMs and veterans aged 18-60 years under the care of a mental health clinician or service provider working at or associated with Canadian Forces Base Edmonton, an Operational Stress Injury Clinic in Edmonton and Calgary, Alberta, or Veterans Affairs Canada. All participants met the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5) [34] criteria for PTSD diagnosis and had a score of ≥30 or higher on the Clinician-Administered PTSD Scale for DSM-5 Worst Month version. Participants were classified as having treatment-resistant crPTSD, which indicated that they had previously not responded to at least two types of evidence-based treatments, of which at least one must have been a psychotherapeutic intervention. Participants were stable on their current psychotropic medication for at least 4 weeks before entering the study. Individuals with comorbidity (ie, mTBI) were included if they satisfied the other inclusion or exclusion criteria. Participants were English speaking and were able to provide informed written consent.

Measurements and Instruments

In total, two UTAUT questionnaires specific to the patient population were developed specifically for this study. Version 1 (T0) includes questions in the future tense, whereas version 2 (T1) includes the same questions but is modified to reflect the past tense. The 12-question outcome measures are based on a Likert scale with a score of 1-7 assigned to each question, with 1 being *strongly disagree* and 7 being *strongly agree*. A Likert scale with 7 points was used, as the original UTAUT questionnaire by Venkatesh et al [28] used a 7-point scale. The maximum score was 84, and the minimum score was 12. The 12 included questions addressed the five different constructs of the UTAUT (2 PE, 3 EE, 3 SI, 3 FC, and 1 BI) that influence the use of a technological innovation. Gender and age

demographic information was also collected via the UTAUT questionnaire, as they are modifier variables within the UTAUT model.

Two additional open-ended questions were asked as part of both questionnaires: (1) What did you like most about the BrainFx SCREEN? (2) What did you like the least about the BrainFx SCREEN?

Data Collection

The BrainFx SCREEN and both UTAUT questionnaires were completed on the same day within 30 minutes. The BrainFx SCREEN and UTAUT questionnaires were administered by the CBA. First, the participants were provided with an explanation of the purpose of the BrainFx SCREEN by the CBA. Second, the participants were presented with the BrainFx SCREEN tablet and asked to read the introduction screen and acknowledge that they understood the purpose of the assessment. They were then presented with a paper version of the first UTAUT questionnaire (version 1; future tense, intended to measure expectations of the technology). After completing this questionnaire, the full BrainFx SCREEN was executed on the tablet. On completion of this, the second paper-based UTAUT questionnaire (version 2; past tense, intended to measure actual intention to use technology) was completed by the participant.

Data Analysis

PLS-SEM was used for this study based on the UTAUT, which uses a reflexive path model. The expectations from T0 and the actual experience from T1 were statistically analyzed using PLS-SEM with both a within-sample path model and a pre or post analysis (multigroup analysis [MGA]).

SEM is considered a second-generation technique of multivariate analysis that allows researchers to incorporate unobservable variables measured indirectly by indicator variables [35]. PLS-SEM is variance based, as it accounts for the total variance and uses this to estimate parameters [35]. In this method of analysis, the algorithm computes partial regression relationships in the measurement and structural models using ordinary least squares regression [35,36]. In an exploratory study such as this, data analysis is concerned with testing a theoretical framework from a prediction perspective, making PLS-SEM an ideal method for analysis [36].

The path model must be analyzed through measurements and structural model assessments [35,36]. Reflexive measurement models were evaluated based on internal consistency (Cronbach α), convergent validity (average variance extracted [AVE]), and discriminant validity (cross-loading analysis, Fornell-Larcker criterion analysis, and Heterotrait-Monotrait ratio [HTMT]) [35]. Evaluation of the structural model included an analysis of collinearity, significance, the coefficients of determination (R^2), size and significance of the path coefficients,

effect size (f^2), and predictive relevance (q^2). Goodness-of-fit was not assessed, as this is an exploratory PLS path model with both reflexive (measurement model) and formative (structural model) components, rendering current model fit measurements unnecessary and inappropriate [35].

As PLS-SEM does not assume that data are normally distributed, it relies on a nonparametric bootstrap procedure to test the significance of estimated path coefficients in PLS-SEM. With bootstrapping, subsamples are created with randomly drawn observations from the original set of data (with replacement) and then used to estimate the PLS path model [37]. In this study, only participant data that were complete with pre- and postresults were included; therefore, a strategy to manage missing data was not required.

SmartPLS [38] was used for the PLS analysis. The maximum iterations were set at 300 with +1 for the initial value for all outer loadings and the path weighting scheme and the stop criterion at 1×10^7. A minimal number of bootstrap repetitions needed depends on the desired level of accuracy, the confidence level, the distribution of the data, and the type of bootstrap CI constructed [39]. It is commonly accepted that 5000 bootstrap repetitions meet this minimum threshold [40]. Basic bias-corrected bootstrapping was performed with 5000 samples at a significance level of $P<.05$. SPSS (2017; IBM Corporation) [41] was used to analyze descriptive statistics (mean and SD), frequency counts, Pearson Chi-square test, and the Harman single-factor test [42,43]. Webpower [44] was used to verify the nonnormality of the data before analysis. Qualitative data from the questionnaires were assessed using NVivo (QSR International) [45] software to identify key themes. A concurrent parallel approach following a data transformation model was used in the data analysis process to converge the data to compare and contrast quantitative statistical results with qualitative findings [46].

Results

Overview

Demographic information of the sample (N=21) is presented in Table 1. The sample was largely male (n=20), which prevented the use of gender as a moderator variable in the research model. In addition, the age of the participant (young or middle aged) did not demonstrate to have an effect in the research model and was therefore removed for the final PLS model. The psychometric properties of the raw data of the survey items used to measure the latent variables are presented in Tables 2 and 3. The difference between the means of the pre- and postscores was a 2.6% increase (Table 3). When pre- or postscores indicate a less than 5% difference in change, this is indicative that the expectations of the participants regarding technological innovation were met within the constructs tested [28].

Table 1. Sample demographic information (N=21).

Characteristics	Participant, n (%)
Gender	
Male	20 (95)
Female	1 (5)
Age (years)	
18-34 (young)	10 (48)
35-60 (middle age)	11 (52)
Military employment status	
Regular force member	8 (38)
Veteran	13 (62)
Education	
High school diploma	21 (100)
Diploma	6 (29)
Degree	1 (5)
Graduate degree	1 (5)
Missing	4 (19)
Previous mild traumatic brain injury or traumatic brain injury	14 (67)
Current cognitive dysfunction	18 (86)

Table 2. Psychometric values of indicator variables.

Exogenous latent variables (indicators)	Value, mean[a] (SD)	Value, median[b]
Performance expectancy (two indicators)		
1. Using the BrainFx SCREEN would improve my medical condition.	4.143 (1.424)	4
2. Using the BrainFx SCREEN would have a positive effect on my medical condition.	4.524 (1.292)	4
Effort expectancy (three indicators)		
1. I believe my interaction with the BrainFx SCREEN will be clear and understandable.	5.5 (1.383)	6
2. Interaction with the BrainFx SCREEN will be easy for me.	5.452 (1.301)	5
3. I believe that it is easy to get the BrainFx SCREEN to do what I want it to do.	5.119 (1.382)	6
Social influence (three indicators)		
1. I would use the BrainFx SCREEN because my colleagues will use it too, to improve their medical condition.	4.5 (1.502)	4
2. People who are important to me think that I should be involved in using the BrainFx SCREEN.	4.667 (1.14)	4
3. In general, my organization has supported my involvement in utilizing the BrainFx SCREEN.	4.833 (1.057)	4
Facilitating conditions (three indicators)		
1. I believe specialized instruction concerning the interaction with the BrainFx SCREEN will be available to me.	5.81 (1.063)	6
2. I believe guidance will be available to me during my utilization of the BrainFx SCREEN.	6.119 (1.234)	6
3. I have the necessary resources to use the BrainFx SCREEN.	5.881 (1.108)	6.5
Behavioral intention (one indicator)[c]		
1. I am willing to use the BrainFx SCREEN in the future.	6.333 (0.845)	7

[a]Raw mean scores of items within scale where each item is measured on a 7-point Likert scale (1=strongly disagree; 7=strongly agree). The higher the indicator score, the more agreement with the statement.

[b]Median scores of each question.

[c]Single indicator.

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Table 3. Descriptive analysis of total pre- or postscores.

Total score	Value, mean (SD)[a]	Value, median[b] (range)
Pre (T0)	62.05 (8.87)	60 (48-76)
Post (T1)	63.71 (9.71)	64 (42-84)

[a]Mean total and SD of pre and post raw scores.

[b]Median of the means of pre and post raw scores.

In addition, a Pearson Chi-square test was used to measure whether participants who reported experiencing an mTBI were more likely to report ongoing cognitive symptoms. Participants who reported a previous mTBI were significantly more likely to report currently experiencing symptoms of cognitive impairment ($P<.001$).

Measurement Model

The results of the measurement model evaluation, including the factor analysis, internal consistency (Cronbach α), convergent validity (AVE), and composite reliability, are presented in Table 4. The factor indicators, which are known as the outer loadings or reflexive indicator loadings, should be ≥0.5 to demonstrate that the indicator variable is a good measurement of the latent variable [47]. Only one outer loading for SI was below this threshold, indicating good indicator reliability (Table 4). All the latent variables, with the exception of SI, demonstrated values of above 0.70 for both Cronbach α and AVE, which indicated the good validity and reliability of the latent variables [35]. A single-item construct, such as BI, is not represented by a multi-item measurement model; thus, the relationship between the single indicator and latent variable is 1 [35]. As there are no established criterion variables to correlate with the BI indicator, criterion validity and reliability cannot be determined for this construct [35]. Composite reliability is presented in Table 4, and all values, with the exception of SI, were ≥0.7, which is acceptable.

Table 4. Measurement model.

Latent and indicator variables	Outer loadings[a]	Cronbach α[b]	Average variance extracted[c]	Composite reliability[d]
BI[e,f]		1.000	1.000	1.000
1. BI indicator	1.000			
EE[g]		.857	0.776	0.912
1. EE indicator	0.866			
2. EE indicator	0.926			
3. EE indicator	0.849			
FC[h]		.874	0.798	0.922
1. FC indicator	0.885			
2. FC indicator	0.928			
3. FC indicator	0.866			
PE[i]		.885	0.875	0.933
1. PE indicator	0.881			
2. PE indicator	0.987			
SI[j]		.446	0.402	0.559
1. SI indicator	−0.011			
2. SI indicator	0.601			
3. SI indicator	0.919			

[a]Outer loadings of ≥0.5 indicate indicator reliability.

[b]With a reflective model, internal consistency is measured by Cronbach α; values of ≥.7 indicates good indicator reliability.

[c]Average variance extracted values of ≥0.5 indicates convergent validity.

[d]Composite reliability values of ≥0.5 indicates good internal consistency.

[e]BI: behavioral intention.

[f]Single indicator.

[g]EE: effort expectancy.

[h]FC: facilitating conditions.

[i]PE: performance expectancy.

[j]SI: social influence.

To evaluate discriminant validity, cross-loading, the Fornell-Larcker criterion, and HTMT (Table 5) were used. These measures demonstrated good discriminant reliability for all latent variables, except for SI. FC demonstrated the highest correlation with BI based on this analysis. Potential common method bias was assessed with the Harman single-factor test, yielding cumulative and variance loadings under 50% (34.43%).

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Table 5. Discriminant validity.

Measure	Latent variables[a]				
	BI[b,c]	EE[d]	FC[e]	PE[f]	SI[g]
Fornell-Larcker criterion					
BI[b]	1.000	—[h]	—	—	—
EE	0.467	0.881	—	—	—
FC	0.736	0.564	0.893	—	—
PE	0.052	0.343	0.025	0.935	—
SI	0.340	0.173	0.393	0.325	0.634
Heterotrait-Monotrait ratio					
BI[b]	—	—	—	—	—
EE	0.495	—	—	—	—
FC	0.776	0.654	—	—	—
PE	0.045	0.339	0.122	—	—
SI	0.336	0.403	0.438	0.985	—

[a]Diagonals are the square root of the average variance extracted of the latent variables and indicate the highest in any column or row.

[b]Single indicator.

[c]BI: behavioral intention.

[d]EE: effort expectancy.

[e]FC: facilitating conditions.

[f]PE: performance expectancy.

[g]SI: social influence.

[h]Not applicable.

The measure of lateral collinearity of the structural model demonstrated inner variance inflation factor values below 5 for all latent variables. The coefficient of determination (R^2) measures the proportion of variance in a latent endogenous variable that is explained by other exogenous variables expressed as a percentage. The explained variance (R^2) of the structural model was 0.549, indicating that >50% of BI was explained by this model and moderate predictive accuracy. The effect size (f^2) for each latent variable is listed in Table 3. On the basis of this analysis of the structural model, the largest path coefficient and effect size were for FC, indicating that it was the strongest predictor of BI (Table 6 and Figure 3).

Table 6. Structural model evaluation and hypothesis testing.

| Relationship[a]	Standard β	SE	Critical t value	Effect size, f^2	Predictive relevance, q^2	95% CI
Performance expectancy - >BI[b]	.013	0.11	0.176	0.001[d]	−0.04	−0.215 to 0.212
Effort expectancy - >BI	.108	0.153	0.598	0.01	0	−0.179 to 0.409
Social influence - >BI	.075	0.108	0.669	0.008	−0.03	−0.152 to 0.277
Facilitating conditions - >BI	.643	0.166	3.950[c]	0.492	0.443	0.285 to 0.95

[a]Effect size (f^2) and predictive relevance (q^2) values under 0.02 denote small effect size or predictive relevance, whereas values of >0.35 indicate large effect size or predictive relevance [33].

[b]BI: behavioral intention.

[c]$P \geq .05$.

Figure 3. Path analysis model of the Unified Theory of Acceptance and Use of Technology for predicting BI. Facilitating conditions is the largest predictor of BI (path coefficient=0.657; R2=0.549). The thicker the arrow, the larger the effect on the variable or construct in the measurement or structural model. BI: behavioral intention; EE: effort expectancy; FC: facilitating conditions; PE: performance expectancy; SI: social influence.
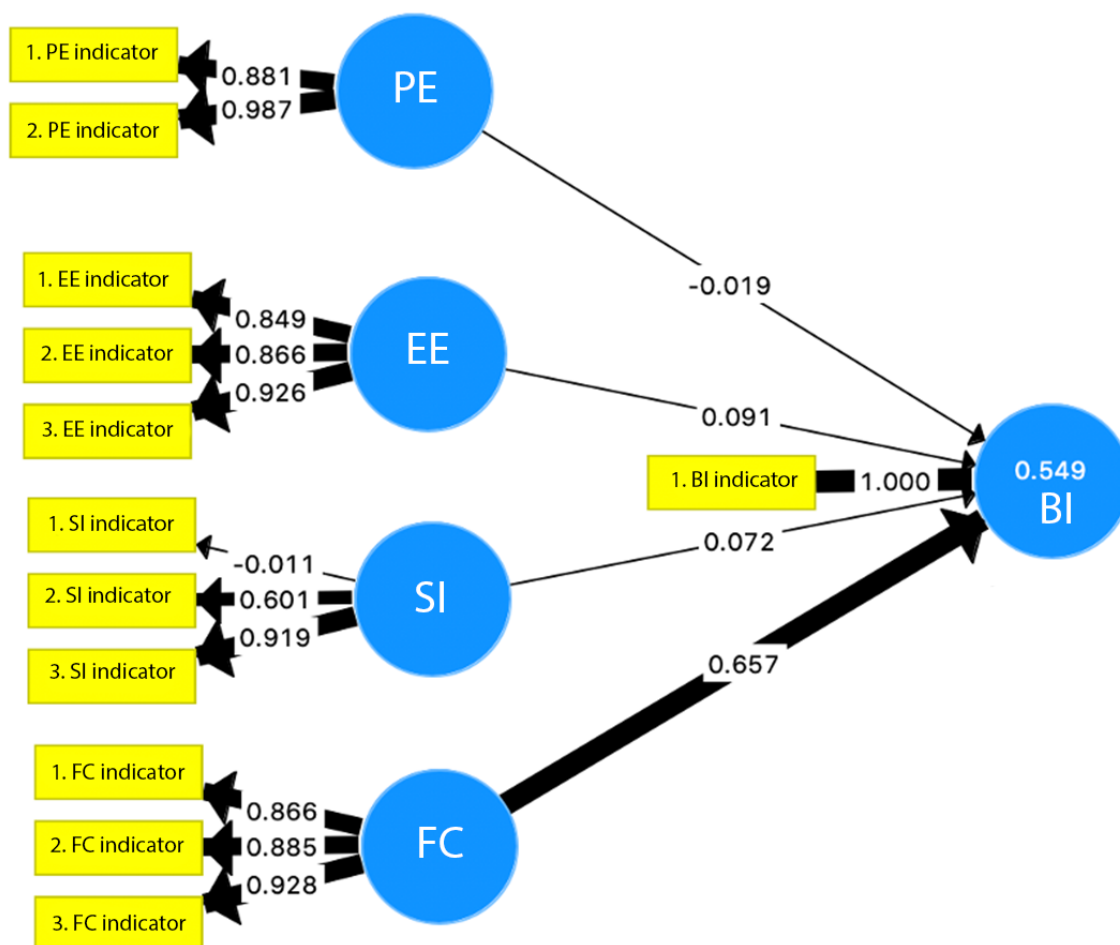
On the basis of the MGA, there was a statistically significant increase ($P=.007$) in the scores for FC in the version 2 UTAUT questionnaire (post: T1) data compared with the version 1 UTAUT questionnaire (pre: T0) data. A statistically significant decrease in EE was noted in the version 2 UTAUT questionnaire (post: T1) data compared with the version 1 UTAUT questionnaire (pre: T0) data, where the latent variable EE was a significant predictor of BI within the pregroup but not the postgroup (Table 7; $P=.03$). Combined, this rendered EE to not be statistically significant in predicting BI. There were no statistically significant changes in the PE or SI pre- or postgroups (Table 7).

Table 7. Pre- or postmultigroup analysis.

Latent variable	Critical *t* value	*P* value
Performance expectancy	0.008	.99
Effort expectancy	2.355	.03[a]
Social influence	0.173	.86
Facilitating conditions	2.997	.007[a]

[a]Significant at $P \leq .05$.

Finally, a brief thematic analysis was conducted by analyzing the responses to the open-ended questions from the UTAUT questionnaires (pre and post). The first two themes, likes and dislikes, were imposed on the data, whereas the third theme, the unclear purpose of cognitive assessments, arose inductively. The qualitative results were triangulated with the quantitative data and discussed further (Table 8).

Table 8. Thematic analysis results of qualitative questions from the Unified Theory of Acceptance and Use of Technology questionnaire.

Categories	Participant statements
Likes	
Challenges the brain	"Challenged myself to multitask, test my short-term memory."
Fun, engaging, and interactive	"Interaction with tablet. No writing. Fun."
Easy to use	"Ease of use."
Quick to complete	"Quick."
Clear instructions	"Clear Instructions."
Dislikes	
Math questions not enjoyable	"I hate math."
Fear of the unknown	"(I have) anxiety about what it will be like."
Screen sensitivity	"Touch screen delay, would rather use paper."
Clarity of instructions	"Instructions not clear."
Difficult to predict what stimuli can be a trigger	"Disturbing images"
Unclear purpose of cognitive assessments	"Alternative treatment, mood alteration."; "Help[ed] me to get rid of my anger."

Discussion

Principal Findings

The UTAUT model was used as the theoretical foundation for understanding the BI of CAF-SMs and veterans with crPTSD to use the BrainFx SCREEN. FC were the most notable predictor of BI and increased after using the BrainFx SCREEN, whereas EE decreased. PE, EE, and social interaction were not factors predicting BI. On the basis of the study results, the BrainFx SCREEN appears to be a feasible, usable, and accepted assessment tool for CAF-SMs and veterans who experience PTSD.

A number of notable findings from this mixed methods pilot study warrant consideration. Demographically, 67% (14/21) of participants reported a previous mTBI or TBI as comorbid with their PTSD, and those who reported a previous mTBI or TBI were significantly more likely to report currently experiencing symptoms of cognitive impairment. The relationship between PTSD and mTBI, as well as its effect on cognition, is complex and continues to be a topic of research that is being explored among military and veteran populations. The most recent literature points to symptoms of PCS being largely attributed to PTSD as opposed to mTBI pathologies. If PCS are mostly attributable to mental health conditions in those with co-occurring mTBI, it would be assumed that those with and without past mTBI or TBI would report subjective cognitive impairment at the same rate.

Overall, CAF-SMs and veterans rated all the latent variables (PE, EE, FC, and SI) and BI favorably for the BrainFx SCREEN. The lowest mean latent variable score was for PE (4.334), whereas the highest was for BI (6.333), indicating that the participants generally agreed or strongly agreed with the statements made in the UTAUT questionnaires. The results of the PLS-SEM analysis demonstrated good internal consistency, convergent validity, composite reliability, and discriminant validity of the indicators, except for SI. The model explained

50% of BI, which indicated moderate predictive accuracy; however, the analysis of the structural model indicated that only FC had a significant effect on BI. FC had the largest path coefficient and effect size, indicating that it was the strongest predictor of BI. A statistically significant increase in FC and a decrease in EE were noted in the pre- and post-MGA. The less than 5% (2.6%) change in the pre- and postscores indicated that the expectations of the BrainFx SCREEN were generally met. The pre- and postchanges in the other latent variables were not significant.

The analysis of the open-ended questions revealed a number of themes that could be attributed to the latent variables of the UTAUT and BI as a construct. To understand the results of the PLS-SEM and qualitative data, triangulation can provide a clearer explanation of why the relationships in the path model exist [46].

As previously mentioned, PE refers to the degree to which an individual believes that using the system will help the person attain gains in performance [28]. In the context of the BrainFx SCREEN, cognitive functioning in different neurofunctional domains is measured [19]. It is integral to the validity of the BrainFx SCREEN that the participant does not receive any feedback on their performance from either the CBA or the software and platform. The participants were limited to their intrinsic subjective insight to speculate their performance, which may be a logical explanation as to what PE did not register as an important factor in BI and did not demonstrate a significant pre- or postchange.

SI is the degree to which an individual perceives that important others believe that they should use the new system [28]. As the BrainFx SCREEN was performed within a research study with only a CBA present and confidentiality maintained, it is unlikely that the participants perceived SI specifically to the technology. This was demonstrated to be an accurate hypothesis, as SI was the least influential latent variable in the prediction of BI.

EE is the degree of ease associated with the use of a system [28]. Many of the *likes* of the participants fell into the category of EE, including that the BrainFx SCREEN was *quick* and *easy to do*. Comments obtained from participants written in answer to open-ended questions in the UTAUT postquestionnaire corroborate with why perceptions of EE decreased after the assessment. There was some frustration for some participants with the touch screen sensitivity or *touch screen delay*. Some felt the instructions were *clear*, whereas others felt they were not. The report of unclear instructions did not apply to the overall BrainFx SCREEN instructions but to certain instructions for specific tasks.

FC is the degree to which an individual believes that an organizational and technical infrastructure exists to support the use of the system [28]. This variable had the largest effect on the BI. Before using the BrainFx SCREEN, some participants subjectively reported that they had reservations about the unknown, "anxiety about what it will be like," and uncertainty about what to expect. It is reasonable that the participants felt supported by the CBA, organization, and other facilitators in the immediate environment during the assessment, which reduced their *fear of the unknown*. This could explain the statistically significant improvement in FC in the pre- and post-MGA.

The thematic analysis also revealed some unexpected findings that could not be categorized into the variables of the UTAUT model. Some participants reported that the BrainFx SCREEN was *fun* and *engaging*. These experiences may fit better within the update to the UTAUT model, the UTAUT 2 (Figure 4) [48]. This model aims to provide a more consumer-based explanation of BI and use for technology by incorporating a number of additional latent variables, including price, habit, and hedonic motivation. Although the model is geared toward the consumer context, UTAUT 2 has been used in studies addressing technology in the health care context and is emerging in the technology acceptance literature [49].

Figure 4. The Unified Theory of Acceptance and Use of Technology 2.
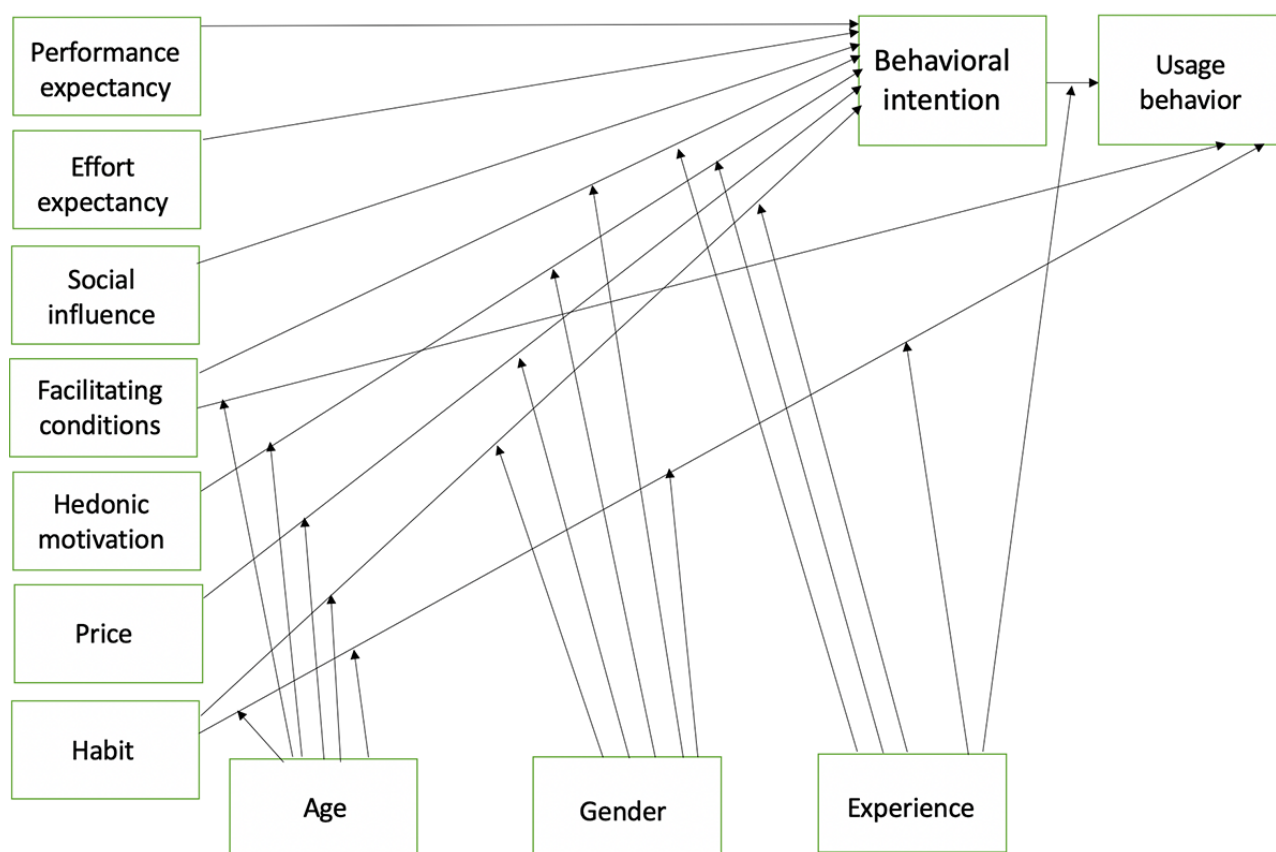
As the BrainFx SCREEN does not cost the participants money, price would not be a factor that affects BI for this user group. As the screen is not intended to be used by the patient routinely, habit is also not an appropriate variable to be included in the research model. On the basis of the thematic analysis responses, hedonic motivation may be a variable that may influence BI in this study. Hedonic motivation is defined as "the fun or pleasure derived from using technology, and it has been shown to play an important role in determining technology acceptance and use" [50]. The perceived enjoyment of technological innovation has been found to influence technology acceptance and use directly for consumers [50]. Statements within the qualitative data analysis involving one's enjoyment of the BrainFx SCREEN fit better within the definition of hedonic motivation than the other latent variable definitions, which suggests that this may have been an unaccounted factor that unexpectedly influenced BI. Hedonic motivation may be a variable that warrants further consideration when considering technology acceptance and usability in health care and potentially military contexts.

Another unexpected observation was that participants may not have understood the purpose of cognitive assessments in general.

Even with written and verbal explanations of the purpose of and reason for the BrainFx SCREEN that was similar to or more comprehensive than that provided in a typical clinical environment, it was observed during data analysis that some participants did not fully understand these explanations. Some of the qualitative responses indicated that participants felt this tool was for the purpose of improving their cognition or a brain game. This may be due to the myriad of tablet-based apps currently on the market being advertised as mHealth tools, despite limited evidence of their efficacy for improving cognitive status [24]. It is also possible that some participants experienced cognitive impairment that hindered their ability to fully comprehend the instructions and explanations. Additional comorbidities, aside from mTBI and PTSD, that may adversely affect cognition and presented among the participants included other mental health diagnoses, chronic pain, fatigue, sleep challenges, and use of prescription medications. As stated, the presence of comorbid conditions among military personnel and veterans is not uncommon. Although the indicators for PE showed good reliability and validity, it is possible that a misunderstanding of the purpose of the BrainFx SCREEN could negatively affect this. This serves as a reminder that as researchers and health care professionals alike, the purpose of assessment and screening tools must be explained explicitly, especially with populations who may be experiencing cognitive impairment.

Of note, one participant reported feeling disturbed by the images in the BrainFx SCREEN. Although the imagery within the assessment is generic and positive (eg, candy, animals, or plants), it is an important reminder that items within any assessment can potentially act as a trigger for a person experiencing PTSD and may increase levels of distress.

Limitations of This Study

Although PLS-SEM is ideal for exploratory research and is flexible with its nonparametric lack of assumptions regarding data distribution, a number of limitations need to be considered. First, measurement errors always exist to some degree and are challenging to quantify accurately. The PLS-SEM bias refers to the tendency of the path model relationships to be frequently underestimated, whereas the parameters of the measurement model, such as the outer loadings, are overestimated when compared with covariance-based SEM. Measurement error can also be introduced by variables such as the participants' understanding of the questionnaire items. As discussed, the level of understanding of the purpose of cognitive assessments may have been an issue, which raises questions about the participants' understanding of other aspects. In addition, the administrative burden of the study when combined with other outcome measures attributed to the RCT with which this study was affiliated may have caused some participants to rush through final questionnaires or experience fatigue and a reduced level of engagement. Second, the lack of global goodness-of-fit measures is considered a drawback of PLS-SEM, which is unavoidable. Third, in the measurement model, BI had only one indicator variable. This made it impossible to evaluate it in a manner similar to the other latent variables. In the future, this could be resolved by adding additional items (indicators) to the UTAUT questionnaires related to BI. Finally, because the study

was affected by a COVID-19–related shutdown, the original statistical power was not reached at 1% significance. The required sample size of a minimum of 24 participants was not attained, so the significance was 5% (N=21; R^2=50%) [33]. Furthermore, the small sample size made it impossible to incorporate the moderator variables of age and gender, as was originally planned in the research model (Figure 2).

Future Research

A range of future research endeavors would enhance the understanding of the relationship of the patient, whether military or civilians, with technological innovations. The technology acceptance and usability of the BrainFx SCREEN, as well as other assessments using digital health care technology, warrant evaluation within military and civilian health care and at multiple user levels, including patients, health care professionals, and organizations. This also extends to the use of virtual health care technologies where the patient is at a separate location from the health care professionals—a practice that is becoming increasingly widespread since the onset of the COVID-19 pandemic. It is important for health care professionals to become stakeholders in the process of adopting new health care technology. Studies with larger sample sizes may also allow for a research model with the ability to incorporate moderator variables, such as age, gender, voluntariness of use, and experience, as well as to investigate the effect of hedonic motivation as a latent variable.

The use of the UTAUT as a model for health care technology and patient user groups warrants continued investigation in both civilian and military settings. Furthermore, the appropriateness of the UTAUT and possibly other technology acceptance models within military contexts remain to be an area where research is scarce.

The limitation of the existing technology adoption models is the lack of task focus (fit) between users, technology, and organization, which contributes to the mixed results in information technology evaluation studies [51]. Notably, within the military context, the environment and culture will have an effect on this at multiple user levels. The organization itself is considered a key factor in the effective use of information technology. To fully evaluate user acceptance of technology, the fit between the user, the technology, and the organization needs to be evaluated together [52,53]. *Fit* needs to be integrated with existing technology models to better understand issues surrounding the implementation of new technology [53]. Multiple models and frameworks addressing technology acceptance and usability as well as fit exist, including the Task-Technology Fit model [54], Fit between Individuals, Task, and Technology framework [55], and Design-Reality Gap Model [56].

Information security has not been incorporated within technology adoption models or frameworks related to user acceptance. This may have important implications in both the military and clinical contexts. When users perceive that a particular technology provides features that prevent unauthorized access to the clinical-related database, they are more likely to trust and accept it [53]. The incorporation of information

security and its involvement in technology acceptance and usability could be an interesting and relevant direction of research in military organizations.

Conclusions

mTBI was labeled the *signature injury* of military conflicts during the War on Terror, in which National Atlantic Treaty Organization forces, including Canada, participated [3,57]. In addition, numerous military personnel and veterans from around the globe who have returned from deployments to this conflict continue to struggle with symptoms of PTSD either in isolation or comorbid with mTBI or TBI. Despite the plethora of research, publications, and attention that mTBI and PTSD have received in recent years, both in the military and sport contexts, many questions remain regarding the complexities of assessing and treating neurological symptomatology attributed to these diagnoses, including cognitive dysfunction. The BrainFx SCREEN appears to be a promising NCAT with good acceptability by CAF-SMs and veterans with crPTSD in this study. Future research is needed to address other factors of the BrainFx SCREEN, including its validity, reliability, effectiveness, feasibility, and sensitivity. As civilian and military health care systems increasingly integrate technological innovations to improve the services and care provided to their patients, research must continue to address the use of these novel assessments and interventions at the micro, meso, and macro levels.

Conflicts of Interest

None declared.

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Abbreviations

AVE: average variance extracted
BI: behavioral intention
CAF-SM: Canadian Armed Forces service member
CBA: Certified BrainFx Administrator
CFHS: Canadian Forces Health Services
crPTSD: combat-related posttraumatic stress disorder
DSM-5: Diagnostic and Statistical Manual of Mental Disorders, 5th Edition
EE: effort expectancy
FC: facilitating conditions
HTMT: Heterotrait-Monotrait ratio
MGA: multigroup analysis
mHealth: mobile health
mTBI: mild traumatic brain injury
NCAT: computerized neurocognitive assessment tool
PCS: postconcussive symptom
PE: performance expectancy
PLS: partial least square
PTSD: posttraumatic stress disorder
RCT: randomized controlled trial
SEM: structural equation modeling
SI: social influence
TBI: traumatic brain injury

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UTAUT: Unified Theory of Acceptance and Use of Technology

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Review

Web-Based Peer Support Interventions for Adults Living With Chronic Conditions: Scoping Review

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Abstract

Background: Globally, 1 in 3 adults live with multiple chronic conditions. Thus, effective interventions are needed to prevent and manage these chronic conditions and to reduce the associated health care costs. Teaching effective self-management practices to people with chronic diseases is one strategy to address the burden of chronic conditions. With the increasing availability of and access to the internet, the implementation of web-based peer support programs has become increasingly common.

Objective: The purpose of this scoping review is to synthesize existing literature and key characteristics of web-based peer support programs for persons with chronic conditions.

Methods: This scoping review follows the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) extension for scoping reviews guidelines. Studies were identified by searching MEDLINE, CINAHL, Embase, PsycINFO, and the Physiotherapy Evidence Database. Chronic diseases identified by the Public Health Agency of Canada were included. Our review was limited to peer support interventions delivered on the web. Peers providing support had to have the chronic condition that they were providing support for. The information abstracted included the year of publication, country of study, purpose of the study, participant population, key characteristics of the intervention, outcome measures, and results.

Results: After duplicates were removed, 12,641 articles were screened. Data abstraction was completed for 41 articles. There was a lack of participant diversity in the included studies, specifically with respect to the conditions studied. There was a lack of studies with older participants aged ≥70 years. There was inconsistency in how the interventions were described in terms of the duration and frequency of the interventions. Informational, emotional, and appraisal support were implemented in the studied interventions. Few studies used a randomized controlled trial design. A total of 4 of the 6 randomized controlled trials reported positive and significant results, including decreased emotional distress and increased health service navigation, self-efficacy, social participation, and constructive attitudes and approaches. Among the qualitative studies included in this review, there were several positive experiences related to participating in a web-based peer support intervention, including increased compassion and improved attitudes toward the individual's chronic condition, access to information, and empowerment.

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Conclusions: There is limited recent, high-level evidence on web-based peer support interventions. Where evidence exists, significant improvements in social participation, self-efficacy, and health-directed activity were demonstrated. Some studies incorporated a theoretical framework, and all forms of peer support—emotional, informational, and appraisal support—were identified in the studies included in this review. We recommend further research on web-based peer support in more diverse patient groups (eg, for older adults and chronic conditions outside of cancer, cardiovascular disease, and HIV or AIDS). Key gaps in the area of web-based peer support will serve to inform the development and implementation of future programs.

Introduction

Background

In Canada, 1 in 5 adults live with cardiovascular disease, cancer, diabetes, or chronic respiratory disease [1]. These chronic conditions account for 65% (153,000) of deaths in Canada each year [2] and are the leading causes of death globally [1]. These chronic conditions account for 42% of direct health care costs in Canada or Can $39 billion (US $32 billion) per year [2]. The total economic burden is a combination of medical costs (Can $38.9 billion; US $31.9 billion) and indirect productivity losses (Can $54.4 billion; US $44.6 billion) [2]. Globally, 1 in 3 adults live with multiple chronic conditions [3], and among Americans aged ≥65 years, approximately 3 in 4 adults have multiple chronic conditions [4]. Thus, effective interventions are needed to prevent and manage these chronic conditions and to reduce the associated health care costs.

Teaching effective self-management practices to people with chronic diseases is one strategy to address the burden of chronic conditions [4]. For example, in the United States, the Affordable Care Act encourages chronic disease self-management practices [5]. The Affordable Care Act offers reimbursement opportunities for providers of chronic disease management services and provides government support for the development of programs aimed at self-management [5]. In the context of chronic conditions, self-management refers to a patient's ability to manage various physical and psychosocial ailments and lifestyle changes [6,7]. Previous research has indicated that peers can support chronic disease self-management [8] in a cost-effective manner [8-10]. For example, an economic evaluation conducted by Graffy et al [11] found lower total health care costs due to decreased hospitalization expenses among individuals with diabetes who had received peer support (group or one-to-one delivery) compared with those among control groups.

In the context of chronic disease management, peer support refers to providing assistance to other individuals with similar conditions [8,11]. Programs with an associated peer support component have 3 commonalities: support for emotional, informational, and appraisal needs [12]. Emotional support includes caring, empathy, and encouragement of the individual. Informational support refers to providing advice, suggestions, and alternative actions. Appraisal support involves affirmation, constructive feedback, and the provision of information useful for self-evaluation [13]. Peer support programs can be delivered using a wide variety of modalities, including face-to-face, telephone, or internet. With the increasing availability and access to the internet (eg, over 32 million people in Canada [14] and 55.1% of the world's population [15]), the implementation of web-based peer support programs, in particular, has become increasingly common and relevant [14-16].

Objective

With the increasing implementation of web-based peer support interventions, there is a need to examine the characteristics of these interventions and determine the gaps in this emerging literature. The purpose of this scoping review is to synthesize the existing literature and key characteristics (eg, duration; frequency; delivery setting; type of intervention; type of support provided, including emotional, informational, and appraisal; and underlying theories for the intervention, behavior change techniques, or mechanisms) of web-based peer support programs for persons with chronic conditions.

Methods

Overview

The methodology for this scoping review has been previously published [17], but it is briefly described below. This scoping review follows the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) extension for scoping reviews guidelines [18].

Search Strategy and Information Sources

A comprehensive literature search was conducted by an experienced librarian (LP) with input from the investigators. Literature search strategies were developed using medical subject headings and text words related to chronic conditions and peer support interventions. The MEDLINE search has been previously published in our protocol paper [17]. The search was initially run on May 6 and 8, 2017, and rerun on June 6, 2018. The following databases were searched: MEDLINE (OVID), MEDLINE In-Process & Other Non-Indexed Citations (OVID), MEDLINE Epub Ahead of Print (OVID), Embase (OVID), CINAHL (EBSCOhost), Physiotherapy Evidence Database, and PsycINFO (OVID). A validated search filter for identifying age-specific studies that specifically identified citations for adults was added to MEDLINE, Embase, and CINAHL. Duplicates were removed by using EndNote's duplicate identification feature and by reviewing records manually. Searches were limited to studies conducted from 2012 to 2018 and English language studies. Studies were included from this 6-year window to increase the relevance to the current health care context. Due to time and resource constraints, we were

unable to extend the search beyond this 6-year window. In addition, for feasibility considerations, no hand searching was performed.

Eligibility Criteria

Chronic diseases identified by the Public Health Agency of Canada (PHAC), including cancer, heart disease (cardiovascular disease), hypertension, stroke, chronic respiratory diseases (asthma, chronic obstructive pulmonary disease, and sleep apnea), diabetes, inflammatory bowel diseases (Crohn disease and ulcerative colitis), multiple sclerosis, neurological conditions (eg, Alzheimer disease and other dementias), cerebral palsy, epilepsy, multiple sclerosis, Parkinson disease or parkinsonism, traumatic brain injury, traumatic spinal cord injury, arthritis, and osteoporosis, were included [19]. This list of chronic conditions is consistent with other global definitions of chronic conditions (eg, the World Health Organization) [20]. This review included studies involving individuals with chronic conditions, including comorbid mental illness. Studies must have reported on adults (age≥18 years) with one of the previously listed PHAC chronic conditions or HIV or AIDS. Although mental illness is included in the PHAC list of chronic diseases, it was excluded for the purposes of this review because peer support interventions for this specific group may have unique features (eg, coping with stigma, including self-blaming, guilt, and shame) that may not be generalizable to other patient populations with chronic disease [21,22]. Similarly, although not included in the PHAC list, due to the high volume of web-based peer support interventions reported on individuals with HIV or AIDS, it was included in this review's list of chronic diseases [23]. In addition, including HIV or AIDS in this list of inclusion criteria was further rationalized by a similar review conducted by Lauckner et al [12], who examined peer support for people with chronic conditions in rural areas.

Our review was limited to peer support interventions delivered on the web. Studies were included if a web-based peer component was part of their intervention. Support must be provided by a peer who has the same chronic condition. Examples of web-based peer interventions include video-based discussions using formats such as Skype, social media peer interactions, and text messages from peers. Peer-led interventions that used a web-based modality in combination with another modality, such as telephone or face-to-face interventions, were included. Interventions describing professional-led groups involving community health workers who are not peers (eg, health care professionals), e-counseling service interventions, studies reporting on outcomes of usability testing but not the outcomes of the participants, support group interventions, and telephone-based peer support interventions were excluded. In addition, studies were excluded if they described the benefits of using the internet generally but did not describe an intervention and the reported outcomes of that intervention. If the study described an intervention that had a combination of peer- and professional-led support, it was excluded.

To further describe the types of articles that were included and excluded in this review, we provide an example of 1 study that was included and 2 that were excluded.

The study *Development of Trust in an Online Breast Cancer Forum: A Qualitative Study* by Lovatt et al [24] was included in this review. This study explored the breast cancer care forum by collecting discussion threads and analyzing them. In this case, the web-based forum was the modality for delivering peer support. The study *The Emerging Diabetes Online Community* by Hilliard et al [25] was excluded from our study. Although the study reported on multiple web-based platforms (eg, forums, blogs, video or podcasts, and social media websites used by individuals living with diabetes), the study did not report on the outcomes or experiences of a specific web-based peer support intervention. Finally, the study *Online support for individuals with spinal cord injuries: An ethnographic investigation* by O'Riley et al [26] was excluded. This study involved interviews to explore how individuals with a spinal cord injury could benefit or might use the internet for support. However, no specific peer support intervention had been implemented. Finally, all study designs (eg, observational studies, randomized controlled trials, and qualitative studies) were included.

Study Selection

The studies were screened using a 2-step process. First, the titles and abstracts were screened in duplicate by independent reviewers, followed by full-text screening, which was conducted in duplicate. Both level 1 and level 2 screening followed the same screening form. DistillerSR reference manager was used by independent reviewers to keep track of the decisions. Discrepancies were resolved by discussion between reviewers and, if necessary, the senior author (SEPM).

Data Abstraction

Data abstraction forms developed by the research team were used. The information abstracted included year of publication, country of study, purpose of the study, participant population (eg, chronic condition, age, sex, gender, and education), key characteristics of the intervention (eg, duration; frequency; delivery setting; type of intervention; type of support provided, including emotional, informational, and appraisal; underlying theories for the intervention, behavior change techniques, or working mechanisms; and context), outcome measures, and results. Results including *P* values were collected for the quantitative studies; themes and subthemes were abstracted for the qualitative studies. For qualitative studies, similar themes across studies were clustered together by the lead author (SNH) in consultation with the senior author. Data abstraction was conducted independently in duplicate.

Results

Overview

The literature searches yielded 13,286 articles. After duplicates were removed, 12,641 articles were screened. After level 1 screening, 368 articles were included in the full-text screening. Of these 368 items, 5 oral presentations and 37 abstracts from conferences were excluded, as it was not possible to obtain full-text articles. A total of 9 protocol papers were excluded because there were no data on the results of the reported interventions. After level 2 screening, data abstraction was completed for 41 articles. The reasons for article exclusion

varied but were primarily related to not having a peer support component implemented in the studied intervention. Further rationale as to why articles were excluded are described above within the *Eligibility Criteria* section. The PRISMA flowchart is shown in Figure 1.

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flowchart.
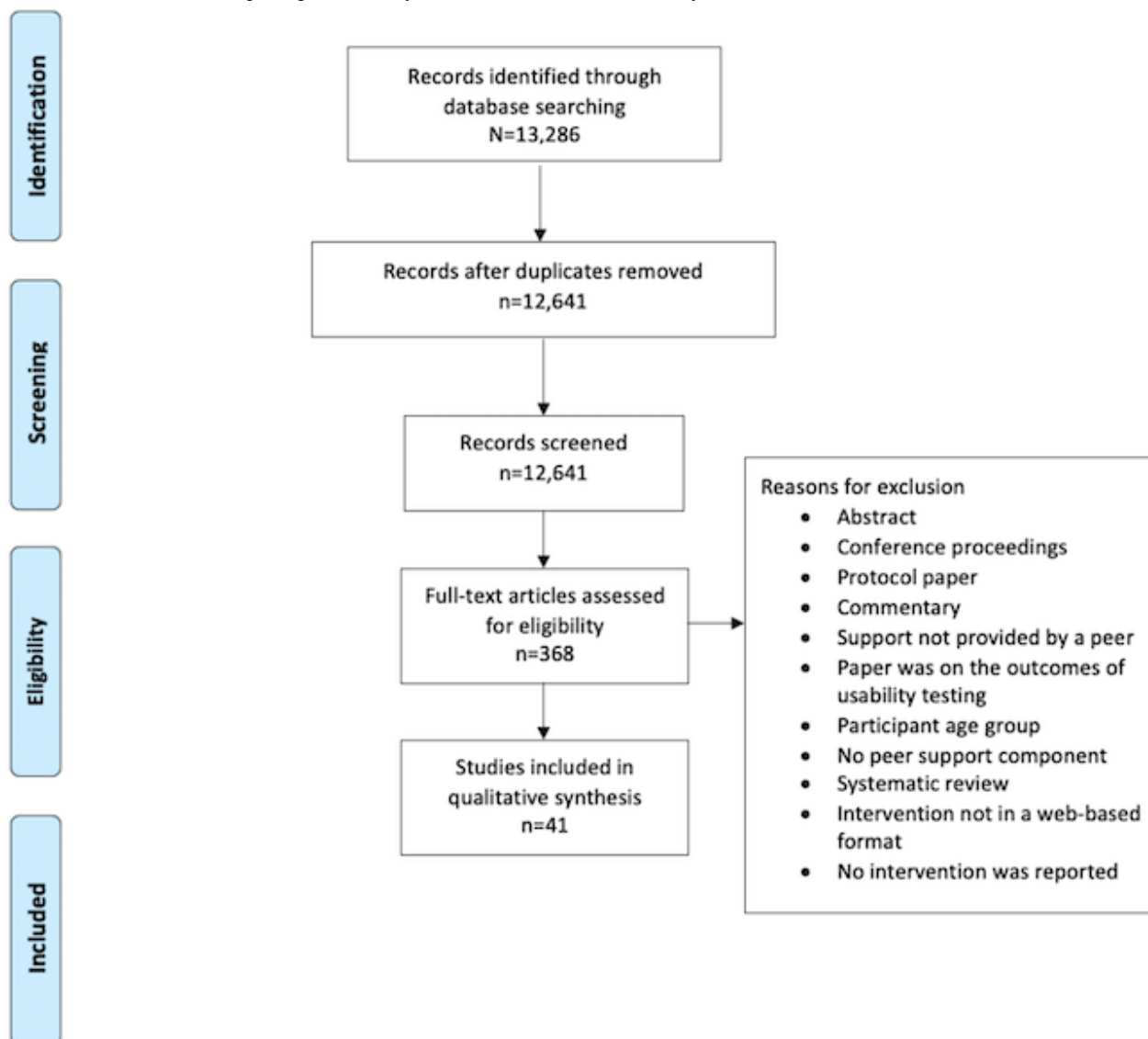
Study Characteristics

A summary of the included studies with information on patient characteristics, peer support intervention characteristics, outcome measures, and impact is included in Multimedia Appendix 1 [24,27-65]. A total of 18 studies were conducted in the United States, 5 in Australia, 5 in the United Kingdom, and 4 in Canada. The remaining 9 studies were conducted in Finland, Sweden, Germany, China, Italy, South Africa, and Sweden.

Around half of the studies included in this review were qualitative (20/41, 49%). Specifically, 14 of these studies analyzed content posted on web-based discussion forums, whereas the other 6 were qualitative studies that reported on the experiences of the patients participating in a web-based peer support program. The quantitative studies included in the review were randomized controlled trials (6/41, 14%) and cross-sectional studies using a survey design (8/41, 19%). The

remaining studies were mixed methods studies (4/41, 10%), nonrandomized controlled trials in which matched controls served as the comparison group, quasi-experimental studies (1/41, 2%), and integrative reviews (1/41, 2%).

There were various limitations to the included studies. Among the randomized controlled trials, there were small sample sizes (sample sizes ranged from 30 to 227) [27-32], weak validity and reliability of the measures included [30], and the type of control group used in the trial (eg, control condition involved usual treatment) [31]. In terms of the limitations of the qualitative studies, some examples included selection bias [33], limited transferability of the study findings [34], and the potential for information to be removed by a moderator [35].

Patient Characteristics

The studies included participants with cancer (15/41, 36%), diabetes (9/41, 21%), and HIV (7/41, 17%). The remaining 10 studies included participants with arthritis (2/41, 4%), atrial

fibrillation (1/41, 2%), chronic pain (1/41, 2%), inflammatory bowel disease (1/41, 2%), multiple sclerosis (2/41, 4%), peripartum cardiomyopathy (1/41, 2%), and stroke (2/41, 4%). The individuals included in the studies were aged between 19 and 70 years. This broad range of age groups made it difficult to summarize the studies based on specific age groups. In the majority of the studies, the ratio of male to female participants varied, except in studies on chronic conditions that are of higher prevalence in a specific sex (eg, breast cancer and prostate cancer) [24,33,36-39,66]. Specifically, of the 3 studies that reported on breast cancer, 2 reported that all participants were female.

Key Characteristics of the Peer Support Interventions

This section outlines the following key characteristics of the studies on web-based peer support interventions included in our review: duration; frequency; delivery setting; type of intervention; type of support provided, including emotional, informational, and appraisal; and underlying theories for the intervention, behavior change techniques, or mechanisms.

Duration and Frequency

For the included studies, the duration and frequency of the interventions varied. Of the 41 included studies, 15 (36%) had interventions lasting for 2 weeks to 16 weeks [27-31,33,40-47,66], whereas some interventions (2/41, 4%) lasted for 1-2 years [48,49]. The frequency of peer interaction ranged from weekly interactions to monthly updates [27,29-31,41,43,46,48].

Delivery Setting

A total of 15 of the 41 studies described a web-based discussion board as the means of delivering the intervention [24,32-35,39,40,43,45,50-54,66]. Moreover, 9 of the 41 studies used an existing social network site such as Facebook, Twitter, or Myspace [29,36,37,44,47,48,55-57]. In addition, 6 of the 41 studies described a unique web-based platform that consisted of different components such as information modules, live chats, and web-based discussion boards to create a community of participants involved in web-based discussions [30,31,38,49,58,59]. Furthermore, 5 of the 41 studies used a combination of delivery mechanisms, including Skype, social networking sites, forums, telephone, and face-to-face [42,60-63]. One of the 41 studies used Skype video conferencing [41], whereas another study used another web-based video conferencing software [27]. A total of 2 of the 41 studies used a web-based chatroom interface [64,65], and an additional 2 studies used text messaging as a means of peer support (Multimedia Appendix 2) [28,46].

Types of Interventions

Of the included studies, 21 of the 41 studies reported on using a group-type intervention [27,29-33,35,40,43-45,47-49,51, 53,55,57-59,64]. A total of 5 of the 41 included studies had web-based peer support delivered through a one-on-one format [24,28,39,41,46]. In the remaining studies (15/41, 37%), it was unclear whether the type of support was delivered through a group or one-on-one format.

Type of Support

No studies have reported on interventions that included only one type of support. Instead, the interventions provided a mix of emotional, informational, and appraisal support. A total of 29 studies failed to define a theoretical framework underpinning the intervention.

Underlying Theories

In total, 12 studies included the following underlying theories, models, or approaches: social learning theory [50,58,67], social comparison theory [37,68], social support theory by La Coursiere [42,69], self-management theory by Bandura [28,70,71], Information-Motivation-Behavioral Skills model [46,72], self-efficacy theory [30,70], person-centered care approach [32,73], stress process model [31,74], the concept of human bonding and social support as defined by Namkoong et al [34,75], and the conceptual framework outlined by Dennis [76] (emotional, informational, and appraisal support).

Outcomes Measures and Impact

Among the randomized controlled trials (6/41, 15%), the outcomes used were participant openness, trust, motivation, knowledge, self-efficacy, self-care behavior levels, social relationships, emotional distress, depression, mastery, self-esteem, social support, and general well-being [27,28,30-32]. The measures included were the Working Alliance Inventory [27], California Psychotherapy Alliance Scale [27], Patient-Reported Outcome Quality of Life subscales of body change [30], Positive Outlook Self-Efficacy Scale [30], Health Education Impact Questionnaire [30], and Well-being Questionnaire [32]. The randomized controlled trials included in this review reported on the following conditions: diabetes (2/6, 33%) [28,32], HIV (2/6, 33%) [29,30], cancer (1/6, 17%) [27], and stroke (1/6, 17%) [31].

A total of 2 of the 6 randomized controlled trials on diabetes management reported no statistically significant differences between groups for self-efficacy, general well-being, or self-care behaviors (eg, general diet, exercise, and smoking) [28,31]; however, a higher level of disease-specific knowledge was reported in the group of participants receiving web-based peer support [28]. The remaining 4 of the 6 randomized controlled trials reported positive and significant results, including increased feelings of acceptance and respect by others, health service navigation, self-efficacy, social participation, and constructive attitudes and approaches and decreased emotional distress [28,46-48].

In the qualitative studies, some of the positive experiences of participating in an web-based peer support program included increased compassion and improved attitudes toward their condition (ie, people felt that they were not alone in their struggles or that peer support reduced isolation) [38,52], access to information that people could not access through their health care professionals (ie, experiences of people with a similar condition and the gathering of information about a treatment option) [38,52,60], and empowerment (ie, taking an active role in one's condition) [33]. Among these qualitative studies, several barriers and enablers to obtaining peer support were identified. Some of the barriers to participating in the web-based peer

support program included challenges of timing with other life events, a lack of availability or access, the perception of not fitting in with a web-based group, and the need for more condition-specific content [33,38,52]. Enablers to using the program included the use of appropriate language (ie, clear and easy to understand), flexibility or self-pacing, appropriate module length (ie, did not represent a burden to the participant),

and the usability of the platform [38,42,48,50]. Furthermore, studies have reported that participants viewed web-based support programs as a unique resource that allows them to be engaged in a program from home anonymously [37,60,65]. To exemplify some of the web-based peer support interventions described in the studies included in this review, we have presented 2 case examples in Figures 2 and 3.

Figure 2. An example of an article included in this study. De Simoni et al [35] reports on web-based stroke forum.
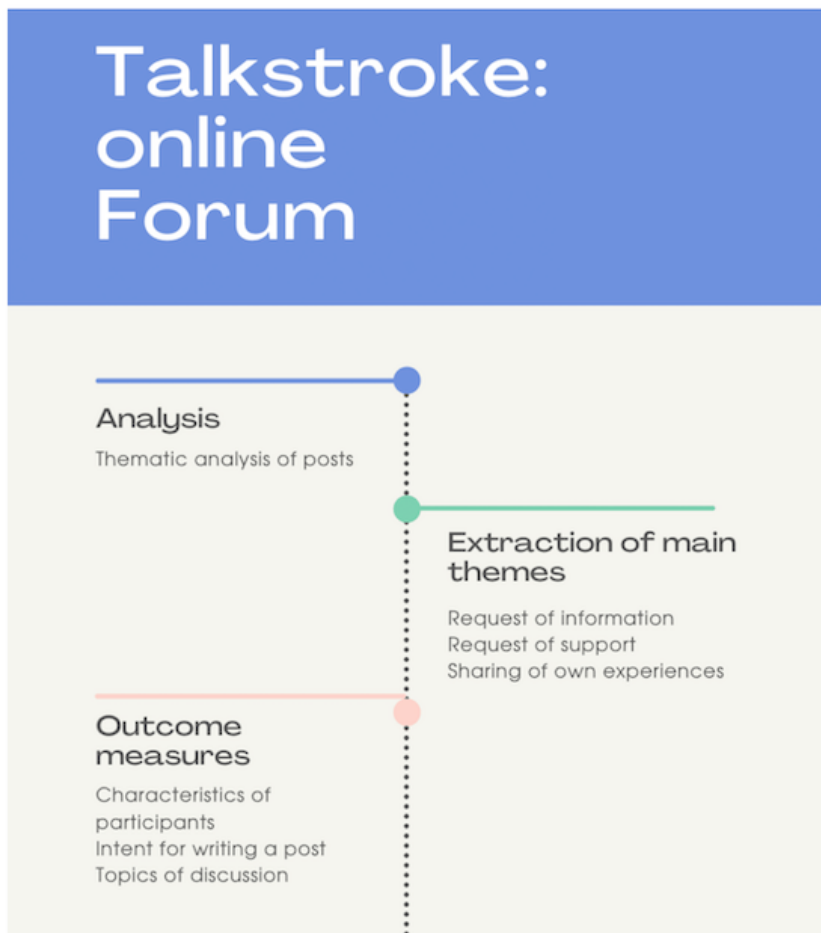
Figure 3. An example of an article included in this study. Lovatt et al [24] reports on the difference between standard of care and web-based support.
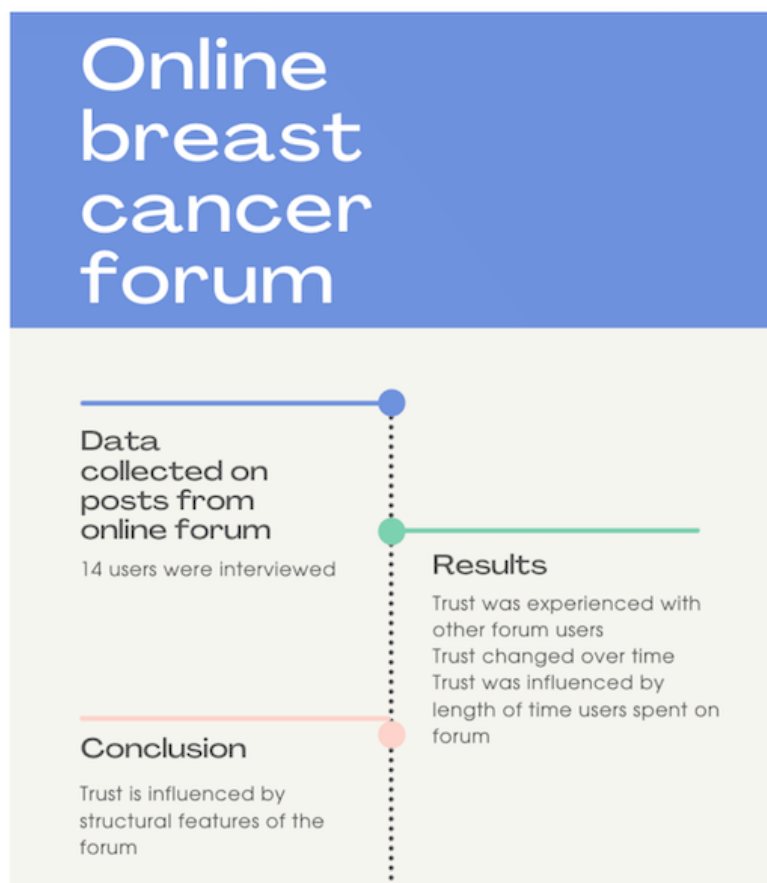
Discussion

Principal Findings

Overview

This scoping review aims to determine what is known from the existing literature about the key characteristics (eg, duration; frequency; delivery setting; type of intervention; type of support provided, including emotional, informational, and appraisal; and underlying theories for the intervention or behavior change techniques or mechanisms) of web-based peer support interventions for adults with chronic conditions. The main findings of this review were as follows: (1) a lack of participant diversity in the included studies, specifically with respect to the conditions studied (ie, the majority of the studies included were related to cancer, cardiovascular disease, and HIV or AIDS) and the exclusion of older participants (ie, the age range for included studies was 19-70 years); (2) few studies used a randomized controlled trial design; (3) over one-third (15/41, 37%) of the interventions included involved web-based discussion boards, and just over half (21/41, 51%) of the included studies involved group-type peer support; (4) the interventions provided a mix of emotional, informational, and appraisal support, but the majority of studies did not report on an underlying theory or conceptual framework for the intervention; and (5) in terms of outcomes, among the quantitative studies, 4 of the 6 randomized controlled trials demonstrated increased feelings of acceptance and respect by others, health service navigation, self-efficacy, social participation, and constructive attitudes and approaches and decreased emotional distress [28,46-48], whereas for the qualitative studies, participants reported increased compassion and improved attitudes toward their condition [38,52]. To the best of our knowledge, this is the first scoping review to synthesize evidence on web-based peer support interventions across a variety of chronic conditions.

Patient Characteristics

Across the 41 included studies, the age range was 19-70 years. Although it is recognized that some conditions are more common among younger individuals (eg, HIV or AIDS), the absence of recent evidence on web-based peer support interventions for individuals aged ≥70 years is noteworthy. For example, in Canada, about 20% of breast cancers are diagnosed in women aged <50 years, whereas almost 30% are diagnosed in women ≥70 years. Individuals ≥70 years are more likely to be socially isolated and lonely [77], and thus, they have the potential to benefit the most from a web-based peer support intervention. For example, in a pre-post pilot study of a peer-to-peer support program engaging older adults to provide companionship to less-able older persons (mean age 69 years) via home visits and phone calls, Geffen et al [78] demonstrated significantly decreased reporting of reduced social interaction and reduced loneliness in addition to increased levels of self-reported well-being, improved emotional and informational support, increased mood scores, and increased levels of physical activity.

The findings of this review suggest that there is a need for more studies on web-based peer support interventions for individuals ≥70 years, in these and other specific disease populations, and for improved methods to target these vulnerable groups. Furthermore, Statistics Canada indicates that rates of internet use vary across age groups within the senior population, with 81% use among older adults aged 65-69 years, compared with 74% use among those aged 70-74 years, 64% use among those aged 75-79 years, and 49% use among those aged ≥80 years [79]. Although it is unclear whether these decreased rates are due to issues related to internet access and/or computer literacy, these potential barriers should be addressed to realize the benefits of web-based peer support (including the benefits outlined in the current review) for older adults with chronic health conditions. In terms of the breadth of chronic diseases included, our results align with a scoping review on peer support for people with chronic conditions in rural areas in terms of identifying studies on a limited range of chronic conditions. Specifically, Lauckner and Hutchinson [12] determined that many studies were related to individuals with diabetes.

Duration and Frequency

We determined that there was a lack of consistency in terms of reporting intervention characteristics. Similarly, in a systematic review of peer support interventions for individuals with acquired brain injury, cerebral palsy, and spina bifida, members of our research team concluded that experts from relevant disciplines collaborated to develop the peer support interventions, but they did not specify the methods by which the key components of the interventions such as session duration, frequency, and intervention length were chosen or how these decisions were informed. Given this lack of consistency, it is suggested that future studies reporting on web-based peer support interventions consistently use the better reporting of interventions: a Template for Intervention Description and Replication checklist and guide [80]. This guide includes the following items: brief name, why, what, who provided, how, where, when and how much (ie, duration and frequency), tailoring, modifications, and how well. The application of this checklist could promote the replicability of the intervention and an understanding of the program components that are associated with improved outcomes. At the same time, it is important to recognize that the need to better report the intervention duration and frequency does not apply equally to all web-based peer support contexts. Finally, the number of trials included in this review was too small to draw any associations between the frequency of the peer interactions and the duration of the programs and associated outcomes. However, future trials in this area should examine these associations (ie, dose response).

Delivery Setting and Types of Intervention

Other important aspects of this review were the delivery settings and the types of interventions. In terms of the randomized controlled trials, as previously mentioned, the number included was too small to draw any associations between the delivery setting and the type of interventions and outcomes. Among the studies involving nonexperimental designs, 37% (15/41) used web-based discussion boards with a group type of intervention.

Group peer-to-peer discussion boards may be particularly valuable, as noted by a qualitative study on the perspectives of individuals with type 1 diabetes using an internet self-management system, as they allow patients to share tips and advice on managing their conditions and provide an opportunity to relate to fellow patients [81]. Similarly, in a qualitative study on one-to-one versus group-based peer support for breastfeeding, Hoddinott et al [82] determined that group-based peer support was more popular, as it normalized breastfeeding in a social environment, which in turn improved participants' sense of well-being. Participants also indicated that the group format in particular assisted women with decision making [82]. The impact of web-based, one-to-one versus group-based peer support could be the focus of future randomized controlled trials.

Types of Support Provided

In our review, we identified all 3 types of support—emotional (eg, communicating a sense of belonging, inclusivity, and reinforcing the presence of others), informational (eg, asking others for guidance and providing detailed explanations), and appraisal (eg, goal setting and action planning that can provide opportunities for constructive feedback)—across the included studies. A review by Lauckner and Hutchinson [12] determined that the majority of programs provided general social support and support related to the development of new skills (eg, appraising health information using a computer; preparing meals; and improving self-management skills, goal setting and problem solving, and general skills to support lifestyle changes). Although they did not identify the specific constructs of emotional, informational, and appraisal support as we did in our review, there appears to be an overlap between the types of support identified in their review and our review, particularly in the areas of informational support (eg, development of new skills) and appraisal support (eg, goal setting and problem solving).

Underlying Theories for the Intervention

Only 12 of the 41 studies provided an underlying theory or model or approach, with some of these studies reporting only an underlying approach (ie, person-centered care approach). Previous research suggests that a thorough approach to intervention development, including a clear rationale for the design and development of interventions, is recommended [83,84]. Thus, future peer support interventions should implement an underlying theory or model to inform interventions, which in turn would support the intended outcomes of the intervention.

Impact

Lauckner and Hutchinson [12] determined that of the 9 studies that reported on program outcomes, 8 reported positive outcomes, whereas 1 study reported mixed results. Overall program success, participants valuing the social components of the program, improved activity or weight loss, and participants feeling an increased sense of efficacy were the related positive outcomes reported. Similarly, among the trials included in our review, it was demonstrated that web-based peer support programs resulted in improved social participation, self-efficacy,

and health-directed activity. Thus, peer support may serve as an important supplement to formal care, as noted by Smith et al [85] in an evaluation of a web-based peer support community intervention. Furthermore, Lauckner and Hutchinson [12] noted that the use of telecommunications with deidentification protocols, such as passwords and pseudonyms, decreased the perceived stigma related to program participation. They also noted that this is particularly important for vulnerable populations. This perspective was noted across many of the included qualitative studies in our review, where participants appreciated the anonymity that a web-based program affords [60,65]. Lauckner and Hutchinson [12] reported that studies that used telecommunications as part of the intervention often provided technical support services to ensure effective program implementation. Similarly, we determined that the availability of technical support was a key enabler for the implementation of web-based peer support interventions. The review by Lauckner and Hutchinson [12] and our review across similar chronic conditions suggests that the impact of face-to-face peer support interventions may be comparable with web-based peer support interventions, with web-based peer support interventions promoting accessibility and potentially reducing the stigma associated with face-to-face interventions.

Limitations

We acknowledge some limitations of this scoping review. This review did not include primary mental health conditions and a variety of other disabilities. As previously mentioned, interventions that focused on mental illness were excluded from our list of chronic diseases, given that peer support interventions for this group may have unique features not generalizable to other patient populations with chronic disease, and a systematic review of digital peer support interventions for people with lived experience of a serious mental illness has recently been completed [86]. As web-based interventions also relate to computer science and information studies, there are additional databases that could have been included and would likely have identified a separate subfield of studies. Potential databases include IEEE and ACM, and they should be explored in future reviews on web-based interventions. This review did not look at the types of funding each study was provided with, and therefore, we cannot make definitive conclusions on whether interventions were scaled up. Furthermore, this review was limited to English language studies only and the published research literature. As a result, we likely have a bias toward studies from English-speaking countries, and we acknowledge that we likely excluded reports on other available, relevant programs (ie, but not published in peer-reviewed journals). Similarly, we excluded conference abstracts of posters or oral presentations (ie, without an accompanying, published article).

Conclusions

The results of this review demonstrate that there is a limited, recent high-level evidence (ie, randomized controlled trials) on web-based peer support interventions. Where evidence exists, significant improvements in social participation, self-efficacy, and health-directed activity were demonstrated. However, these trials were limited to 4 conditions only: diabetes, HIV, cancer, and stroke. Thus, we recommend the study of web-based peer support in a much broader range of conditions. We further recommend the use of web-based peer support for older adults (ie, aged >70 years) with chronic conditions. We determined that some of the included studies incorporated a theoretical framework, and all forms of support—emotional, informational, and appraisal—were identified in the studies included in this review. Future peer support interventions should implement an underlying theory or model to inform interventions, which in turn would support the intended outcomes of the intervention. Future studies should also consistently report on the intervention characteristics, including the frequency and duration of the intervention, to promote replicability and to draw associations between intervention characteristics and specific outcomes. Overall, the results of this review have identified key gaps in the area of web-based peer support that will serve to inform the development, implementation, and evaluation of future programs.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Complete data set.
[XLSX File (Microsoft Excel File), 42 KB - rehab_v8i2e14321_app1.xlsx]

Multimedia Appendix 2
Frequency of delivery settings.
[PNG File , 45 KB - rehab_v8i2e14321_app2.png]

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Abbreviations

PHAC: Public Health Agency of Canada
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

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Review

Alternative and Augmentative Communication Technologies for Supporting Adults With Mild Intellectual Disabilities During Clinical Consultations: Scoping Review

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Abstract

Background: People with intellectual disabilities (IDs) face significant communication barriers when accessing health care services; they find it difficult to identify and describe conditions clearly enough to support practitioners in making an accurate diagnosis. In addition, medical professionals generally have little knowledge and understanding of the needs of people with ID, which may result in the use of consultation techniques that do not cater to their patients' skills.

Objective: This review aims to identify and synthesize the literature on alternative and augmentative communication technologies that are used to support adults with mild ID during the exchange of information with medical practitioners.

Methods: We performed a scoping review of studies published in English that describe the technologies that are used to promote communication with patients with mild ID during medical consultations. The databases searched were PubMed, ACM Digital Library, and Google Scholar. A qualitative framework-based approach was used to synthesize the data and discern key recurring themes across the identified literature.

Results: Of the 1557 articles screened, 15 (0.96%) met our inclusion criteria. The bulk of the communication aids used focused on low-tech solutions, including patient passports, note-based prompts, Talking Mats, health diaries, and easy-read information sheets. Their influence on current practice ranged from advancing medical professionals' knowledge of the health and communication needs of people with ID to increasing interagency collaboration, patient advocacy skills, and health promotion activities. The major barriers to the implementation of low-tech aids were a lack of portability and increased maintenance efforts. Only 3 studies explored the use of mobile apps to promote communication. Their findings indicated that high-tech solutions offer greater customization with regard to the accessibility and health care needs of people with ID.

Conclusions: Alternative and augmentative communication technologies have the potential to increase the quality of care provided to patients with mild ID; however, little work has been carried out in this area. Greater emphasis must be placed on (high-tech) two-way communication aids that empower patients to become involved in decisions regarding their care. Quantitative evaluation methods should be used to discern the true benefits of such aids, and researchers should describe their study protocols in depth to promote replication and generalizability.

KEYWORDS

Introduction

Background

People with intellectual disabilities (IDs) are consistently subjected to health inequalities [1-5], which significantly affect the length and standard of their lives [4,6,7]. Heslop et al [4] demonstrated this in 2013 while studying the deaths of 247 patients with ID in southwest England; of those deaths, 103 (41.7%) were classified as unexpected or premature, with 68 (27.5%) directly attributable to low-quality care. In addition, the patients suffered from an average of five long-term or treatable conditions during the period leading up to their deaths [4], several of which were straightforward to diagnose and cure, for example, constipation in 37% of cases and pressure sores in 34% of cases.

Previous literature has suggested that many of the inequalities experienced by patients with ID are preventable, particularly the breakdown in communication with health professionals [1-3,5]. To overcome such communication barriers and therefore provide improved person-centered care, practitioners are encouraged to use national [8,9] and international [10] guidelines. Much of this advice centers on the implementation of reasonable adjustments that cater to the patient's individual needs. These adjustments include aspects such as using the patient's preferred method of communication, avoiding the use of medical jargon to cater to their reduced vocabulary and cognitive abilities, and ensuring that patients understand the information conveyed to overcome impairments in their receptive skills [8-10]. In addition, the practitioner should consider and be vigilant for gestures that emphasize the information being exchanged, assign additional time to the consultation to allow the patient to deliberate what has been said, and provide information in advance of the appointment to allow the patient to prepare adequately [8-10].

However, medical professionals frequently report that they are undertrained on the health and accessibility needs of people with ID [11-13] and therefore lack the confidence and skills to implement the proposed guidelines. In this context, innovative practices have been introduced to improve the standard of care administered [1,2]. The bulk of these innovative practices attempt to mitigate the gaps in knowledge held by staff via the establishment of patient-focused training sessions and the increased availability of ID information resources. In addition, health care organizations have changed their pathways to include targeted health check programs that assist in diagnosing common conditions experienced by people with ID. Multidisciplinary teams of health professionals have also been formed to support this process, including the specialized skills possessed by ID nurses [1,2].

Nevertheless, medical staff are currently overworked [14,15], meaning they have limited opportunities to seek additional training. This, combined with the decline in the number of specialized professionals such as ID nurses [16], suggests that other forms of support must be explored to promote communication between practitioners and patients with ID.

Objective

Technology has the potential to provide such support as it has been shown to enhance the lives of people with cognitive, intellectual, or physical disabilities [17-19]; however, little is known about its use in the clinical context for people with ID. Consequently, we conducted a scoping review to synthesize the literature on the use of communication technologies to support people with mild ID during clinical consultations. The results of our review are presented in the form of four themes that were developed using thematic framework analysis.

Methods

ID Definition

Throughout this paper, we refer to the term *intellectual disabilities* by using the World Health Organization definition: "a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning) and begins before adulthood, with a lasting effect on development" [20]. There are several manifestations of ID, with their impact on an individual's social and cognitive functioning ranging from mild to severe [21]. This review focuses on people with mild ID who, in general, live independent lives but may require support to complete complex processes such as understanding medical conditions. We hypothesize that this population is more likely to benefit from health-related interventions, such as digital communication aids, as people with severe ID tend to seek support during basic tasks, meaning they are unlikely to use such technologies autonomously or be in charge of their own health care.

Aim

This review aims to identify and synthesize a range of technologies and modalities used to promote communication between patients with mild ID and health professionals. Consequently, the research question underpinning this review is, "What technologies are being used to support adults with mild ID to communicate more effectively with medical practitioners?"

In addition to these research questions, the scoping review has the following objectives:

- Subobjective 1: determine how the identified aids were being used by patients with mild ID and medical professionals
- Subobjective 2: determine how the benefits of the aids were evaluated

Our work differs from that of Chinn [22], as its focus is on the technologies being used by patients with mild ID instead of other forms of support such as health-related training courses.

Research Methodology

Arksey and O'Malley [23] presented four common scenarios where scoping reviews are an appropriate methodology to use, two of which align with our research objectives: (1) examining the extent, range, and nature of research activity within a domain

and (2) identifying research gaps within the existing literature. As such, the framework of Arksey and O'Malley [23] was used to rapidly map the key concepts within our target domain, which consisted of the following 5 flexible steps:

- Research question formulation (*Aim* section)
- Identification of relevant studies (*Search Strategy* section)
- Study selection (*Inclusion Criteria* and *Study Selection* sections)
- Charting the data (*Data Charting* section)
- Collating, summarizing, and reporting the results (*Analysis* section)

Search Strategy

To conduct a holistic search that included technological, sociotechnical, and disability-focused communication studies, 3 databases were queried (PubMed, ACM Digital Library, and Google Scholar) using the terms shown in Textbox 1. These phrases were based on Medical Subject Headings relating to communication, ID, and clinical consultations in conjunction with a variety of alternative and augmentative communication (AAC) technologies. In all, 15 queries were carried out (Textbox 1), resulting in the identification of 1737 articles published before November 2019: 747 from PubMed, 140 from ACM, and 850 from Google Scholar. Separate queries were used per database because of their differing scopes. For example, it was not appropriate to search for Talking Mats or patient passports in the ACM database as the articles returned primarily focused on high-tech interventions such as mobile apps.

PubMed was selected because of its focus on medical studies, including those that discuss the implementation of interventions. Each of the unique articles retrieved from PubMed had their titles and abstracts screened by RCG against the inclusion and exclusion criteria described in the following subsection. Potentially relevant articles were then read in their entirety to identify those that adhered to the selection criteria, with more obscure articles being analyzed by MMB before their inclusion or omission. The areas of conflict between the first and second authors were resolved by MDD. Searches across the 3 databases resulted in 5 articles that were reviewed by RCG and MMB, of which 2 were also reviewed by MDD.

ACM was identified because of its focus on technology, particularly articles centering on the development of AAC aids. In addition, the literature returned by ACM does not overlap with that identified by PubMed, which increases the comprehensiveness of the search. Relevant articles were chosen using the same process as described above.

Finally, Google Scholar was selected as it is often used to supplement evidence searches by returning relevant articles cataloged in databases beyond those originally queried [24]. Researchers often limit their Google Scholar queries to the first 50 to 100 articles [24] because as a ranked retrieval system, the relevance of the literature diminishes as the search progresses. However, we increased this number to 200, based on the following procedure: the search results for query 1 (Textbox 1) were split into groups of 50. The first batch of 50 was then screened (using the same process as the previous databases), with the investigators moving on to the next batch only if a potentially relevant article was identified via its abstract; otherwise, the search was terminated. This procedure was repeated for queries 2 to 5, with the highest batch number being used as a limit for all Google Scholar searches. To elaborate, a relevant article was identified in the third batch of the second query, meaning the first 200 results of the other queries were scrutinized where possible. Nevertheless, it is important to note that some of the searches returned less than 200 articles, meaning all were scrutinized as the N size fell below the defined limit.

Figure 1 contains a PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram [25] detailing the steps involved in identifying relevant articles. These articles were then subjected to a qualitative framework-based analysis to synthesize the results and determine key recurrent themes (*Analysis* section).

Textbox 1. Search queries and search terms.

PubMed

- Query 1

  - (("intellectual disability"[MeSH Terms] OR ("intellectual"[All Fields] AND "disability"[All Fields]) OR "intellectual disability"[All Fields]) AND ("communication"[MeSH Terms] OR "communication"[All Fields])) AND ("referral and consultation"[MeSH Terms] OR ("referral"[All Fields] AND "consultation"[All Fields]) OR "referral and consultation"[All Fields] OR "consultations"[All Fields])

- Query 2

  - ((Alternative[All Fields] AND Augmentative[All Fields] AND ("communication"[MeSH Terms] OR "communication"[All Fields])) AND ("learning disorders"[MeSH Terms] OR ("learning"[All Fields] AND "disorders"[All Fields]) OR "learning disorders"[All Fields] OR ("learning"[All Fields] AND "disabilities"[All Fields]) OR "learning disabilities"[All Fields])) AND clinical[All Fields]

- Query 3

  - (("speech"[MeSH Terms] OR "speech"[All Fields] OR "talking"[All Fields]) AND "mats"[All Fields])) AND clinical[All Fields]

- Query 4

  - (alternative[All Fields] AND augmentative[All Fields] AND ("communication"[MeSH Terms] OR "communication"[All Fields])) AND clinical[All Fields]

- Query 5

  - (("communication"[MeSH Terms] OR "communication"[All Fields] OR ("personal"[All Fields] AND "communication"[All Fields]) OR "personal communication"[All Fields]) AND passports[All Fields]) AND clinical[All Fields]

- Query 6

  - (pictures[All Fields] OR images[All Fields] OR graphics[All Fields]) AND clinical[All Fields] AND ((intellectual[All Fields] OR ("learning"[MeSH Terms] OR "learning"[All Fields])) AND disabilities[All Fields])

- Query 7

  - (("communication"[MeSH Terms] OR "communication"[All Fields]) AND ((("learning"[MeSH Terms] OR "learning"[All Fields]) OR intellectual[All Fields]) AND disabilities[All Fields])) AND clinical[All Fields]

ACM Digital Library

- Query 1

  - (("intellectual" AND disability") AND communication) AND consultations

- Query 2

  - ("Alternative" AND "Augmentative" AND "Communication") AND ("Learning" AND "Disabilities") AND "clinical"

- Query 3

  - (pictures images graphics "clinical" disabilities) AND recordAbstract:(+intellectual +learning)

Google Scholar

- Query 1

  - (("intellectual" AND "disability") AND "communication") AND "consultations"

- Query 2

  - ((("Alternative" AND "Augmentative" AND "communication")) AND "learning disabilities") AND "clinical")

- Query 3

  - ("Talking" AND "Mats") AND ("learning" AND "disabilities") AND "clinical"

- Query 4

  - ("personal" AND "communication" AND "passports") AND ("learning" AND "disabilities") AND "clinical"

- Query 5

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- allintitle: "clinical" AND "disabilities" AND "pictures" OR "images" OR "graphics" OR "intellectual" OR "learning"

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flowchart of this scoping review.
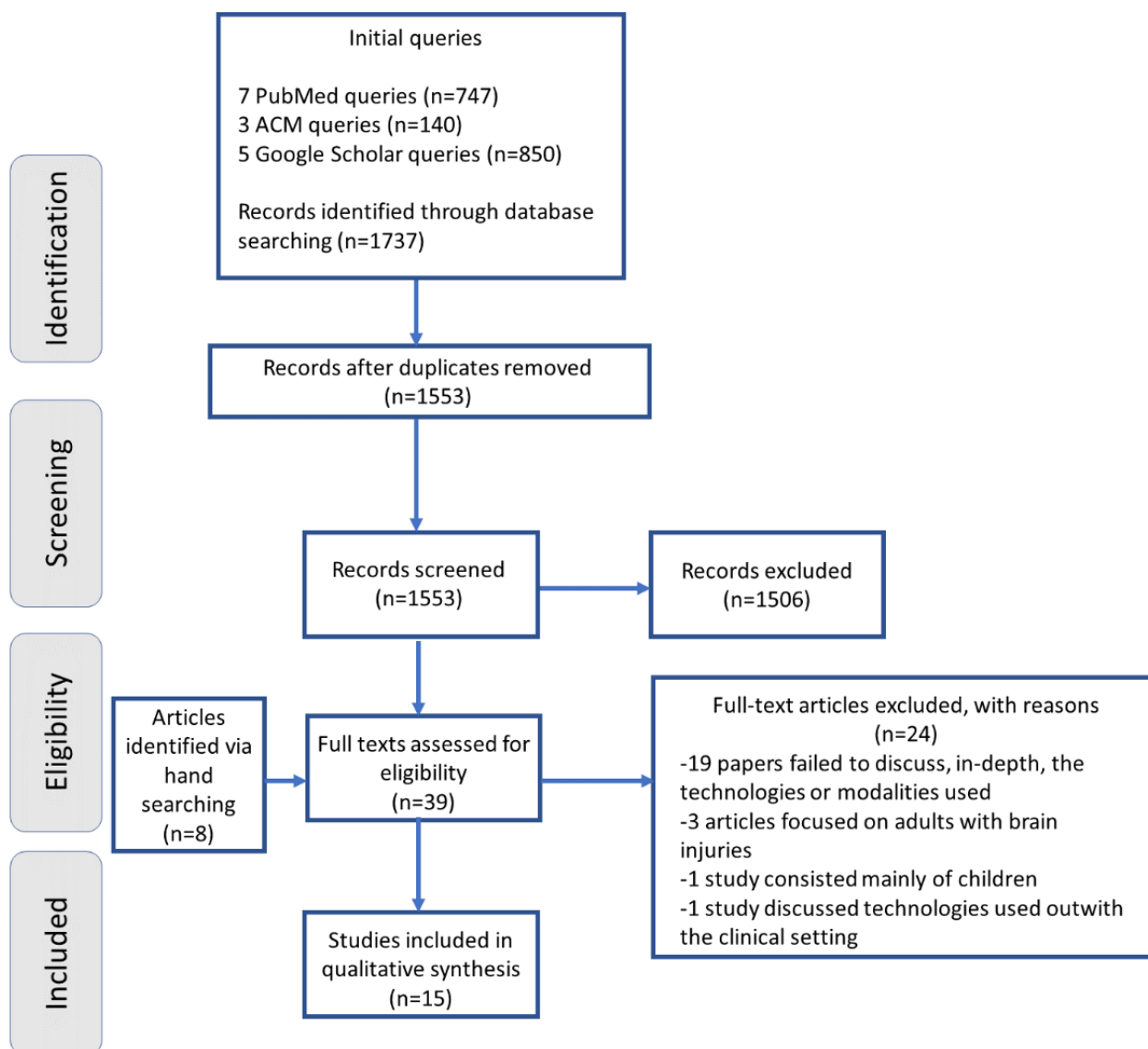
Inclusion Criteria

The review was restricted to literature that discussed the use of technology to promote communication between patients with mild IDs and health professionals. Textbox 2 describes the inclusion criteria used to screen relevant articles based on the PICOS (participants, intervention, comparison, outcomes, and study) search tool [26].

Articles may also have been excluded if they were deemed to be of low quality by any research team member. This was

assessed using the following three characteristics based on the aspects identified by Alborz et al [1]: (1) clarity of research questions or goals; (2) appropriateness of the methods employed in relation to the research questions; (3) and consideration of study limitations.

N size is often used as a proxy for the quality of a study; however, it was not considered appropriate for article exclusion because of our interest in the development of technologies and their implementation.

Textbox 2. Inclusion criteria for relevant articles.

Participants

- Adults aged 18 years or older with mild intellectual disabilities and health professionals; studies were also included where little information on the participants' intellectual disability was provided.

- We used the World Health Organization's definition of intellectual disability [20], which therefore rules out conditions linked to cognitive decline because of aging or other neurological disorders acquired later in life, for example, dementia. Participants with physical disabilities (eg, cerebral palsy) and no accompanying cognitive impairments were also excluded.

Interventions

- A range of communication modalities or technologies used to promote the exchange of information between patients with mild intellectual disability and health professionals during clinical consultations. This, therefore, excludes clinical studies with no focus on communication and evaluation of aids used to manage a specific condition. To be considered relevant, articles had to describe the components that comprised the aid. For example, it was not enough to state that a patient passport was used; rather, the characteristics included in the passport also had to be described. As such, the elements that influenced practice could be identified.

Comparator

- The review was not limited to comparator studies.

Outcomes

- Qualitative and quantitative data reporting the effects of communication aids and modalities on clinical consultations involving adult patients with mild intellectual disability.

Study type

- Primary studies only were considered relevant in this review.

Study Selection

As shown in Figure 1, a total of 15 articles met our inclusion criteria. Of the initial 1553 articles that had their abstracts screened, 1514 (97.49%) were immediately excluded from the review. Consequently, 39 were read in their entirety, of which 15 (38%) were deemed appropriate for inclusion in the review. A total of 20 articles were excluded because they did not fit our intervention inclusion criteria, and a further 4 were excluded because they failed to meet our participants' inclusion criteria. No articles were excluded based on quality.

Data Charting

RCG and MMB jointly developed a data-charting form to extract relevant information from the identified studies. The characteristics within this form were similar to those proposed by Arksey and O'Malley [23] and included authors year of publication, study location, study aim, intervention, study design, populations, and key results. The same authors independently charted the data and discussed their conclusions with MDD on hand to resolve any discrepancies. A summary of the charted data is provided in Multimedia Appendix 1 [27-41].

Analysis

A deductive, framework-based analysis [42] was used to synthesize charted data. RCG developed an initial thematic model capable of answering the research objectives proposed by using the communication barriers or facilitators discussed in other reviews [43,44]. This model was then discussed by the coauthors and agreed upon by consensus. RCG then applied the framework to a subset of the articles (consisting of 1 study per distinct AAC aid identified) and subsequently extended it where necessary, under the guidance of Gale et al [42], to include important aspects of the data that did not immediately adhere to the original concepts. To limit bias, Gale et al [42] also suggested that researchers reach a consensus on the coding applied to at least the first few transcripts. As such, MMB proceeded to review the tagged data, with any discrepancies in the applied framework being resolved by MDD. The remaining articles were then analyzed by RCG using this framework, with additional subthemes being created as required. MB and MDD were consulted on the creation of new tags to ensure that they were necessary and did not align with the other concepts. The final revised thematic framework can be found on the the University of Strathclyde website [45]; a summary of the themes is provided in Textbox 3.

Textbox 3. Thematic framework.

Communication barriers and facilitators

- This theme addresses the various practices that have an adverse or positive impact on information exchanges between medical professionals and patients with mild intellectual disability, covering aspects such as organizational procedures, fragmentation of care, education and training opportunities, and person-centered care.

Technological aids

- This theme identifies the various forms of communication aids used by patients and practitioners during clinical consultations and has been split into two primary subthemes: paper-based technologies and more complex digital technologies. An overview of the features included within each aid is provided.

Communication modalities

- This theme introduces the communication modalities employed throughout the aids, including the benefits and drawbacks of each. It also highlights the need for technologies to be adaptive because of the wide range of skills and needs experienced by people with intellectual disability, meaning a one-size-fits-all approach is unsuitable.

Evaluation and impact

- This theme discusses the various qualitative and quantitative methods used within the identified studies. It also introduces the perceived impact of the communication aids under scrutiny.

Results

In this section, we first present the general characteristics of the identified studies (publication and participants) before discussing the results of the framework-based thematic analysis. An in-depth description of the selected studies may be found in Multimedia Appendix 1, with a short summary provided in Table 1.

Table 1. Short overview of the identified studies.

Study (Author [year]; assessment tool)	Complexity		Modality			Participants		Evaluation	
	High-tech	Low-tech	Text	Imagery	Speech	Mainly people with ID[a]	Mainly other populations	Qualitative	Quantitative
Jones and Kerr [27] (1997); paper-based checklist		✓[b]	✓			✓			✓
Dodd and Brunker [28] (1999); image cards and training session		✓	✓	✓		✓		✓	
Lennox et al [29] (2001); CHAP[c]		✓	✓			✓		✓	
Lennox et al [30] (2004); Ask It Health Diary		✓	✓	✓			✓	✓	
Bell and Cameron [31] (2008); Talking Mats		✓	✓	✓		✓		✓	
Lennox et al [32] (2010); CHAP and Ask It		✓	✓	✓		✓			✓
Turk et al [33] (2010); hand-held health record		✓	✓			✓			✓
Brodrick et al [34] (2011); patient passport		✓	✓				✓	✓	
Bell [35] (2012); patient passport		✓	✓			✓		✓	
Heifetz and Lunsky [36] (2018); patient passport		✓	✓				✓	✓	
Gibson et al [37] (2018); tablet app	✓		✓	✓	✓		✓	✓	
Gibson et al [38] (2019); tablet app	✓		✓	✓	✓		✓	✓	
Gibson et al [39] (2019); tablet app	✓		✓	✓	✓		✓	✓	
Raemy and Pignon [40] (2019); patient passport		✓	✓				✓	✓	
Chinn [41] (2019); easy-read health information		✓	✓	✓		✓		✓	

[a]ID: intellectual disability.

[b]Checkmark indicates the presence of that characteristic within the study.

[c]CHAP: Comprehensive Health Assessment Program.

Overview of the Studies Selected

Publication

Of the 15 articles that met our inclusion criteria, 9 (60%) were retrieved from PubMed [27,29,30,34,36,38-41], 5 (33%) from Google Scholar [28,31-33,35], and 1 (7%) from ACM [37]. In total, 13% (2/15) were published in the 1990s [27,28], 20% (3/15) were published in the 2000s [29-31], and 67% (10/15) in the 2010s [32-41]. This finding highlights a substantial increase in the number of studies published on the focus of our review since the turn of the millennium and is in line with the heightened awareness of issues relating to the accessibility of services for people with ID [46,47]. However, despite such an increase, the study of Hemsley and Balandin [43] on the quality of communication between medical professionals and patients with severe communication disabilities concluded that the use of AAC in this context remains limited. Environmental barriers were cited as negatively affecting the implementation of AAC technologies, as was the knowledge of staff who find it difficult to adapt to technologies brought in externally by patients [43].

Furthermore, all studies identified during the data collection phase were carried out in countries that are members of the Organization for Economic Cooperation and Development (OECD), with most centering on the health care infrastructure of the United Kingdom [27,28,31,33-35,37-39,41] and Australia [29,30,32]. As such, the generalizability of the findings may be limited, particularly regarding the impact of AAC technologies on patients with ID from non-OECD nations.

Participants

Participants Involved in the Design and Development of an Intervention

In total, 6 of the articles described the design and development of an intervention to promote communication between adult patients with mild ID and health professionals [30,34,37-40]. Surprisingly, target stakeholders were not heavily involved in the design process (despite increasing expectations of the use of co-design methodologies [48]), with investigators largely deferring to the views of other populations. For example, Lennox et al [30] relied upon an advisory group (consisting of 2 individuals with ID, 2 support workers, 2 parents, 2 advocacy

organization representatives, and an occupational therapist) to develop a health diary for persons with ID. Their initial designs were then scrutinized, before implementation, by 101 people across 15 focus groups, yet health professionals (1 general practitioner [GP] and 2 psychologists) and patients with ID (8 persons) were underrepresented during this process.

Both Brodrick et al [34] and Raemy and Paignon [40] also followed the approach of using a multidisciplinary team to develop their respective interventions—a 1-page patient passport and an emergency admission sheet. However, the authors failed to report the exact demographics of the members involved, meaning it was difficult to discern the influence people with ID had on the design process. This was particularly true in the study of Brodrick et al [34], where it was unclear whether the ID population had any input on the intervention design.

Finally, Gibson et al [37-39] used a variety of experts in ID (researchers, support workers, health professionals, and representatives from ID charities) to develop a technology probe of an AAC app to support adults with ID when communicating with GPs. This probe will be embedded in future user-centered design sessions involving participants with mild ID to ensure that the representative requirements for the proposed app are established. Consequently, the lessons disseminated by Gibson et al [37-39] are likely to be premature and subject to change based on the views of the target stakeholders.

Participants Involved in the Evaluation of an Intervention

In contrast, participants with mild ID contributed highly to most studies focusing on the evaluation of an intervention [27-29,31-33,35,41]. The only exceptions were the evaluation of a health passport by Heifetz and Lunsky [36], in which only 3 participants with ID completed the feedback questionnaire compared with 25 family members or support workers, and the evaluation of the Comprehensive Health Assessment Program (CHAP) by Lennox et al [29], where the views of practitioners were sought exclusively. A study (Turk et al [33]) reported that a high number of participants with ID (35/108, 32.4%) dropped out before completion. This was attributed to people with ID being more likely to refuse follow-up interviews as well as having a higher probability of changing GPs than the general population, meaning they were exempt from the study.

Although people with ID were prevalent throughout the evaluations, only 4 of the articles offered concrete or partial statistics on the etiology of their participants' disability [27,29,32,33]. As such, we were unable to decipher the characteristics of 72.5% (384/530) of the participants with ID involved in the evaluation studies. In total, 18.5% (98/530) had Down Syndrome [27-29,32,33]; 3.9% (21/530) had autism [33], 3% (16/530) had cerebral palsy [33]; and 2.1% (11/530) had other congenital factors, perinatal birth problems, or epilepsy [33]. The authors noted that cerebral palsy and epilepsy are not often a direct cause of ID but instead coincide with this condition. Nevertheless, we have included them to provide an accurate summary of the participant characteristics reported by the identified studies. Lennox et al [32] primarily measured the severity, but not the cause, of ID present in their participants and found that 44.2% (107/242) had mild or moderate ID and 26.5% (62/242) had severe ID, whereas 30.2% (73/242)

participants had an unknown level of ID. Jones and Kerr [27] also followed the same approach, with 25.2% (28/111) of their participants having mild or moderate ID and 35.1% (39/111) having severe ID. Consequently, researchers must provide a consistent, in-depth description of the populations targeted by their studies to increase the generalizability of their findings.

Thematic Analysis

Communication Barriers and Facilitators

Several studies performed qualitative investigations on the barriers and facilitators to effective communication between health professionals and patients with mild ID. Their findings primarily align with the literature (such as the studies by Alborz et al [1], Krahn et al [2], Ali et al [3], Murphy [13], Hemsley and Balandin [43], Selick [49], Chew et al [50], and Pelleboer-Gunnink [51]) and highlight the factors being targeted by the aids introduced in theme 2—*Technological Aids*.

Organizational Barriers and Facilitators

Collation of Data

Both Raemy and Paignon [40] and Jones and Kerr [27] suggested that a limited collation of health care data regarding ID was a major barrier for patients' access to effective services. Raemy and Paignon [40] revealed that Switzerland is yet to implement a national policy regarding the health needs of people with intellectual or developmental disabilities, meaning that institutions are not expected to record the details of a patient's ID, nor have appropriate strategies in place to do so. As such, medical professionals may remain unaware of their patients' additional needs and therefore fail to conduct the recommended reasonable adjustments to their consultation methods. In addition, the recruitment pathways available to researchers are impacted considerably, as highlighted by Raemy and Paignon [40], who were forced to identify participants via residential accommodation.

Jones and Kerr [27] also acknowledged that it might be difficult for institutions to recognize patients with milder ID. They expected to locate approximately 150 registered patients with ID across 5 GP practices (based on national figures) throughout their study, yet could only identify 39. Consequently, there may be a hidden population of patients with mild ID who are unable to receive the same benefits as those known to medical professionals.

Collaboration

In addition to the lack of guidance from national strategies, local health care infrastructure may impede collaboration between medical professionals treating patients with ID. Fragmentation of care was recognized by Bell [35] and Heifetz and Lunsky [36], stemming from a lack of coordination across faculties [35,36] and between health care organizations and social care [36]. As such, people with ID are less likely to receive optimal care because they are prone to developing comorbidities [52], which require treatment from a variety of specialists. Furthermore, patients might find it difficult to adapt to the procedures employed by separate institutions if they are not standardized.

In addition, Heifetz and Lunsky [36] noted that there might be some resistance to agencies moving away from their own practices and instead adopting standard processes or tools, even if there are clear benefits of doing so. In such cases, it is important to establish a champion who can provide strong leadership in overseeing the adoption of the intervention, which may include scheduling regular feedback meetings with stakeholders and periodically reviewing the positive effects of the intervention. This is particularly important in projects where benefits are not immediately clear [36].

Time

Dodd and Brunker [28] and Ramey and Paignon [40] highlighted the impact time constraints might have on consultations involving patients with ID. First, Dodd and Brunker [28] suggested that this population is often rushed to communicate their health needs to practitioners, which opens up the possibility of caregivers becoming overinvolved to ensure everything is addressed. As such, the accuracy of the information being provided may be significantly reduced (see the *Support* section). Instead, caregivers should aim to remain in a purely supportive role and encourage patients to proceed at their own pace while interacting with a doctor [28]. In addition, Raemy and Paignon [40] observed that time constraints, particularly in emergency situations, prevented medical professionals from thoroughly exploring all possibilities of an individual's condition. This included examining the patients often extensive medical histories to gauge whether they had displayed similar symptoms in the past.

Education

As discussed previously, medical professionals tend not to be well educated on the health and communication needs of people with ID [11,12]; 4 of the identified studies discussed how this can have a negative impact on the quality of care provided [35,37,38,40]. First, Raemy and Paignon [40] suggested that a lack of knowledge regarding the health trends experienced by people with ID may result in the overshadowing of conditions (ie, the association of a symptom with the disability itself, as opposed to some other disorder) and poor coordination of care. Gibson et al [37,38] and Bell [35] also indicated that insufficient training could affect health professionals' ability to perform reasonable adjustments, particularly when exchanging information via verbal communication is not an option. Practitioners also complained that they were ill-equipped to overcome the challenging behaviors presented by patients with more severe ID [35].

Due to the shortcomings of undergraduate medical courses [11,12], Bell [35] and Raemy and Paignon [40] called for the introduction of compulsory training sessions on how to treat patients with ID effectively. Bell suggested that this content should focus on the specific communication strategies employed by the ID population, including basic signing systems and other modalities such as imagery [35]. Raemy and Paignon [40] developed a variety of educational resources in conjunction with people with ID to suit the specific needs and workloads of a variety of health professionals. These resources (which ranged from a 15-min educational session to a 5-day training program) covered important aspects such as behavioral traits, including

how patients with ID express pain, common health conditions affecting the ID population, and communication strategies to ensure patients are involved in the decisions regarding their care. There is also scope to explore whether training support workers and family members would also have an impact on the health of people with ID [40].

Support

There was some disagreement on the impact that external support may have on consultations involving adults with ID. Turk et al [33], Heifetz and Lunsky [36], Gibson et al [37,38], and Lennox et al [30] recognized the important role that caregivers play in empowering individuals with ID to provide their own views. This typically involves serving as a mediator between the patient and health professional to ensure that both sets of stakeholders communicate in a manner understood by the other. In addition, they may be familiar with the patient's everyday needs and routines [30], which can assist in determining the optimal course of treatment for individuals with ID.

However, the described benefits are largely dependent on the level of involvement a support worker has in the patient's life. For example, Gibson et al [38], Turk et al [33], and Heifetz and Lunsky [36] noted that some people with ID have to cope with everchanging support workers. Therefore, new staff may be unaware of the person's health history and specific communication needs, meaning they will have less of an impact on the consultation. Furthermore, there is a possibility that caregivers become overinvolved in the consultation and begin communicating on behalf of the patient [28]. This could reduce the accuracy of the information conveyed because of their own opinions, differing from that of the individual with ID. Finally, Raemy and Paignon [40] demonstrated the advantages of employing more specialized medical professionals to support frontline staff. For 3 years, an ID nurse provided training to less-educated professionals, which improved the standard of care provided to 1017 patients with ID.

Person-Centered Care

Lennox et al [30] and Bell [35] noted that optimal care was administered by practitioners who went out of their way to meet individual patient needs. This included simple adjustments such as allowing extra time for the individual to get across their views, being kind and empathetic toward a patient's situation, interacting directly with a patient rather than their caregiver, using appropriate communication strategies to ensure the patient understands the information conveyed, and looking past a person's disability to treat them like a human being.

Two strategies were discussed that may assist practitioners in carrying out such adjustments. First, medical professionals should be given access to the personal characteristics of their patients, for example, their preferred method of communicating the terms *yes* and *no*. Second, patients should be encouraged to seek appointments with the same medical professional, thus allowing a relationship to form over time [30,35]. Consequently, practitioners can become increasingly aware of the specific needs of individuals with ID, yet Chinn [41] suggests that this

may be difficult for traditional medical professionals in comparison with ID nurses.

Technological Aids

In this section, we analyze the various technologies used in the identified studies. To do so, we grouped these technologies into two main categories: low-tech communication aids and high-tech communication aids. We define a low-tech aid as a nonelectronic tool, external to an individual's body, that assists the user in communicating a message to a relevant partner. In contrast, a high-tech aid is a complex electronic device that permits the storage and retrieval of messages, many of which are used during the formulation of speech output [53].

Low-Tech Aids

Patient Passports

The bulk of the studies (Brodrick et al [34], Bell [35], Heifetz and Lunsky [36] and Raemy and Paignon [40]) centering on low-tech communication aids used some sort of patient passport. Patient passports encapsulate an individual's characteristics to assist medical professionals in adjusting their consultation methods to provide consistent, person-centered care. They are typically short in length to allow relevant information to be accessed quickly and may be maintained by all sets of stakeholders involved in a medical consultation, that is, clinicians, support workers, family members, and the patient themselves. As such, they are likely to contain a range of perspectives on the optimal way to interact with a patient with ID, thus increasing the probability of doing so effectively.

The passports implemented shared common features but were often tailored to meet the requirements and infrastructures of the organizations they were employed in. This was demonstrated concretely by Heifetz and Lunsky [36], who developed passports for 3 institutions within the same catchment area. Each institution requested a tool that differed in size (wallet size vs 1 full-page, double-sided tool vs 4 pages) and visual appearance (plain written information vs pictures to complement text). However, all formats summarized information on the same aspects, including the patient's medical history, baseline behaviors (eg, potential triggers, communication methods, or contingency plans for when the patient becomes agitated), and the emergency contact details of support workers and family members.

Brodrick et al [34] and Bell [35] encapsulated similar details in their double-sided and 3-page patient passports, respectively. Nevertheless, they used color to demonstrate the most relevant aspects required in a critical situation. For example, the medical needs of the patient (eg, existing conditions and allergies) were prioritized by both sets of authors, meaning this information was coded in red to signify its importance. Further information, such as the patient's environment or support needs—those deemed to be relevant but not critical to the patient's care—was coded in more neutral colors such as amber and green.

Raemy and Paignon [40] recognized that passports could only be effective if they accompany patients throughout the health care system, a process that may be difficult to achieve using physical resources. Consequently, they developed a digital

version and integrated it within their electronic patient data system to increase the portability of the aid produced. Multiple health care professionals may also have access to passports at the same time if required.

CHAP or Notes-Based Prompts

Lennox et al [29,32] and Jones and Kerr [27] explored using note-based prompts to support medical professionals in investigating specific areas of a patient's health. The CHAP [29,32] is composed of a list of screening opportunities and preventive activities commonly used by people with ID. Practitioners then use this information to determine whether appropriate health checks have been carried out periodically with the patient. As a result, the CHAP is less likely to positively affect time-critical environments, such as primary care consultations, where the emphasis is placed on treating the most immediate symptoms present [32]. Instead, it is more suited to interventions such as the ID annual health check, as medical professionals have an extended amount of time to consider all aspects of a patient's well-being.

In addition to the CHAP, Lennox et al [29] supplied health professionals with a short summary of the recent health trends of people with ID, a strategy they found most convenient to use in general practice. Jones and Kerr [27] also employed a similar approach to encourage practitioners to be vigilant for, and follow-up on, conditions that may otherwise have been missed or overshadowed. They combined such evidence with a synopsis on the best practices to implement when interacting with a patient with ID, thus potentially increasing the amount and accuracy of information being extracted. Nevertheless, they found that the paper-based nature of the aid meant it was not used prominently by health professionals [27] and could therefore be replaced by more appropriate digital solutions.

Health Diaries

Lennox et al [30,32] and Turk et al [33] described the development of health care diaries to empower patients with ID to understand their needs better as they progress over time. Once again, all stakeholders were responsible for maintaining the document, meaning that observations on the patient's well-being could be recorded by health professionals, support workers, family members, or the individual with ID. The approach of Turk et al [33] separated the diary into sections based on the common conditions experienced by people with ID, ranging from everyday ailments to more complex disorders such as epilepsy. There was also space dedicated to the treatments being received by the individual as well as advice on how to live a healthy lifestyle.

The diary of Lennox et al [30,32] was significantly more substantial in that it contained segments on how to improve communication during the consultation, in addition to those focusing on recording health information. These segments were aimed at both the health professional and the individual with ID and included a patient passport, general strategies that practitioners may use to improve the quality of care being provided, and tips for the patient on how to prepare for a consultation, along with several resources to support them during this process, such as picture symbols and pain recording tools. Consequently, the health professional's knowledge of the

patient's communication or treatment preferences and specific health needs should be notably increased.

Easy Read

Dodd and Brunker [28] and Chinn [41] used easy-read documents to support patients with ID in understanding medical conditions or symptoms. *Easy read* is the term given to information resources that have been specifically adapted to suit the complex needs of people with ID. This is primarily achieved through the implementation of short, jargon-free sentences supplemented with identifiable imagery.

In the study of Dodd and Brunker [28], flashcards of various body parts, types and intensities of pain, and periods of time were issued to patients with ID to increase the accuracy of the symptoms being described. The approach by Chinn [41] was different in that she directed medical professionals toward existing easy-read resources on clinical conditions and monitored whether these resources had a direct impact on communication throughout a consultation. The documents included an accessible summary of the effects and potential treatments of a condition. Consequently, they were used as a form of support during situations where a patient could not understand what the practitioner was conveying or was opposed to the course of treatment being offered. Despite the documents being publicly available before the commencement of the study, many of the GPs were largely unfamiliar with such resources, thus potentially limiting their impact on consultations. This contrasted with the more specialized health care professionals (ID nurses) who regularly used, and were involved in the development of, easy-read resources [41].

Talking Mats

Bell and Cameron [31] identified Talking Mats as a potential tool for supporting a patient with mild ID in discerning aspects of their mental health—a process that they were finding difficult to overcome using traditional consultation methods. Talking Mats is a communication aid that primarily relies on images to form a concrete representation of an individual's views. A visual scale was first placed at the top of a physical mat. The discussion was then broken down into manageable topics, and for each topic, the individual should place an image that encapsulates their opinion under the appropriate section of the visual scale. Consequently, the aid is particularly effective for individuals who lack the social skills to converse with authoritative figures, as it lifts the burden of direct interactions [31]. In addition, Talking Mats may provide a voice for those who are unable to communicate verbally, thus increasing their participation in decisions regarding their care.

High-Tech Aids

Only 1 set of authors (Gibson et al [37-39]) explored the development of high-tech aids to support patients with mild ID when communicating with medical professionals. They proposed a digital questionnaire based on the most common medical conditions experienced by people with ID. Each question should be presented using the easy-read format discussed above to increase the probability of users selecting the symptoms they are experiencing. In addition, any information extracted from the patient should be used to influence the future questions

presented, thus ensuring that the questionnaire is tailored to their own health care needs. The app should also be customizable to account for the patient's accessibility profile and may be combined with other AAC strategies, such as patient passports, to increase the quality of care being provided [39].

Extracting symptoms from patients with ID before the consultation may have multiple advantages. The results may be used as a referent by the patient when presenting their views to health professionals; time constraints may be reduced with the practitioner able to build upon preselected information; and finally, there may be increased exposure to commonly overshadowed conditions [37-39]. However, without a concrete evaluation (which includes the involvement of target stakeholders), such benefits may be speculative, with the lessons disseminated by Gibson et al likely to change as further studies are carried out.

Communication Modalities

In total, 67% (10/15) of studies, including the studies by Dodd and Brunker [28], Lennox et al [29,30,32], Bell and Cameron [31], Heifetz and Lunsky [36], Gibson et al [37-39], and Chinn [41], described their implemented technologies well enough for the authors to determine the range of communication modalities employed.

Imagery

The bulk of the articles discussed the importance of imagery in supporting patients with ID to understand and communicate about their symptoms. Nevertheless, the depth and context of the use of medical images differed. For example, Bell and Cameron's [31] application of Talking Mats resulted in a patient with mild ID providing information on their psychological health via the development of a pictorial framework. This, therefore broke the reliance on disseminating information through speech, with the individual only being required to elaborate on those selections that were unclear or of particular importance to their diagnosis. The visual feedback offered by the mat also enabled the patient to reflect on and refine their selections, thus increasing the quality and quantity of information provided.

Lennox et al [30,32] and Dodd and Brunker's [28] use of imagery was less extensive in that their resources enhanced an individual's communicative abilities instead of primarily replacing them. In both cases, this involved developing colorful pictures to support a patient with ID in expressing pain symptoms, including its site, severity, [28,30,32], intensity, and duration [28]. Heifetz and Lunsky [36] also found it beneficial to include a photograph of the patient in any resources used, to give practitioners a reference of how they should look while healthy.

Finally, the imagery employment of Chinn [41] and Gibson et al [37-39] was aimed at enhancing patients' understanding of relevant medical information. In the study by Chinn [41], health professionals used easy-read documents at times when a patient was unable to understand what was being conveyed or disagreed with the course of treatment proposed. These documents contained information on the manifestation, effects, and possible treatments of a condition and were made more accessible to the ID population by introducing imagery. Therefore, the ability of

patients to be involved in decisions regarding their care should have increased. Gibson et al [37-39] applied a similar strategy during the design of a clinical AAC tablet app, with images being used to supplement the patients' understanding of the symptoms presented as part of a medical questionnaire. In addition, symbols were used to indicate the functionality of the buttons embedded in the app's user interface, albeit varying degrees of success [37,38].

Despite their reliance on imagery throughout the technologies implemented, none of the authors discussed the design decisions taken during the development of such resources. Furthermore, none of the image sets were made publicly available, which impacts the ability of researchers to reuse them or indeed create their own. Lennox et al [30] also noted that images could be expensive and time-consuming to produce, and this could be a problem considering that a one-size-fits-all approach is unlikely to be effective for the ID population [37-39]. For example, some patients may already use Makaton symbols [54] in their everyday lives, and therefore expect a similar style of image to be employed, whereas others might find realistic photographs to be more relatable.

Text and Speech

In total, 5 studies (Lennox et al [30], Gibson et al [37-39], and Chinn [41]) indicated that written information, enhanced by identifiable imagery, provided patients with an accessible means of two-way communication. Gibson et al [37-39] went one step further and suggested that the playback of textual information should also be incorporated, where possible, to ensure illiterate or semiliterate users are not disadvantaged in any way. Therefore, targeting a range of modalities ensures that information is presented in a variety of different manners, with the individual able to use the form that makes the most sense to them in each scenario. For example, a patient with ID may prefer to use images when receiving information but also has the option to fall back on the text when a particular image is unclear.

While developing textual information, Chinn [41] and Gibson et al [37-39] emphasized the importance of following accessible language guidelines, such as National Health Service England's [55]. This included the use of plain and simple sentences that focused on solitary ideas. However, Gibson et al [38] also recognized that some complex terminology, such as medication brand names, was crucial to patient comprehension, meaning it is important to develop such resources in conjunction with target stakeholders to ensure their needs are met.

When presenting questions to patients with mild ID, different strategies were employed depending on the context of the consultation and the technologies used. For example, Bell and Cameron [31] primarily presented open-ended questions when using Talking Mats to establish the factors having a negative impact on the psychological health of a patient with ID. They felt that open-ended questions could improve the quality and depth of information being extracted, although they recognized that the ID population might have greater difficulty in constructing responses to them. In contrast, Gibson et al [37-39] used closed questions that focused on a narrow range of medical symptoms, thus enabling them to break the consultation process

down into manageable steps while building an overall picture of the patient's health care needs.

Training

Bell also suggested that health care professionals remain undereducated on the communication strategies employed by patients with ID [35]. Consequently, she called for the enhancement of existing training programs to include information on how to effectively target a range of communication modalities instead of just using speech. This included basic signing systems such as Makaton [54,56], in addition to simplified language and imagery.

Evaluation and Impact of the Technologies

In this section, we analyze the evaluation techniques employed in the identified studies. The perceived impact of the technologies that emerged as a result of these evaluations will also be discussed.

Qualitative Evaluations

Most studies primarily used qualitative methods to evaluate the effect of their technologies on current practice; this included interviews, focus groups, and questionnaires [28-31,34-36,40], the analysis of a reflective journal [35], posttask walkthroughs [37,38], and conversational analysis of the interactions between health professionals and patients with ID [41].

Interviews, Focus Groups, and Questionnaires

The CHAP

Lennox et al [29] initially assessed the benefits of their CHAP, which included a checklist of preventive activities, a synopsis of the literature on the current health trends of the ID population, and a health record audit tool, by issuing a self-evaluation form to the practitioners involved in the study. Of the 45 GPs who agreed to participate, only 15 (33.33%) completed all the study components. This, combined with the lack of involvement of the 38 patients with ID in the intervention evaluation phase, significantly restricts the strengths of the conclusions made, as highlighted by the fact that only descriptive results were reported. In terms of effectiveness, the GPs reported that all interventions were beneficial in assisting their provision of care. Nevertheless, the synopsis of the literature was most productive in improving their knowledge of the health demographics of people with ID and was considered the most practical to use [29]. The checklist was most likely to raise awareness of the health needs of the patient and therefore prompted the greatest amount of action that may not have been carried out otherwise. Communication was reported to have increased between carers, hospitals, and specialists, as were consultation times, although no quantitative measures were carried out to confirm this.

Ask it Health Diary

Lennox et al [30] employed a similar evaluation form to determine the appropriateness of an educational session that preceded the implementation of a health advocacy diary. The finer details of the form were not disclosed, yet the feedback indicated that the session was useful in reinforcing the responsibilities of both the patient and the health professional. In addition, the session also introduced the steps involved in becoming an effective advocate. A short pilot study was

conducted with the following 2 groups to evaluate the health diary: (1) 19 parents of adults with ID who used a nongovernmental support service and (2) 7 people with ID who used a nongovernmental accommodation service. The participants took part in the educational sessions mentioned above and were then issued with the health diary. Next, they were required to familiarize themselves with the tool for 2 weeks before completing an interview on the phone or in person, the protocol of which was not described. The qualitative data indicated that the diary improved the advocacy skills of two-thirds of the participants and improved their relationship with the GP in 50% of cases. The results were also used to improve the technology before a more thorough evaluation was conducted in [32].

Talking Mats

Bell and Cameron [31] conducted 2 separate interviews to validate the health information extracted from a patient with mild ID using Talking Mats. The patient's concerns extracted during these interviews were collated into a single document, with arrows being included to show how they had changed. This information was then passed on to the individual's support worker to ensure that actionable change was carried out to improve their mental health. Bell and Cameron [31] found that the Talking Mats framework made it possible to "extend the use of therapies that rely heavily on verbal communication to those people who not only find verbal communication difficult in a general sense but also in a specific situational sense." Visual feedback, along with the open-ended questions presented, may also increase the depth and quality of the information being extracted.

Easy-Read Communication Cards

Dodd and Brunker [28] issued a questionnaire at the start of their project to determine the health advocacy skills of 10 patients with ID. After 6 months of using easy-read communication cards and participating in the accompanying training sessions, participants were required to redo the questionnaire to determine if their skills had improved. Brief multiple-choice questionnaires were also completed by the participants, GPs, and key workers each time a participant became ill or was in pain and visited their doctor. In total, 3 follow-up evaluation cards were completed by the participants involved, meaning that the authors were only able to provide tenuous remarks regarding the feedback received [28]. The benefits reported included an increase in knowledge on recognizing the signs of being unwell and what to do when ill, an increase in two-way communication using the pictorial aids issued, and an increase in the ability of the patients to be involved in the decisions regarding their care. Nevertheless, there was some variance in the results extracted, with only those participants who used the aid regularly with their support worker or doctor demonstrating increased retention of health care information.

Patient Passports

Heifetz and Lunsky [36] also used both questionnaires and interviews to evaluate patient passports across 3 institutions in Canada. Their descriptions of the protocols employed were more complete, thus increasing the replicability of their findings.

A total of 18 semistructured interviews were conducted on the phone with a variety of stakeholders, including hospital clinical staff, community health and ID service providers, community-based health care coordinators, and 1 parent. Participants with ID were not included in this stage, as the focus of the interviews was on the implementation of the passports rather than their use. Instead, the ID population's views were extracted using a questionnaire, along with support workers and family members, to determine the fit and user-friendliness of the passport and its potential benefits. Both closed- and open-ended questions were used to achieve this.

Overall, 75% (21/28) of the participants involved in the questionnaire felt that the tool provided health care professionals with relevant background information on the patient. In total, 65% (18/28) suggested that such an approach can assist practitioners in carrying out reasonable adjustments to their consultation methods, with 79% (18/28) recognizing an improvement in communication between all stakeholders involved in a consultation. Consequently, the tool has the potential to support practitioners in conducting better-informed health care decisions. Nevertheless, these results may be speculative as only 3 of the participants who completed the questionnaire had ID, 25 did not have ID, and 82% (23/28) had no experience in using the aid within a health care context. The interviews also highlighted the variable degree to which passports were adopted across each institution. Strong leadership in monitoring and educating professionals on using tools has been reported as increasing community awareness and buy-in [36].

Brodrick et al [34] conducted a short pilot study of a 1-page patient passport across 2 sites in England in October 2009. Residential managers from each service were trained using passports before introducing the aid to frontline care staff. During 1 month, 150 passports were produced, with both the researchers and residential managers remaining on hand to provide additional training and support. Quality checks were carried out on these resources, and a final round of focus groups was conducted at the end of the pilot phase to obtain feedback from the health care staff. Nonetheless, the components being reviewed throughout the quality checks and the tasks employed in the focus groups were not reported. The potential benefits of the passport were similar to those reported by Heifetz and Lunsky [36] in that it provided staff with the necessary information to deliver person-centered care. Passports also increased the continuity of care as patients moved across departments while promoting collaboration between health care providers. However, their initial quality was extremely variable and only improved once extra training and support were provided, along with passports deemed to be of high caliber.

Reflexive Journal Analysis

Bell [35] used multiple methods to evaluate their version of a patient's passport. A variety of perspectives were extracted, thus improving the strengths of the findings obtained via data triangulation. First, 12 family caregivers and health and social care staff participated in a series of semistructured interviews to determine their experiences using the passport. In addition, a focus group involving 8 adults with ID was conducted, with

emphasis being placed on aspects that had, or had not, helped them feel comfortable in a hospital context. Nevertheless, only 1 participant had experience using the passport employed, which potentially limits the impact of the findings from this part of the study. Finally, Bell [35] observed and recorded notes on passports being implemented in practice, which was analyzed using a reflexive process. As with Heifetz and Lunsky [36] and Brodrick et al [34], increased collaboration and continuity of care were recognized across multiple health care providers.

Conversational Analysis

Chinn [41] recorded the interactions between health professionals and patients with ID to determine the effects easy-read information sheets had on consultations. A total of 41 recordings were made, 32 of which involved a patient with ID attending a health check with primary care clinicians and 9 with specialist ID nurses. Conversational analysis was then used to examine the interactional micropractices that framed literacy events involving easy-read resources. Reflective interviews were also conducted with a subset of the participants (9 patients and 9 health professionals) to determine the reasons behind certain actions. The study by Chinn [41] was carried out in the context of annual health checks to ensure the identification of appropriate participants. However, this environment restricted the opportunity for health professionals to introduce easy-read information sheets, as highlighted by their visibility in just 22% (7/32) of the appointments recorded. The ID nurses involved were also far more likely to use the information sheets than the GPs (because of their specialized skills) despite Chinn's best effort to educate the participants on the benefits of such resources. When used, the easy-read information sheets effectively supported the medical professional to offer unsolicited advice, particularly when patients were resistant to change. This was because of the aid reinforcing the practitioner's views and reminding them of important aspects to forward on to the patient.

Posttask Walkthrough

Gibson et al conducted posttask walkthroughs with 4 experts in ID to ensure that the technology probe of a clinical AAC tablet was accessible to the target population [37,38]. The experts were required to select various symptoms within the probe before answering questions on their experience with the app. Particular attention was paid to any area of interest noted by the researchers during the experts' interactions. The benefits of the app listed by the participants included an increase in communication via the use of an accessible list of symptoms as a referent, a rise in awareness of the conditions commonly overshadowed by practitioners, and the mitigation of time constraints by providing information to the GP before the consultation. Nonetheless, such benefits may be premature, with Gibson et al revealing their intentions to extract the views of health professionals and adults with mild ID during future work before carrying out a pilot study within the clinical environment [37,38].

Quantitative Evaluations

Only 3 studies [27,32,33] used quantitative methods, via randomized controlled trials (RCTs), to determine the effect of their interventions on current practice.

Ask It Health Diary and CHAP

Lennox et al [32] followed on from their earlier studies [29,30] to perform a clustered RCT with people with ID living in private dwellings throughout the Greater Brisbane area of Australia. They examined the effect of their interventions using a 2×2 factorial design, with the units of randomization being assigned to clusters of participants interlinked by sharing a GP practice. These clusters were organized into 4 blocks according to their size; 1 cluster from each block was then assigned to a factorial group by a statistician using computer-generated random numbers. The effects of the interventions on clinical activity (eg, health promotion and disease prevention) were measured for 12 months and compared with the same activities in the preceding year.

The CHAP had a statistically significant effect on health promotion, disease prevention, and case finding activities across a number of components. Outcomes related to sensory systems (eg, hearing and vision tests) increased, as did all 5 of the immunizations highlighted by the program. There was also a substantial increase in the number of patients who underwent weight measurements. There were no significant changes in the measured outcomes of the group assigned to the *Ask It* health diary alone, with only modest effects being noted on epilepsy review and constipation investigation. This contrasts with the findings of [30], which suggested that the health diary could lead to an improvement in the patient's health advocacy skills, and as such, increase the number of conditions being identified. Lennox et al suggested that the trial may have been too short to recognize the true benefits of the diary [32].

Notes-Based Prompt

Jones and Kerr [27] also used an RCT to evaluate their note-based prompt, a tool that was similar to the CHAP program described above. A total of 5 primary care practices participated in the study and identified 88 patients with ID who were randomly allocated to the active or control group. The active group had access to the prompt immediately, whereas the control group endured an embargo for 6 months. After the initial 6-month period, data were collected on a wide range of variables related to health promotion, consultation patterns, and physical, psychological, and social well-being. This was compared with information on consultation patterns during the previous 4 years as well as life-long records of general health issues. In contrast to Lennox et al [32], no significant differences were observed in consultation patterns (location, nature, and outcome) or health promotion. Jones and Kerr [27] attributed this to the paper-based nature of the aid, with medical professionals preferring to use digital resources. In addition, they suggested that without statutory regulations and considering the current workloads experienced by GPs, screening opportunities are unlikely to be carried out on an opportunistic basis.

Hand-Held Health Record or Diary

Finally, Turk et al employed an RCT to evaluate their hand-held health diary [33]. A total of 40 primary care practices were randomized to the control or implementation groups, with 163 patients with ID completing all stages of the trial. Initial interviews were carried out with patients and caregivers to determine aspects such as basic background information,

knowledge of health problems and medical terminology, information on GP visits in the past year, and whether specific health checks were up to date. Follow-up interviews were then conducted 1 year after the study's start date and were identical to the initial interviews, except that additional questions were asked about the individuals' experience with the health diary where appropriate. Upon completion of the study, a nurse researcher accessed the patients' medical records from a year before the initial interviews up to the time of the follow-up interview to measure a number of health-related outcomes.

Similar to Lennox et al [32], no statistically significant outcomes were achieved by the hand-held health diary [33]. However, there were some improvements concerning the number of GP visits per year (an increase of 1.4), the ability of patients to report health-related problems, and their ability to recognize medical jargon. The qualitative data extracted during the follow-up interviews indicated that only 18% (10/56) of the patients with ID involved in the intervention group used the diary, and 39% (22/56) of caregivers used it on behalf of the patient. This may partially explain the limited impact that the diary had on consultation patterns, the impact that was attributed to a high turnover in support staff, and other factors such as carers forgetting it, being too busy, or being concerned about taking up the GPs' time. Nevertheless, those who had used the diary generally expressed satisfaction with it and suggested that it helped them know more about the patient's health and was useful during visits to the GP or hospital.

Raemy and Paignon's [40] evaluation phase is currently in process; therefore, no concrete results have been reported. In addition, the study by Gibson et al [39] only focused on the extraction of design requirements, meaning no evaluation was conducted.

Discussion

Principal Findings

Despite communication barriers being well recognized within the literature (eg, in the studies by Alborz et al [1], Krahn et al [2], Ali et al [3], Hanlon et al [5], and Hemsley and Balandin [43]), little is known about the use of technology to support the exchange of information between patients with mild ID and medical professionals. Our review therefore maps the literature within this domain while exposing potential gaps that may be addressed in future work. We identified only 15 studies focusing on the development and/or implementation of AAC devices, with most investigating one-way communication aids [27,29,32-36,40]. Notes-based prompts (Jones and Kerr [27], Lennox et al [29,32]) were statistically significant in increasing the number of targeted checks performed by medical professionals in problematic areas, such as hearing difficulties [32]. Passports and health diaries (Turk et al [33], Brodrick et al [34], Bell [35], Heifetz and Lunksy [36], and Raemy and Paignon [40]) aimed to increase practitioners' knowledge of their patients' medical and communication needs, thereby facilitating reasonable adjustments and recognizing commonly overshadowed conditions. However, these interventions centered on the way medical professionals present information to their patients instead of empowering individuals with mild ID to take

an active role in their care. This goes against Chinn's [22] view that the best outcomes for consultations occur when both parties receive support to enhance communication.

In contrast, the interventions described by Dodd and Brunker [28], Lennox et al [30], Gibson et al [37-39], and Chinn [41] aimed to facilitate improved two-way communication. Images of symptoms and body parts were used in multiple ways by Dodd and Brunker [28], Lennox et al [30], and Bell and Cameron [35] to promote discussion on such topics. Easy-read resources were also embedded in consultations to enhance patients with mild ID knowledge of certain conditions or procedures, thus improving their ability to provide informed consent [41]. Finally, Gibson et al [37-39] investigated the use of digital questionnaires to produce an easy-read summary of the main symptoms experienced by an individual with ID. Both the patient and the medical professional may then build upon this summary throughout the consultation. Ensuring that all stakeholders share a mutual understanding of the clinical information being discussed is likely to lead to more accurate diagnoses being carried out. As such, the authors agree with Chinn [22] that greater emphasis should be placed on developing and evaluating two-way communication aids.

Nonetheless, one-way communication aids, particularly patient passports, still play a role in environments that are time-critical (eg, accident and emergency) or difficult to navigate (eg, large-scale hospitals, multiple wards) to ensure consistent care is administered [34,35]. However, Hemsley and Balandin [43] recognized that overly long summaries of an individual's needs might result in medical professionals ignoring such information, with the patient having to repeat themselves on multiple occasions. This could, therefore, explain the change in focus toward 1-page patient passports [34-36].

Systemic Change

The bulk of the communication barriers discussed within our review match the findings of Hemsley and Balandin [43]. However, not all may be alleviated by the simple introduction of AAC technologies and require much more systemic changes. Hemsley and Balandin [43] noted that government and health care agencies must do more to reduce the inequalities experienced by patients with complex communication needs. An instance in which this is abundantly clear is Switzerland's failure to implement a national ID strategy, meaning that institutions lack the appropriate guidance and resources to treat patients with ID effectively [36]. Therefore, additional services, systems, and policies [43] must be developed on a national scale to encourage improved person-centered care. Hemsley and Balandin [43] highlighted various aspects that must be considered during this process: (1) increasing the knowledge of health care staff on effective communication strategies, (2) extending the time available to consult with patients with complex communication needs, (3) increasing interagency collaboration to ensure patients are able to take the optimal pathway through complex health systems, (4) clearly defining the role of caregivers, and (5) increasing access to and encouraging the use of AAC devices within consultations. The studies identified in our review also suggested that targeted health checks [27,29] and the employment of specialized

professionals to support frontline staff, such as ID nurses, could have serious benefits for the well-being of the ID population. Introducing statutory regulations should also help ensure that interventions are used within the practice—a problem identified by some of the reviewed studies [27,35].

Finally, the health inequalities experienced by patients with milder ID may be exacerbated because of the *hidden* nature of their disability [27]. Their symptoms were not as prominent as those of moderate or severe ID, indicating that their diagnosis could be delayed or missed entirely. As such, medical professionals may continue to employ inappropriate consultation techniques because of their ignorance of their patients' additional needs. Consequently, practices should employ ID registers [57] to ensure that medical professionals are aware of their need to conduct reasonable adjustments. In addition, greater emphasis must be placed on strategies to identify people with mild ID.

Study Limitations and Recommendations for Future Work

Our review is the first to explore the types of AAC technologies available to patients with mild ID during clinical consultations. Despite the abundance of evidence detailing the health inequalities experienced by patients with ID, we highlight the limited extent of research being carried out in this area. Further investigations into the potential of two-way communication aids in increasing the health advocacy skills of this population must be conducted to emphasize the use of high-tech aids, as they can be adapted to the working routines of medical professionals. Quantitative measures must also be employed to determine clinical advantages. Nevertheless, this study is a scoping review, not a systematic review, and therefore has some limitations. First, the searches were restricted to 3 primary databases, meaning that relevant literature may have been omitted. Second, only articles published in English were considered, which may explain why the identified studies were carried out by members of the OECD. There is also scope to explore the use of AAC devices to improve the health of other populations, such as those with more severe ID [58] or children [59-61].

Conclusions

Communication aids have the potential to provide immediate health benefits to people with ID in the absence of wholesale changes being carried out in organizational procedures, such as undergraduate training. Therefore, this review summarizes the use of low- and high-tech communication aids by adults with mild ID in the context of primary and secondary care. The advantages of the aids used included assisting medical professionals in making reasonable adjustments to their consultation methods by providing them with personal information on the patient, increasing two-way communication, and enhancing practitioners' awareness of the health trends experienced by people with ID. Nevertheless, there were some deficiencies in the methods used by the identified studies that limited the impact and generalizability of the conclusions. Areas that require further consideration include using quantitative methods during RCTs to determine the true benefits of the aids in a clinical context and additional investigations regarding high-tech two-way communication aids.

Authors' Contributions

RCG was the principal author of this study. He developed and carried out a database search strategy to identify relevant articles for review. In conjunction with MMB, RCG also developed the data-charting form and independently applied this form to the collected studies. Finally, RCG created the initial thematic framework used in the analysis and applied the updated framework to all relevant studies. MMB reviewed potentially relevant articles based on the inclusion criteria. As stated, he also jointly developed the data-charting form and applied it independently. MMB also reviewed the initial thematic framework applied to a subset of the collected articles and confirmed the addition of new codes to the remaining articles. MDD settled disagreements between the other authors during the initial search and data-charting stages. He also reviewed the initial thematic framework applied to a subset of the collected articles and confirmed the addition of new codes to the remaining articles.

Conflicts of Interest

None declared.

Multimedia Appendix 1
In-depth overview of identified studies.
[DOCX File , 48 KB - rehab_v8i2e19925_app1.docx]

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Abbreviations

AAC: alternative and augmentative communication
CHAP: Comprehensive Health Assessment Program
GP: general practitioner
ID: intellectual disability
OECD: Organization for Economic Cooperation and Development
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCT: randomized controlled trial

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Video Telehealth Occupational Therapy Services for Older Veterans: National Survey Study

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Abstract

Background: Occupational therapy (OT) is a vital service that supports older adults' ability to age in place. Given the barriers to accessing care, video telehealth is a means of providing OT. Even within Veterans Health Administration (VHA), a pioneer in telehealth, video telehealth by OT practitioners to serve older adults is not well understood.

Objective: This study examines VHA OT practice using video telehealth with older veterans using an implementation framework.

Methods: A web-based national survey of VHA OT practitioners conducted between September and October 2019 contained a mix of mostly closed questions with some open-text options. The questions were developed using the Promoting Action on Research Implementation in Health Services model with input from subject matter experts. The questions gathered the extent to which VHA OT practitioners use video telehealth with older veterans; are comfortable with video telehealth to deliver specific OT services; and, for those using video telehealth with older veterans, the barriers, facilitators of change, and perceived benefits of video telehealth.

Results: Of approximately 1455 eligible VHA OT practitioners, 305 participated (21.0% response rate). Most were female (196/259, 75.7%) occupational therapists (281/305, 92.1%) with a master's degree (147/259, 56.8%) and 10 years or fewer (165/305, 54.1%) of VHA OT practice. Less than half (125/305, 41.0%) had used video telehealth with older veterans, and users and nonusers of video telehealth were demographically similar. When asked to rate perceived comfort with video telehealth to deliver OT services, participants using video telehealth expressed greater comfort than nonusers, which was significant for 9 of the 13 interventions: activities of daily living ($P<.001$), instrumental activities of daily living ($P=.004$), home safety ($P<.001$), home exercise or therapeutic exercise ($P<.001$), veteran or caregiver education ($P<.001$), durable medical equipment ($P<.001$), assistive technology ($P<.001$), education and work ($P=.04$), and wheelchair clinic or seating and positioning ($P<.001$). More than half (74/125, 59.2%) of those using video telehealth reported at least one barrier, with the most frequently endorsed being *Inadequate space, physical locations and related equipment*. Most (92/125, 73.6%) respondents using video telehealth reported at least one facilitator, with the most frequently endorsed facilitators reflecting respondent attitudes, including the belief that video telehealth would improve veteran access to care (77/92, 84%) and willingness to try innovative approaches (76/92, 83%).

Conclusions: Most VHA OT survey respondents had not used video telehealth with older veterans. Users and nonusers were demographically similar. Differences in the percentages of respondents feeling comfortable with video telehealth for specific OT interventions suggest that some OT services may be more amenable to video telehealth. This, coupled with the primacy of

respondent beliefs versus organizational factors as facilitators, underscores the need to gather clinicians' attitudes to understand how they are driving the implementation of video telehealth.

KEYWORDS

occupational therapy; telemedicine; health services; older adults

Introduction

Background

Veterans Health Administration (VHA), the largest integrated health care system in the United States, has been using telehealth since the 1990s to provide care to a broadly dispersed veteran population. VHA provides care to veterans who served in military, naval, or air services. Approximately 60% of US veterans are enrolled in VHA care, including more than 90% of those who incurred a service-related disability. The median age of veterans is 65 years, including a large portion of rural veterans [1-4]. To ensure access to care by veterans regardless of where they live, VHA has undergone a major expansion of telehealth services, including video telehealth, a live, synchronous encounter in which patients and providers are in 2 different locations, as part of the Veterans Affairs (VA) Maintaining Internal Systems and Strengthening Integrated Outside Networks (MISSION) Act, which expands video telehealth into veterans' homes or another location of choice [5,6]. This represents a dramatic shift from most VHA video telehealth services, which were conducted between 2 clinic locations (eg, large medical centers to community-based clinics). Through strategies including issuing tablets to high-need veterans [7] and developing a dedicated VA videoconferencing app that was compliant with the Health Insurance Portability and Accountability Act and other privacy protections, use of video telehealth increased by 235% in fiscal year 2019, with more than 99,000 veterans using the app from home. More than two-thirds of this increase was for telemental health [8], which has represented the majority of VHA telehealth use since its inception.

Video telehealth for specialty care such as occupational therapy (OT) has historically been underdeveloped; of an estimated 1.5 million total VHA OT encounters in fiscal year 2018, less than 1% were delivered using telehealth [9]. This is despite the integration of telehealth into OT practice being identified as a professional goal [10-12]. Constraining integration is a lack of evidence for OT video telehealth, particularly for older adults. OT plays a key role in supporting older adults' participation in activities of daily living (ADL) such as bathing and dressing [13], instrumental activities of daily living (IADL) such as medication management and meal preparation [14], and home modifications to increase safety and prevent injury [15]. Although evidence for telerehabilitation is growing [9,16-20], with video telehealth being used for exercise [21-23], recent reviews of telehealth OT highlight a paucity of evidence [24-26]. Furthermore, there are barriers to using technology for older adults, including low technical literacy [27] and some older adults' preference for telephone [28]. Telephones are inherently limited for OT clinical care because they lack a visual

component [29]. Similar to telephone, asynchronous technologies such as mobile health apps and tablet-based apps, which have also been used with older adults [29-32], do not have a live component, which is critical to responding to clients' needs in the moment. Thus, video telehealth is a complex occupation [33] that involves sophisticated technologies that may be challenging for those with less technical expertise.

Lack of evidence for OT video telehealth has resulted in a gap in knowledge about how best to integrate video telehealth into OT practice in response to the COVID-19 pandemic [9]. Little is known about how such diverse, complex OT interventions will be delivered using video telehealth, specifically to older adults, a population with distinct needs that may make participation in video telehealth more challenging because of decreased hearing, vision, and sensory processing; increased rates of cognitive impairment and reliance on family caregivers; as well as overall lower rates of technology literacy and use. Our own work providing home safety evaluations using video telehealth in dementia care highlighted numerous technological challenges, including inconsistent audio and visual signals [26].

To optimize the integration of video telehealth solutions, various contextual factors must be considered, according to the Promoting Action on Research Implementation in Health Services (PARIHS) framework. PARIHS was developed as an evaluative framework to support the systematic integration of research findings and intervention strategies into clinical care, thereby enhancing the quality and efficacy of health services [34]. Clinical experiences and preferences are central to successful implementation, and lack of clinician knowledge and acceptability is a known barrier to telehealth [35]. Limited data on OT perspectives on telehealth highlight either negative attitudes toward or knowledge gaps about telehealth. OT faculty hold less than positive views of telehealth [36], whereas previously surveyed OTs lack awareness of telehealth strategies [37]. No extant study has examined OT practitioners' perspectives on the use of video telehealth with older adults.

Objectives

Given this knowledge gap, this study sought to gather OT practitioners' experiences with and perspectives on video telehealth to serve older adults. Specifically, we sought to ascertain the extent to which VHA OT practitioners use video telehealth to serve older veterans; VHA OT practitioners' comfort with video telehealth to deliver specific OT services; and, for those using video telehealth with older veterans, perceived barriers, facilitators of change, and benefits of video telehealth. The aim of this study is to identify barriers and facilitators related to the successful implementation of video telehealth to ensure equitable distribution of this service to older adults.

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Methods

Participants

To gather data, a survey was conducted with a volunteer sample of OT practitioners enrolled in VHA's national internal OT email listserv groups from a network of 1243 health care facilities, including 170 VA medical centers and 1063 outpatient sites. Inclusion criteria were being either an occupational therapist or OT assistant and treating older veterans, who were defined as those aged 65 years or older. No other exclusion criteria were included. The survey flow and inclusion criteria are shown in Figure 1.

Figure 1. Survey flow diagram. OT: occupational therapy.
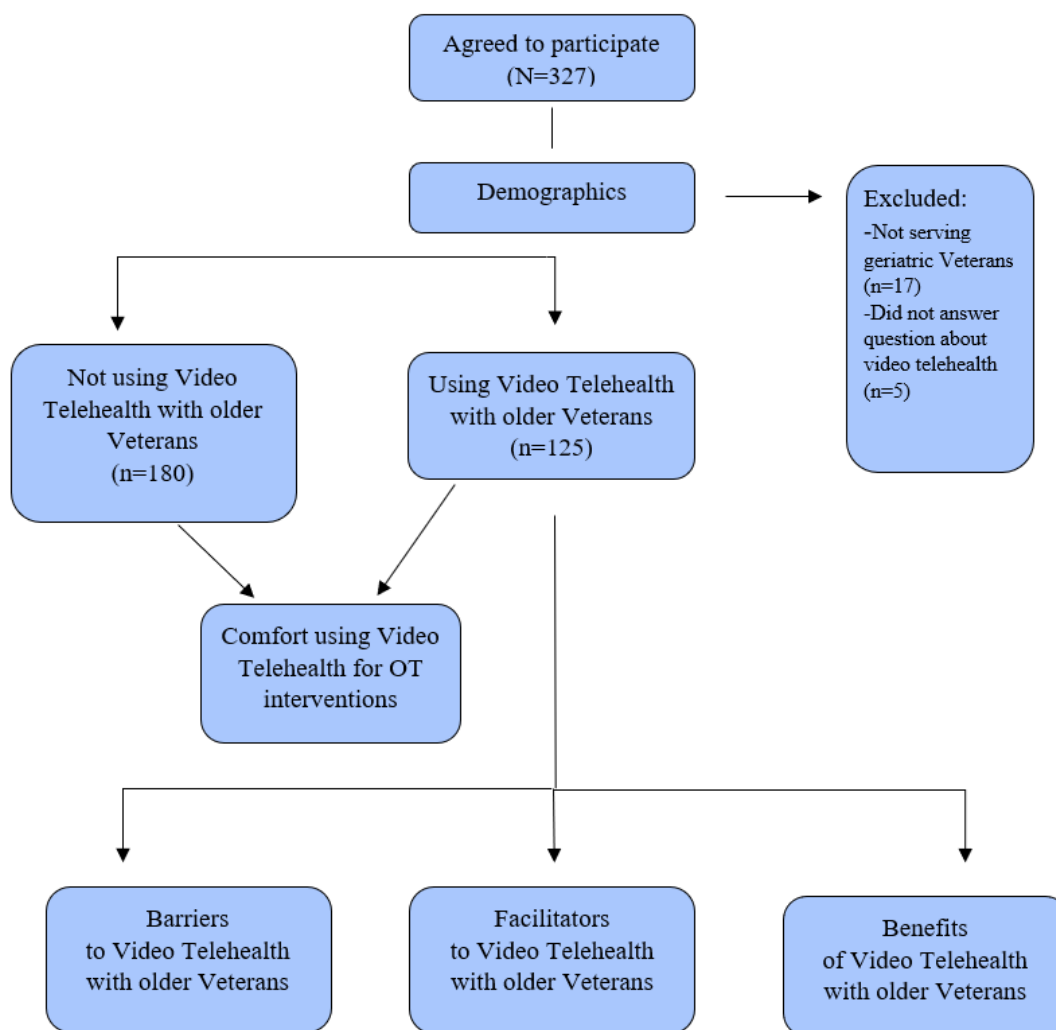
Survey Development

Here, we present survey details in accordance with the Checklist for Reporting Results of Internet E-Surveys checklist [38]. Survey items were developed and informed in accordance with the PARIHS framework domains to gather clinicians' experiences and perceptions of video telehealth to serve older veterans. Specifically, we used a guide developed to operationalize PARIHS concepts [39] as well as our own practice experience with video telehealth and input from VHA stakeholders to develop items that capture contextual factors from the clinicians' perspective. Items were designed to gather clinicians' experiences with and perceptions about video telehealth; clinicians' impressions of veteran experiences, needs, and preferences for video telehealth, to the extent that OT respondents could speak on their behalf; and the characteristics of the local practice, to identify perceived barriers, facilitators, and benefits of video telehealth to serve older veterans.

Items were reviewed for face and content validity by 5 subject matter experts in OT, telehealth, and geriatrics care and revised based on feedback. Before the survey launch, 5 VHA OTs (separate from above) pretested the survey, which involved completing the survey draft via the REDCap (Research Electronic Data Capture) link, followed by cognitive interviews conducted by the first author using predetermined verbal probes [40]. Probes addressed general feedback on survey items and time to administer the survey, which averaged 15 minutes. The survey items were further refined based on the pretesting findings.

The final survey included 17 survey items (Multimedia Appendix 1). Participants were asked if they used or did not use video telehealth with older veterans. Video telehealth was defined as live, synchronous care in which veterans and providers are in 2 locations, connected using Skype-like videoconferencing. Respondents also completed 7 practitioner demographic items, including primary VA medical center and role (eg, occupational therapist or OT assistant). One item addressed respondent comfort with using video telehealth to deliver specific OT interventions. This question included the statement, "We would like to know your level of comfort (that is, the amount of doubt or feelings of stress you feel) about use of video telehealth to deliver OT services at VHA," and included a list of 13 OT interventions. Interventions included ADL (eg, bathing, dressing, and functional mobility), IADL (eg, meal preparation, financial management, and medication management), and home safety. A complete list of interventions is given in Multimedia Appendix 1. Respondents rated their comfort using video telehealth for each intervention on a 4-point Likert scale, ranging from *not comfortable* to *very comfortable*. An option of *not sure* was provided. We collapsed the 4-point comfort scale into 2 categories—*comfortable* and *not comfortable*—as there were insufficient data to retain the 4 categories. The *not sure* option was excluded, as it was found to be uninterpretable. The comfort item, which was not required, was provided to all respondents whether they used video telehealth or not. Six additional checklist items were completed only by those using video telehealth and addressed the perceived barriers (2 items), facilitators (2 items), and benefits (2 items). A complete list of barriers, facilitators, and benefits is given in Multimedia Appendix 1. Barriers, facilitators, and benefits questions each included options for *other* and *none* and an open-text option whereby respondents could write in additional entries via short open-ended responses. For all checklist items, respondents could select more than one option. Respondents were able to review their answers using the back button. Responses were anonymous; however, as each participant was not sent an individualized survey link, respondents could potentially complete the survey more than once.

Survey Administration

The survey was conducted in September and October 2019. Practitioners were invited to participate by emailing a survey link to the VHA OT provider listserv and posting on the VHA's web-based forum for OTs. An anonymous URL link only available on the VA intranet was used. Survey respondents had to be logged into an active VA network account to respond to the survey. The survey was kept open for 4 weeks, with 3 reminder emails and forum posts sent before the survey closed. The email invitation and survey overview specified that participation was voluntary, anonymous, and confidential and that those who agreed to participate agreed to these conditions. Survey data were collected and managed using the REDCap electronic data capture tools hosted at VHA. REDCap is a secure web-based app designed to support data capture for research studies [41]. Survey administration was deemed quality improvement, as it was conducted for VHA organizational purposes. Subsequent analysis of survey data for research

purposes was approved by the VA Bedford Health Care System Institutional Review Board.

Data Analysis

Survey data were exported from REDCap into Excel (Microsoft Corporation) and imported into R for analysis. To statistically examine baseline differences in demographics and differences between perceived comfort for those using video telehealth or not, chi-square or Fisher exact tests (when cell counts were <5) were used for categorical variables and two-tailed t tests were used for continuous variables. Statistical significance was set at $P<.05$. For the purposes of analysis, the categorical item, VHA years of practice, was divided into 2 segments of nearly equal size: 10 years or less and 11 years or more. *Prefer not to answer* responses were excluded from analysis, as this option lacked specificity recommended for demographics questions [42]. Rurality geocoding developed by VHA's Office of Rural Health to estimate the percentage rurality of the catchment area was applied to respondents' primary medical center.

Short open-ended responses to barriers, facilitators, and benefits items were analyzed using conventional content analysis [43]. Two clinician researchers with experience in telehealth and qualitative analysis (MEG and LRM) repeatedly read entries to determine whether open-ended responses differed from checklist item options and to identify keywords and phrases. These were used to elucidate the given categorical entries and to develop categories for any additional barriers, facilitators, and benefits categories from open-text responses.

Results

Overview

Overall, from approximately 1455 eligible VHA OT practitioners, 305 participated (21.0% response rate). The survey flow is shown in Figure 1. Of the 305 respondents, 244 (80.0%) provided complete survey entries, and all entries were included in the analysis regardless of completion.

Participant Characteristics

Table 1 displays respondents' demographics. Most respondents were female (196/259, 75.7% of responses), had a master's degree (147/259, 56.8% of responses), and were occupational therapists (281/305, 92.1% of responses) with 10 years or fewer (165/305, 54.1% of responses) of VHA OT practice. Respondents were from 107 different VA medical centers, the catchment areas of which served a veteran population, which was, on average, 33% rural. Regarding ethnicity, of 258 responses, 16 (6.2%) identified as Hispanic, 197 (76.4%) identified as Not Hispanic or Latino, and 46 (17.8%) preferred not to answer. Regarding race, of 259 responses, 178 (68.7%) identified as White, 50 (19.3%) preferred not to answer, 20 (7.7%) identified as Black or African American, 13 (5.0%) identified as Asian, and 4 (1.5%) identified as American Indian or Alaska Native or Native Hawaiian or other Pacific Islander. Of note, respondents could select more than one racial category. This sample was similar to VHA OT practitioners in terms of years of practice experience, race, ethnicity, and gender, according to the internal administrative VHA data. (VHA data on education were not available.) The sample was considered

representative of OT practitioners nationally, as demographics closely aligned with the American Occupational Therapy Association demographics of OT practitioners in terms of gender, race, ethnicity, and education (The Coalition of Occupational Therapy Advocates for Diversity) [44,45].

Table 1. Respondents' characteristics by use of video telehealth with older veterans.[a]

Demographic variables	Using video telehealth (n=125)	Not using video telehealth (n=180)
Gender, n (%)		
Male	12 (12.9)	21 (13.2)
Female	70 (75.3)	119 (74.8)
Nonbinary	1 (1.1)	2 (1.3)
Prefer not to answer	10 (10.7)	17 (10.7)
Years of VHA[b] practice, n (%)		
<5	20 (16.0)	55 (30.6)
5-10	40 (32.0)	50 (27.7)
11-20	46 (36.8)	52 (28.9)
21-30	16 (12.8)	19 (10.6)
>30	3 (2.4)	4 (2.2)
Highest education level, n (%)		
Associate's	4 (4.2)	4 (2.6)
Bachelor's	27 (29.0)	47 (29.5)
Master's	50 (53.8)	93 (58.5)
Doctorate	10 (10.8)	11 (6.9)
Prefer not to answer	2 (2.2)	4 (2.5)
Rural veterans served at respondent's primary VAMC[c] (%)		
Mean (SD)	34.2 (23.1)	31.5 (21.7)
Range	0-82	0-95

[a]Not all questions were required. Percentages reflect the proportion of respondents who answered the questions.

[b]VHA: Veteran Health Administration.

[c]VAMC: Veterans Affairs Medical Center.

Utilization of Video Telehealth to Serve Older Veterans

Less than half (125/305, 41.0%) of survey respondents used video telehealth with older veterans. There were no statistically significant differences between respondents using video telehealth and those not using video telehealth according to demographic characteristics. The sample characteristics using video telehealth are shown in Table 1.

Association Between Comfort Using Video Telehealth for Specific OT Interventions and Use of Video Telehealth

Multimedia Appendix 2 displays comfort using video telehealth to deliver specific OT interventions in 2 categories—*comfortable* and *not comfortable*—by using video telehealth. Respondents who used video telehealth were more likely to express comfort using video telehealth, which was true for 9 out of 13 interventions, except for leisure, social participation, rest and sleep, and sensory or cognitive strategies. More respondents were comfortable with the idea of using video telehealth for these 9 interventions than were not comfortable with them. This

was true among both those who had and had not used video telehealth; however, the comfortable versus not comfortable difference was greater for users. Mean comfort ratings with confidence intervals are given in Multimedia Appendix 3.

The 9 interventions showing this statistically significant relationship, with sample sizes for users versus nonusers of video telehealth in parentheses (as this question was not required, respondent totals varied), were ADL (n_{user}=69; $n_{nonuser}$=67), IADL (n_{user}=66; $n_{nonuser}$=101), home safety (n_{user}=78; $n_{nonuser}$=117), home exercise or therapeutic exercise (n_{user}=75; $n_{nonuser}$=118), wheelchair clinic or seating and positioning (n_{user}=53; $n_{nonuser}$=97), durable medical equipment provision or follow-up (n_{user}=80; $n_{nonuser}$=115), veteran and/or caregiver education or training (n_{user}=85; $n_{nonuser}$=114), education and work (n_{user}=55; $n_{nonuser}$=97), and assistive technology provision or follow-up (n_{user}=69; $n_{nonuser}$=101). No significant relationships between comfort and use of video telehealth were found for the interventions of sensory or cognitive strategies (n_{user}=52; $n_{nonuser}$=90), social participation (n_{user}=52;

$n_{nonuser}=101$), leisure ($n_{user}=52$; $n_{nonuser}=103$), and rest and sleep ($n_{user}=51$; $n_{nonuser}=100$).

Barriers for Those Using Video Telehealth

Table 2 displays a list of organizational barriers and their frequency. The total number of barriers selected by respondents ranged from 1 to 4, with an average of 1.76 per respondent. More than half (74/125, 59.2%) of those using video telehealth encountered at least one barrier. Of 146 total barriers (respondents could select more than one), the most frequently selected barrier was *Inadequate space, physical locations and related equipment*, selected by 50% (37/74) of respondents reporting barriers, whereas lack of leadership support was the least frequent, selected by 8% (6/74) of respondents. More than a quarter (19/74, 26%) indicated that they encountered no barriers. Of the 74 respondents, 23 (31%) provided short, open-text *other comments*, which were then categorized as one of the listed barriers or as novel. Most open-text comments expanded on the barriers selected from the list provided. For example, some described challenges related to technology, such as decreased connectivity or veterans' lack of technical ability.

Table 2. Responses from occupational therapists using video telehealth to the questions "What, if any, barriers have you encountered in adding video telehealth to your practice?" and "What has helped you to add video telehealth to your practice?" (n=74).[a]

Question category	Responses, n (%)
Barriers	
Inadequate space, physical locations, and related equipment	37 (50)
Delays in process to set up video telehealth (eg, clinic creation and establishing TSA[b])	35 (47)
Lack of administrative support (eg, assistance with scheduling and setting up clinics)	26 (35)
Other	23 (31)
None	19 (26)
Lack of leadership support	6 (8)
Facilitators	
Belief that video telehealth with improve veterans' access to care	77 (83)
Willingness to try new approaches	76 (82)
Belief that video telehealth will improve veteran care	62 (67)
Leadership support	54 (58)
Administrative support (eg, assistance with scheduling and setting up clinics)	47 (51)
Adequate space, physical locations, and related equipment	40 (43)
Other	2 (2)
None	1 (1)

[a]Items rank ordered by the most frequent barrier or facilitator. Totals may exceed 100%, as respondents could select more than one option. Percentages reflect the number of respondents who selected a given option divided by the number of respondents who answered the question.
[b]TSA: telehealth service agreement.

Facilitators for Those Using Video Telehealth

Reported facilitators, which included both organizational factors and practitioner beliefs, are given in Table 2. The total facilitators selected ranged from 1 to 6 and averaged 3.89 facilitators per respondent, with only 1 respondent selecting *none*. Most (92/125, 73.6%) respondents using video telehealth reported at least one facilitator. The most frequently endorsed facilitators reflected respondent attitudes, including the belief that video telehealth would improve veterans' access to care (reported by 77/92, 84% reporting facilitators) and willingness to try innovative approaches (reported by 76/92, 83%). Organizational facilitators, such as leadership support, were reported to a lesser degree. *Adequate space, physical locations and related equipment* was the least selected facilitator, which is in concordance with inadequate space being the top barrier. *Other* and *none* were rarely reported.

Benefits for Those Using Video Telehealth

Table 3 shows the reported benefits. Most (92/125, 73.6%) of those using video telehealth reported at least one benefit, with total benefits ranging from 1 to 6 and averaging 3.35 per respondent. No respondent selected *none*. Top-ranked benefits related to access, with 94% (87/92) of respondents reporting benefits of remediating veteran distance from the medical center or difficulty getting to the medical center. The impact of video telehealth on efficiency, as indicated by the ability to serve more veterans or to see veterans more often, was reported to a lesser degree (39/92, 42%, and 29/92, 32%, respectively). Short open-ended entries primarily elaborated access benefits, with respondents indicating increased opportunities through video telehealth, such as wheeled mobility specialists, to collaborate with other team members.

Table 3. Response to the question "As a practitioner, what benefits do you experience from using video telehealth with Veterans?"[a]

Benefit	Responses, n (%)
I can see veterans who live a distance from VA[b]	87 (94)
I can see veterans who have difficulty coming to VA	87 (94)
I get a view into veterans' homes	63 (68)
I can see more veterans	39 (42)
I can see veterans more often	29 (32)
Other	7 (8)
None	0 (0)

[a]Item rank is ordered by most frequent benefit. Totals may exceed 100%, as respondents could select more than one benefit. Percentages reflect the number of respondents who selected a given benefit divided by the number of respondents who answered the question.

[b]VA: Veterans Affairs.

Discussion

Principal Findings

Most VHA OTs who responded to the survey had not used video telehealth with older veterans, with those using video telehealth demographically similar to those not using video telehealth. Differences in comfort with video telehealth for specific OT interventions suggest that some OT services may be more amenable to video telehealth. This, coupled with our finding that respondent beliefs were more pronounced than organizational factors as facilitators, suggests the importance of clinicians' attitudes in the implementation of video telehealth.

This is the first study to provide insights into the state of OT video telehealth with older adults, a population of heightened interest because of changing demographics and their increased risk of complications and infections related to COVID-19 [46]. Before COVID-19, older adults were an underserved group for telehealth, as Medicare has until recently [47] been most restrictive regarding telehealth reimbursement [48]. COVID-19 prevention protocols, which prohibited older adults from accessing routine and preventive care in the community, sparked a push to provide home video telehealth services to older adults. This survey was conducted in September and October 2019, approximately 5 months before the shift to virtual care in response to the global pandemic. Thus, the perspectives of early adopters of video telehealth, that is, those who integrated video telehealth into their practice before the urgent need to do so because of COVID-19, presents an unbiased perspective on the use of video telehealth [29]. One of our contributions is to provide evidence relevant to building capacity to support a more robust and rapid uptake of video telehealth by OT practitioners. As such, we offer considerations for OT delivery of video telehealth for older adults.

Considerations for OT Practitioners

Although most respondents were not, at the time of the survey, using video telehealth with older adults, users and nonusers were demographically similar. Given that the highest rated facilitators to and benefits of video telehealth by users included clinicians' attitudes toward video telehealth, such as the belief that video telehealth would increase access to care, emphasis on perceived benefits could help encourage OT practitioners

hesitant to try video telehealth. However, we did not ask those using video telehealth about attitudinal barriers, such as perceived harm or negative impact of video telehealth in terms of decreased privacy or limitations of what can be clinically done in video telehealth. Thus, it is difficult to draw further conclusions about clinicians' attitudes toward video telehealth from these data.

Regarding respondent comfort using video telehealth for specific areas of OT practice, differences between users and nonusers indicate that using video telehealth may enhance comfort with video telehealth. However, the causal relationship between respondent comfort and use of video telehealth is not clear, that is, Does the use of video telehealth enhance comfort or do those who are more comfortable with the technology opt to use video telehealth? This relationship should be examined in future studies.

Interventions receiving higher ratings of *not comfortable* with video telehealth suggest potential practitioner knowledge gaps about certain areas of OT practice, incongruity between practice and application in video telehealth, and potential limitations of video telehealth. Respondents were less comfortable with the use of video telehealth for sensory or cognitive strategies. This warrants further study, as it is not clear (as specific intervention examples were not provided) what sensory or cognitive strategies respondents were thinking about when they answered this question. Rest and sleep was another practice area that had higher uncomfortable ratings. As a newer area of OT practice [49], there is a dearth of evidence in this area; therefore, clinicians may be less aware of this intervention in general.

In addition, lower comfort for leisure and social participation is noteworthy, given the strongly established role of OT in these areas [14]. Several interventions telehealth users indicated they were comfortable using video telehealth for involved potentially billable or chargeable items, such as provision of durable medical equipment like wheelchairs or walkers. Given this, the potential influence of cost and reimbursement on choice of intervention also warrants further study. Although OT's emphasis on participation and function is increasingly recognized as important in the prevention and management of chronic conditions, it is not always supported by payment systems that prioritize symptom-based medical treatment [50].

The findings suggesting that certain OT interventions may be more amenable to a video telehealth platform than others warrant further investigation as to clinician decision making around video telehealth. Both those using video telehealth and those not yet using it felt comfortable with the idea of using video telehealth to provide veteran or caregiver education and training. This may reflect either increased comfort with the use of video telehealth to support interventions relying primarily on verbal engagement or the ubiquity of educational strategies to accompany OT interventions. Relatedly, high percentages of feeling comfortable in using video telehealth for home safety is an interesting finding, given that video telehealth home safety evaluations are complex and may require a caregiver or the patient to ambulate through the home while carrying a portable computing device [5]. Similarly, interventions some respondents were less comfortable using video telehealth for, such as assisting with ADL, may require veterans to move throughout the home (eg, transfer in and out of the bathtub and standing at a kitchen counter), which raises safety concerns. Thus, it is important to gather the perceived drawbacks of video telehealth, including poor audio or video quality, lack of comfort with technology, and safety or privacy concerns.

Considerations for Older Adults

Given that older adults may have less confidence in operating technology and more mobility limitations, OT interventions delivered through video telehealth, particularly more dynamic interventions such as home safety evaluations, should be optimized to meet older adults' needs. Identifying strategies to train and prepare veterans to participate in OT-delivered video telehealth (eg, how to take measurements during a home safety evaluation or how to position the camera to allow for a full-body view when observing functional mobility) may facilitate the implementation of video telehealth. In addition, certain populations may have complex care needs, which hamper their ability to participate in video telehealth. Caregiver assistance, particularly for adults who have cognitive impairment or are at risk of falls, may also be needed. Promoting eHealth literacy and co-designing interventions to match technology with older users' needs will optimize telehealth delivery [51,52].

Perceived benefits, which primarily focused on increased access, corroborate VHA's organizational mission to use video telehealth to increase access to care. Access was partly related to travel distance; however, open-ended responses suggested that access was more broadly conceptualized to include the ability for more timely care and for more care coordination. For example, practitioners noted that video telehealth allowed them to involve different members of the care team. Older adults often manage multiple chronic conditions that require ongoing intervention by several clinicians. Therefore, video telehealth may increase opportunities for interdisciplinary collaboration to address care needs. This may be even more relevant at times such as during the global pandemic when video telehealth is virtually the only option for face-to-face care. Similarly, these findings raise factors relevant to health care systems that aim to integrate video telehealth OT services.

Considerations for Health Care Systems

Given the dynamic nature of many OT interventions, an important organizational consideration is the inclusion of technical support for both OTs and older adults. Technical support as an organizational component of video telehealth may be more critical for OT than other, more stationary video telehealth encounters. Mental health video telehealth, for example, consists of mostly verbal exchange, whereas OT interventions may involve veterans working on a cooking task in the kitchen or transferring in and out of the bathtub. This raises potential problems around bandwidth and lost visual or audio that may require the involvement of technical support, in addition to the aforementioned safety concerns.

Barriers and facilitators reveal additional organizational considerations in the delivery of OT services using video telehealth, beyond the aforementioned need for technical support. Lack of physical space (the most frequent barrier and least reported facilitator) may reflect the fact that OTs are often treating in shared spaces such as rehabilitation gyms, unlike mental health clinicians who usually have private offices. This highlights the need to consider infrastructure and privacy in the implementation of video telehealth for OT services; however, allowing practitioners to deliver video telehealth from home would lessen space demands. This study also has implications for clinician education and training to ensure that interprofessional trainees are prepared to offer telehealth to older adults [53,54]. Of note, VHA conducts the largest medical education training program in the United States [55], providing an opportunity to train the next generation of clinicians in telehealth delivery.

Limitations

This study had several limitations. Regarding survey design, we did not ask practitioners using video telehealth to reflect on barriers such as potential harm, safety risks, disruptions related to video telehealth, increasing workload, or necessary time and training to familiarize themselves with technology, which limits the scope of our findings. As we cannot demonstrate causality between comfort and use of video telehealth, more in-depth surveys or qualitative interviews with OTs may elucidate perceived primary causal issues for comfort as well as perceived barriers and facilitators. The lack of description for certain OT interventions listed in the survey (eg, sensory or cognitive strategies) results in difficulty interpreting some comfort ratings. Nonrespondent bias may also constrain generalizability, as practitioners may have felt pressured to participate or those with a strong interest may have been more likely to participate in the survey. We did not collect data on age, and although years of practice is informative, it is not a proxy for age. Finally, we did not ask whether video telehealth was conducted into the home or between major medical centers and satellite clinics, thereby limiting what conclusions can be drawn regarding video to home, a main telehealth strategy in the post-COVID-19 landscape.

Implications for Practice

On the basis of our findings, the following are some key implications for implementation of video telehealth in delivering

OT services to older adults. Implications reflect the myriad contextual factors vital to ensuring that video telehealth meets the needs of both OT clinicians and patients:

1. Perspectives of early OT adopters of video telehealth, including perceived facilitators, may inform those not yet using video telehealth.
2. The benefit of video telehealth in increasing access to care may encourage increased use of video.
3. Gathering practitioner decision making around the use of video telehealth for specific OT interventions will optimize delivery to clients who face access barriers, increasing the reach of extant providers while potentially saving resources such as clinic space.
4. OT practitioners may have unique infrastructure needs, including dedicated private spaces and need for technical support, in the provision of services using video telehealth.

Conclusions

Video telehealth with older adults as a service delivery model is rapidly expanding, with VHA at the forefront. Early adoption of video telehealth by VHA OT practitioners appears to be driven, in some measure, by clinician experiences and attitudes; however, institutional barriers remain. As the pandemic offered a model of veterans and some clinicians participating in video telehealth from their own homes, institutional barriers such as limited space may be less of a concern in the post-COVID era. Expansion of video telehealth to deliver services to older adults will involve identifying ways to maximize the video telehealth platform through adaptation and tailoring of interventions to provide client-centered care. There is a need for more evidence on video telehealth OT strategies for older adults, which COVID-19 and resulting OT rapid practice change may expedite.

Acknowledgments

Conflicts of Interest

None declared.

Multimedia Appendix 1
Survey questions.
[DOCX File , 20 KB - rehab_v8i2e24299_app1.docx]

Multimedia Appendix 2
Comfort with video telehealth for occupational therapy services for video users and nonusers.
[PNG File , 47 KB - rehab_v8i2e24299_app2.png]

Multimedia Appendix 3
Comfort ratings by use of video telehealth.
[DOCX File , 23 KB - rehab_v8i2e24299_app3.docx]

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Abbreviations

ADL: activities of daily living
IADL: instrumental activities of daily living
MISSION: Maintaining Internal Systems and Strengthening Integrated Outside Networks
OT: occupational therapy
PARIHS: Promoting Action on Research Implementation in Health Services
REDCap: Research Electronic Data Capture
VA: Veterans Affairs
VHA: Veterans Health Administration

Exergaming as a Functional Test Battery in Patients Who Received Arthroscopic Ankle Arthrodesis: Cross-sectional Pilot Study

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Abstract

Background: Recently, movement-based videogames (exergames) have gained popularity in improving the rehabilitation process after surgery. During exergaming, participants are physically challenged as the game component stimulates adherence to the training program. There is no literature on the effect of exergame training interventions in patients who received arthroscopic ankle arthrodesis.

Objective: This pilot study assessed the potency of an existing exergaming tool for the rehabilitation program of patients who received arthroscopic ankle arthrodesis.

Methods: A cross-sectional pilot study was performed, in which patients who received arthroscopic ankle arthrodesis (n=8) were subjected to an exergaming protocol. Gait analysis was performed with a treadmill system. A healthy age-matched control group (n=10) was used as the control group.

Results: The patient group was capable of performing exergaming exercises and they showed no floor or ceiling effect. Only in case of the overall stability, the patient group performed significantly less better than the control group (P=.03). Gait analysis showed equal step length with increased external rotation of the affected limb.

Conclusions: Exergaming seems to be a valuable tool for measuring the ability of patients who received AAA to perform activities of daily living and it has the potential to individualize rehabilitation programs. When exergaming is systematically integrated with patient-reported outcome measures and activity tracking, it has the potential to improve the quality of care.

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KEYWORDS

arthroscopic ankle arthrodesis; exergaming; functional test battery; exergames; serious games; ankle; function; game; exercise; physical activity; rehabilitation; gait; quality of care

Introduction

The use of technology-driven physical activities such as videogames that require participants to be physically active or exercise in order to play the game, also known as exergames, has been proposed as a valuable treatment option to encourage participation in rehabilitation programs and to improve adherence to therapy programs [1]. The challenging element of the game and the accessibility to practice at home will improve the frequency of the exercise, thereby improving the quality and speed of rehabilitation. Further, exergaming might enable patients to participate actively in social and sporting activities sooner [2,3]. Besides using exergaming for rehabilitation, it has

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the potential to be used for functional assessments, thereby providing more insight into the progress of the patients.

Measuring the ability to perform activities of daily living is very informative for evaluating the recovery of patients. Currently, the functional outcomes in the treatment of musculoskeletal injuries are often evaluated with patient-reported outcome measures (PROMs). However, discrepancies in subjective and objective measures are known, and therefore, easy-to-obtain objective measures are needed [4]. With the use of wearable activity monitors, it is possible to objectively measure the physical activity of patients in a free-living environment. Activity monitors can differentiate between different physical activity types in daily living (eg, stand, walk, sit) [5]. Although the accessibility of activity monitors is very low despite the broad acceptance of smartwatches, detailed information on specific activities of daily living is needed. A potential in the development in this direction is exergaming. During exergaming, a person plays a videogame to perform exercises. Exergaming is used in multiple fields of medicine. Every medical (sub)specialty has its own possibilities and challenges.

Exergaming consists of 2 words, that is, exercise and gaming, and the influence of both aspects during playing needs to be understood. Since this concept is still relatively new, little is known about how big the influence of the gaming part during exergaming is. While playing a regular videogame, the player learns the features of the game in a playful manner. The first level of every game makes the player familiar with the game and the game levels gradually increase in complexity. This poses a challenge for exergaming in rehabilitation. This study focusses on how to determine the influence of the gaming part on the score and progress of the rehabilitation. People who are more acquainted with videogaming may have an advantage and may receive higher scores.

Ankle osteoarthritis is an invalidating condition, which causes pain, dysfunction, and immobility [6]. Osteoarthritis, in general, is treated with nonsteroid drugs and physical therapy. For end-stage osteoarthritis, operative treatment options are available. In case of osteoarthritis of the ankle, total ankle replacement or ankle arthrodesis (AA) are the 2 main surgical solutions. Nowadays, AA is the most practiced treatment for osteoarthritis of the ankle, although there is no consensus in the literature about which treatment is superior [7]. These options mostly lead to significant pain reduction, but they do not offer normal ankle function, thereby leading to long rehabilitation periods to regain the ability to perform activities of daily living. We hypothesized that exergaming could be of additional value for the follow-up of our patients in the near future. This pilot study was a stepwise approach to design a test protocol with an exergaming device for the rehabilitation of patients who received arthroscopic AA (AAA). For extrapolation purposes, we performed a gait analysis with a treadmill system.

Methods

Ethical Approval for This Study

This cross-sectional pilot study was performed at the Zuyderland Medical Center, Department of Orthopedic Surgery and Traumatology. This study was approved by the Clinical Research Ethics Committee (protocol 2016/43). Oral and written consent were obtained from all the participants. All patients who received AAA between January 2013 and December 2018 (n=28) at the Zuyderland Medical Center were recruited for study inclusion. Patients were excluded in case of comorbidities with major influence on activities of daily living or when they did not understand the informed consent.

Participants in This Study

At a median follow-up of 2.5 (IQR 1-5) years after AAA, 35% (8/23) of the patients were able and willing to participate in this study. Causes of ankle arthritis in this study population were posttraumatic arthritis (7/8, 88%) and rheumatoid arthritis (1/8, 13%). The distribution of the affected side was equal (left ankle, 4/8, 50%). A healthy age-matched control group (n=10) was formed, consisting of healthy volunteers, 4 of whom were women (Table 1).

Table 1. Characteristics of the patient group and control group.

Characteristics	Patient group (n=8)	Age-matched control group (n=10)	P value
Age at participation (years), median (IQR)	66 (55-73)	58 (46-77)	.005[a]
Sex (male), n (%)	6 (75)	6 (60)	.25
Body mass index (kg/m^2), median (IQR)	28 (27-38)	26 (21-30)	.002[a]

[a]P values were calculated by Mann-Whitney U test; values were significant at P<.05.

Other reasons for not participating in this study were other comorbidities (eg, cerebral vascular accident, heart disease, pulmonary disease), not interested, or not answering the invitation. The test protocol was discussed and designed by subject matter experts (PP, TvdA, and RH). Before the designed protocol was used, it was first tested with a reference group of young healthy men (n=6) recruited from the Department of Orthopedic Surgery and Traumatology. The characteristics and results of this group are described in Multimedia Appendix 1.

Exergaming Device

The Riablo system (CoRehab s.r.l) includes a laptop with custom Linux SO and Riablo software, 3 inertial Bluetooth sensors (cortex M3 @ 72 MHz, 3D accelerometer [SD 16g], 3D gyroscope [SD 2000 dps], 3D magnetometer [f.s. up to 1 KHz]), Bluetooth pressure board [320 pressure sensors]), and a kit of elastic bands for positioning the sensors (Figure 1). Scores in the report were produced by the Riablo software, which included precision (ability to reach the target angle at the right moment), accuracy (ability not to compensate), and stability (ability to keep balance). The inertial measurement has the necessary

accuracy to be safely utilized in rehabilitation programs after orthopedic treatments of the lower limb [8]. This system was used to assess the participant's functionality. A personal platform was created by entering the details of length, weight, and dominant/injured leg of each patient into the system. This system has a preset library of exercises from which to choose to create work programs suitable for each patient or group of patients. Every exercise needs to be specified with the frequency, intensity, time, and type parameters [9]. As the tool was originally intended as an exergaming tool for sports injuries, a specific protocol had to be developed for exercises that could be done by patients who received ankle arthrodesis during the full period of recovery and that had sufficient discriminative power to give insight into the level of functionality. Exercises that were deemed suitable were weight-mono-lateral transfer, squat, stand and sit, start walking, lunge, reverse lunge, and lateral lunge. Measurements took place in an examination room with a television screen connected to the system. Patients were connected to the system with 3 Bluetooth inertial sensors: one

in the middle of the chest and the other two in the middle of the upper leg and middle of the lower leg. Calibration was performed to check the placement and position of the sensors [8]. Before all exercises, a short introduction movie was showed by the system to instruct the patient. Then, the examiner practiced the movement once with the participants. During each exercise, the system gave live feedback to the participant with visual instructions known in games. All patients were granted 2 attempts to perform the exercise correctly; otherwise it was noted as a failure. The best score of each exercise was used. The system produced a report with scores from 0% to 100%, in which a score of 0% was considered to be the lowest score and 100% as the highest score. The quality was registered with indexes that show how each exercise was performed from a quality perspective. The score was built from 3 aspects by assessing the patient for precision (ability to reach the right target at the right time), patient stability during exercise (ability to maintain balance and limit the thorax sways), and accuracy (ability to avoid compensations).

Figure 1. Setup of the Riablo CoRehab system.

Zebris FDM-T

The Zebris FDM-T (Figure 2) includes a laptop with Zebris FDM software Suite, treadmill Zebris-FDM Maxxus, and high-speed SYNCLight Cam (100 Hz, pressure plate FDM 1.5 [158×60.5×2.1 cm], sensor area [149×54.2 cm], 11.264 sensors, sampling rate: 100 Hz, optional 200 Hz/300 Hz, measuring range, 1-20 N/cm). Participants were asked to stand in the middle of the treadmill for 10 seconds to measure the static plantar pressure. Gait analysis was obtained with participants walking barefoot for 1 minute on the treadmill at a pace that was comfortable for a short amount of time. Finally, participants were asked to walk with their shoes on the treadmill for 1 minute at the same pace. In the analysis, the following parameters were examined: step length (cm) and external foot rotation (degrees). This system is validated for measuring the spatiotemporal parameters of gait [10].

Figure 2. Setup of the Zebris FDM-T treadmill.

Statistical Analysis

Nonparametric statistics were used due to the small sample size. Descriptive statistics were calculated by Mann-Whitney U test (continuous variables) to compare the medians between the different groups and Fisher exact test (binary variables) to compare the medians (range). The number of participants were undersized for each group; therefore, the Kolmogorov-Smirnov test was used to compare the results of the CoRehab and Zebris between both groups. The Kolmogorov-Smirnov test was used to compare the medians of different categories between the groups. In this study, the median would produce more representative results instead of the mean. The statistical significance level was comparable or smaller than .05. The data were analyzed using SPSS (version 25.0, IBM Corporation).

Results

No significant differences were observed between the physical functioning of the patient group and the control group (Table 2). The AAA group had a median overall score of 51% (IQR 45%-69%), which was measured with the exergaming system, whereas the control group had a median overall score of 60% (IQR 28%-79%). In the AAA group, the best performed exercise was the reverse lunge with a median score of 78% (IQR 60%-89%) and the worst performed exercise was the squat with a median score of 11% (IQR 0%-42%). The best performed exercises in the control group were the start to walk (median 79% [IQR 43%-90%]) and the lateral lunge (median 79% [38%-91%]) and the worst performed exercise was the squat (median 12% [IQR 0%-73%]).

Table 2. Results of the exercise protocol per group.

Exercises	Patient group score (%), median (IQR)	Age-matched control group score (%), median (IQR)	*P* value
Weight-mono-lateral transfer	50 (0-59)	67 (11-86)	.07
Squat	11 (0-42)	12 (0-73)	.32
Stand and sit	62 (28-77)	68 (23-91)	.49
Start walking	75 (43-90)	79 (43-90)	.52
Lunge	65 (45-79)	52 (4-85)	.20
Reverse lunge	78 (60-89)	74 (8-91)	.21
Lateral lunge	69 (38-91)	79 (28-93)	.61
Overall score	51 (45-69)	60 (28-79)	.32
Average precision	58 (49-75)	65 (35-84)	.34
Average accuracy	87 (67-93)	89 (84-95)	.17
Average stability	73 (59-79)	80 (68-90)	.03[a]

[a]*P* values were calculated by Mann-Whitney *U* test, and they were significant at *P*<.05.

Gait analysis showed more external rotation on the operated site compared to the nonoperated site. The results of the gait analyses are shown in Table 3. The software determines foot rotation as the angle formed by the midline of the foot and the midline of the treadmill. A skewed gait resulting in erroneous values was assessed with camera views and consequently disregarded for further evaluation.

Table 3. Descriptive results of the gait analysis per group for step length and rotation.

Gait analysis	Patient group[a] (n=7)		Age-matched control group[b] (n=7)	
	Operated ankle	Nonoperated ankle	Right ankle	Left ankle
Step length (cm), median (IQR)	50.0 (33 to 64)	49.0 (33 to 64)	46 (38 to 47)	44 (39 to 47)
Rotation (degrees), median (IQR)	9.3 (–2.6 to 13.9)	3.2 (0.9 to 7.6)	13.9 (9.10 to 22.5)	10.1 (1.9 to 21.8)

[a]Incorrect measurements were obtained from 1 participant in this group.

[b]Incorrect measurements were obtained from 3 participants in this group.

Discussion

In this study, with exergaming, the patients who received AAA had a median overall score of 51% (IQR 45%-69%), thus indicating sufficient potential for showing improvement but also having the possibility to indicate deterioration at a median follow-up of 2.5 (IQR 1-5) years after receiving AAA. All patients liked the concept of testing. The big challenge in exergaming is to estimate what the limitations caused by the AAA on the practice effect are and how the score is limited to the skills effect of the gaming. Within this challenge, we have the learning effect of this type of exercise in general, and we have the difficulties for every individual exercise. To counter the learning effect, each participant was granted 2 attempts per individual exercise. In several cases, the participants reported that they found the gaming part during the exercise inspiring, but they sometimes missed the experience and the finesse to do the game. Every individual exercise had its own specific characteristics and patients responded quite heterogeneously to this, but with sufficient room to improve or worsen, as depicted in the average scores. During conventional rehabilitation, these characteristics are usually adjusted during the therapy. In exergaming, these have to be defined beforehand, considering the special skills of the therapist, but the outcome scores need to be considered with more objectivity.

For many rehabilitation protocols finding the right exercises and setting, the parameters are the biggest challenge. The parameters of the exercise components, that is, frequency, intensity, time, and type, as described by Knols et al [9], together form a set of guidelines that help to set up exercise routines. These guidelines should fit the exercise goals and the trainee's level of fitness and is one of the foundations of successful exercise interventions. This combined with the large variance in gaming skills makes it a challenge to find the right testing and training protocol since little experience exists. To obtain a relevant set of exercises, we went through several stages. The available exercises were evaluated whether they would fit the anticipated limitations due to arthrodesis. This process of adapting an exergame for a specific pathology is believed to add positive value, but it also requires experience on both exergaming and the specific pathology [11].

Functional deficit following AA is obvious when comparing to the function of the normal population. Nevertheless, good functional outcomes have been reported mainly using PROMs as an outcome measure [12]. Schuh et al [13] described that most people with ankle osteoarthritis perform activities such as cycling, swimming, hiking, and skiing both at end-stage osteoarthritis and after AA. PROMs are currently used to quantify a disease state or an interventional outcome as perceived by the patient [14]. PROMs suffer from their subjective nature, recall bias, being a time-consuming methodology, low response rates, and completion rate or transcription errors [15]. Furthermore, various PROMs do not capture the changes due to a lack of power of the scores as averse to a lack of change (eg, floor and ceiling effects) [16]. Ankle osteoarthritis results in an unnatural gait pattern. Therefore, gait analysis is done in many AAA studies. Deleu et al [17] quantified the alterations in gait in their meta-analysis. They observed an increase in the walking speed, while step length remained constant. In this study, negative foot rotation angles were found. This can be explained by the angle between the longitudinal axis of the foot and the walking direction; negative values indicate an inward rotation and positive values indicate an outward rotation. Healthy human walking is symmetrical and economical; however, the walking of people who received AA is often asymmetrical and requires more energy [18].

In this study, a mobile treadmill was used to assess the gait pattern at the final follow-up. Our findings were consistent with those of Deleu et al [17]. The increased external rotation during walking compensates for the diminished movement in the ankle. It shortens the lever arm of the forefoot in the sagittal plane, thereby aiding in shifting the weight from back to front [19]. As our population exhibits a walking pattern that resembles that reported by Deleu et al [17], we may assume that our sample represents the "normal" ankle arthrodesis population. Exergaming has some interesting features that may assist in offering high value rehabilitation monitoring while minimizing outpatient controls. The "exer" part enables health care providers to develop pathology/patient-specific routines that change during the rehabilitation process. If exergaming is introduced before surgery, there is ample time to get acquainted with the gaming part and eliminate the confounding factors, as most as possible, thereby emphasizing the advantages of exergaming. The "gaming" part has 2 important strengths. First, it adds a fun factor, which might help in improving adherence to a rehabilitation program [2,3]. Second, it reflects the performance

level. As specific goals are achieved, the game will automatically evolve to the next level in which the exercises will drive the rehabilitation process forward.

With the gaining popularity of smartwatches, the amount of research assessing their ability to track mobility and activity is expanding [20]. Shofer et al [21] concluded that a major positive change was seen at 6 months following ankle arthrodesis. Although step activity demonstrated no improvement at 6 months following ankle arthrodesis, the total number of steps as well as the high-frequency steps continued to improve significantly for up to 3 years following surgery. Exergaming could add the more qualitative assessment of movement to this activity part.

This study has a few limitations. We describe a small population; therefore, one needs to be careful with extrapolation. However, this pilot study supports future studies in using exergaming for monitoring the rehabilitation process. This study offers sound insights to give direction to future work. In the near future, we think that the findings of our study might be helpful in creating a platform for high-quality rehabilitation that is largely home-based with continuous distant monitoring and feedback. The specific goals during different phases of rehabilitation need further attention. We believe that the first phase after immobilization should have a different focus with a specific set of exercises. In case of limited swelling and pain, the final phase should have exercises focusing on the desired endpoint.

Authors' Contributions

TvdA performed the data collection. TvdA, PP, and RH contributed to the development of the test battery. RH and TvdA contributed to the writing process. PP, GK, and MS contributed to the review/writing process.

Conflicts of Interest

PP is a paid employee of ZimmerBiome.

Multimedia Appendix 1
Characteristics and results of the healthy reference group.
[DOCX File , 15 KB - rehab_v8i2e21924_app1.docx]

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Abbreviations

AA: ankle arthrodesis
AAA: arthroscopic ankle arthrodesis
PROM: patient-reported outcome measure

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<u>Original Paper</u>

Feasibility of an Internet-Based Intervention to Promote Exercise for People With Spinal Cord Injury: Observational Pilot Study

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Abstract

Background: People with spinal cord injury (SCI) are less likely to be physically active and have higher chronic disease risk than those in the general population due to physical and metabolic changes that occur postinjury. Few studies have investigated approaches to promote increased physical activity (PA) for people with SCI despite evidence that they face unique barriers, including lack of accessible transportation and exercise equipment. To address these obstacles, we adapted an evidence-based phone-delivered intervention that promoted increased PA among people with SCI into a web-based platform, titled the Workout on Wheels internet intervention (WOW*ii*). The adapted program provides participants with weekly skill-building information and activities, basic exercise equipment, and ongoing support through weekly group videoconferencing.

Objective: This pilot study was conducted to assess the feasibility of using a web-based and virtual format to deliver the WOW*ii* program in a randomized controlled trial.

Methods: We assessed the feasibility of the web-based program by delivering an abbreviated, 4-week version to 10 participants with SCI. Rates of weekly videoconference attendance, activity completion, and exercise activity as tracked by an arm-based activity monitor were recorded for all participants.

Results: Participants averaged 3.3 of 4 (83%) weekly group videoconferences attended, 3.4 of 4 (85%) web-based module activities completed, and 2.3 of 4 (58%) weeks of using the arm-based activity monitor. The majority of the sample (9/10, 90%) synced their arm-based PA monitor at least once, and overall engagement as an average of each component across the 4 weeks was 75%.

Conclusions: The intervention had sufficiently high levels of engagement to be used in a full randomized controlled trial to test its effectiveness in improving levels of PA among people with SCI. The knowledge we gained from this pilot study informed improvements that were made in the full randomized controlled trial.

Introduction

People living with spinal cord injury (SCI) experience increased risk for obesity, excessive fat mass, abnormal lipid metabolism, and glucose intolerance than the general population [1-5]. At the same time, people with SCI have lower activity levels by as much as 45% to 66% than those without disability and still lower levels than groups with other disabilities, such as cerebral palsy, leg amputation, and chronic heart failure [6,7]. Accumulating evidence has demonstrated the positive effects of physical activity (PA) among people with SCI on their fitness, muscle strength, body composition, function, psychological well-being, and quality of life, all of which may mitigate the risk of developing chronic disease in the long term [8-11].

Evidence supports the need to increase PA levels among people with SCI, while a previous review has demonstrated the lack of effective options to increase PA among this population [12].

People with SCI face unique barriers to PA and exercise, including lack of reliable and accessible transportation, which also limits their ability to use community-based recreation centers [13,14]. The lack of recreation facilities with accessible equipment and knowledgeable staff who can assist people with mobility impairments reduces options for exercise [15]. Other barriers include lack of funds to purchase appropriate exercise equipment or gym memberships, plus low self-efficacy for exercise among people with disabilities [14,16-19]. The internet offers a way to overcome these barriers and meet the needs of people with SCI and other disabilities through instant access to information, on demand from the location of their choice, including at home, with the added benefit of connecting with others remotely. Although internet access is lower among those with lower income and racial/ethnic groups, recent US data show that 69.2% of people with traumatic SCI use a computer regularly, and of those, 99.8% have internet access [20]. Despite the lack of access among some groups, current data demonstrate that an internet-based intervention has the potential to reach many participants who would benefit from increasing their PA.

As we have previously detailed [21], internet- or phone-based methods to connect with people with SCI are not yet in widespread use; however, the few reports in existence before this study demonstrated efficacy in providing health education [22], developing self-management skills [23], and reducing depressive symptoms along with pain [24] among people with SCI. Although these studies offer evidence of efficacy that technology-mediated interventions can improve health, to our knowledge, none have focused on using regularly scheduled teleconferencing to overcome transportation barriers and increase PA while facilitating social support among peers. We identified one study from the literature that attempted to facilitate social support virtually through online message boards while investigating the effectiveness of using a web-based intervention to increase PA among adults with physical disability [25]. However, the participants' use of the boards was almost nonexistent, and the overall effectiveness of the intervention was inconclusive [25]. Although the authors noted that the exact reason for low use of the message boards was unknown, some participants stated that they were uncomfortable sharing personal information with strangers on the web [25].

Our team created the Workout on Wheels internet intervention (WOW*ii*) program to meet the unique needs of people with SCI while delivering a theory-based health behavior intervention that facilitates videoconference meetings among groups of people with SCI interested in increasing PA [26]. This intervention was adapted from the Workout on Wheels (WOW) program, a telephone-based program that yielded significant increases in time spent performing aerobic exercise [27]. The WOW program was rooted in relapse prevention and social cognitive theories, both of which have been successfully implemented in interventions to increase PA [28]. Figure 1 depicts how each theory informs key components of the WOW*ii* interventions.

Although the WOW successfully increased PA, the one-on-one meetings conducted by telephone were very time intensive per participant and did not allow the participants to connect with one another, which was a highly requested feature [27]. The Workout on Wheels internet intervention (WOW*ii*) program translates the telephone-based WOW program into a web-based format delivered using web-based modules and virtual, group-based videoconference sessions. The advantages of WOW*ii* include leveraging technology to target groups of people with SCI to make resources available on demand while offering opportunities for participants to make personal connections throughout the intervention. This pilot study sought to characterize the feasibility of delivering the WOW*ii* program to 10 individuals with SCI based on the participants' engagement in the program, defined as their attending weekly videoconference sessions, completing weekly online modules, and syncing their arm-based activity monitors weekly.

Figure 1. Theoretical constructs and key components of the Workout on Wheels internet intervention (WOW*ii*) program.
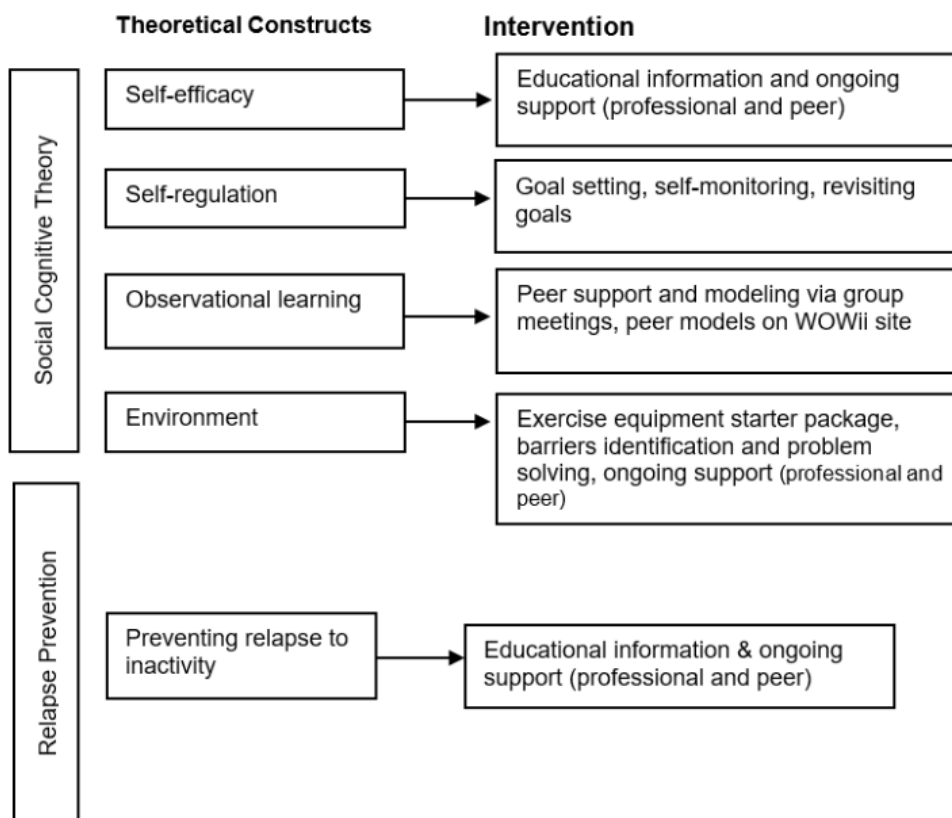


Methods

Recruitment

This study was conducted at Baylor Scott & White Institute for Rehabilitation in Dallas, Texas. Recruitment began in late 2016, and the study activities were concluded by May 2017. The Baylor Scott & White Research Institute human subjects committee approved the study activities (Institutional Review Board #016-091), and all participants provided informed consent prior to beginning study participation. Eligible participants were between 18 and 70 years of age and were not pregnant; lived with an SCI at the level of C5 or below for more than 6 months; used a wheelchair; spoke and read English; had a computer and internet access; and could independently navigate the study website. Former patients with SCI from our inpatient rehabilitation hospital who agreed to be contacted for future studies were invited to participate in the study via telephone call or email, and staff handed out fliers at the outpatient clinic and the monthly support group for people with SCI. Study staff screened potential participants for eligibility by telephone. For those deemed eligible to enroll, study staff obtained a medical clearance by fax to participate in an intervention targeting physical activity from each participant's primary care provider. Participants in this pilot study were not eligible to continue to participate in the full randomized controlled trial (RCT) study, which is currently under review.

Intervention and Data Collection

The WOW*ii* intervention comprises three key components: (1) the WOW*ii* exercise program provided via modules on the WOW*ii* website, (2) a starter package of exercise equipment, and (3) weekly virtual videoconference meetings led by the study staff to facilitate support for exercise. Study staff who led the videoconference meetings held master's degrees in public health. They were trained to deliver the intervention and supervised by the principal investigator, an applied behavioral psychologist who has delivered exercise interventions to people with disabilities for over 20 years.

For this pilot study, participants were given a username and password to access 4 weeks of the WOW*ii* website modules, which addressed getting started (eg, importance of exercise to health, benefits for people with disabilities, progression and safety, exercise basics), goal setting, identifying and addressing barriers to activity, and enlisting support (Figure 2). There was an activity at the end of each module that was designed to reinforce the material covered. Screenshots of the website and activities are available to view in Multimedia Appendices 1-4. The WOW*ii* website uses an application programming interface to collect data from each participant's Polar account, allowing the study staff to download participant exercise data weekly in addition to their completed module activities.

Figure 2. Workout on Wheels internet intervention (WOW*ii*) website and module topics covered during the pilot study.
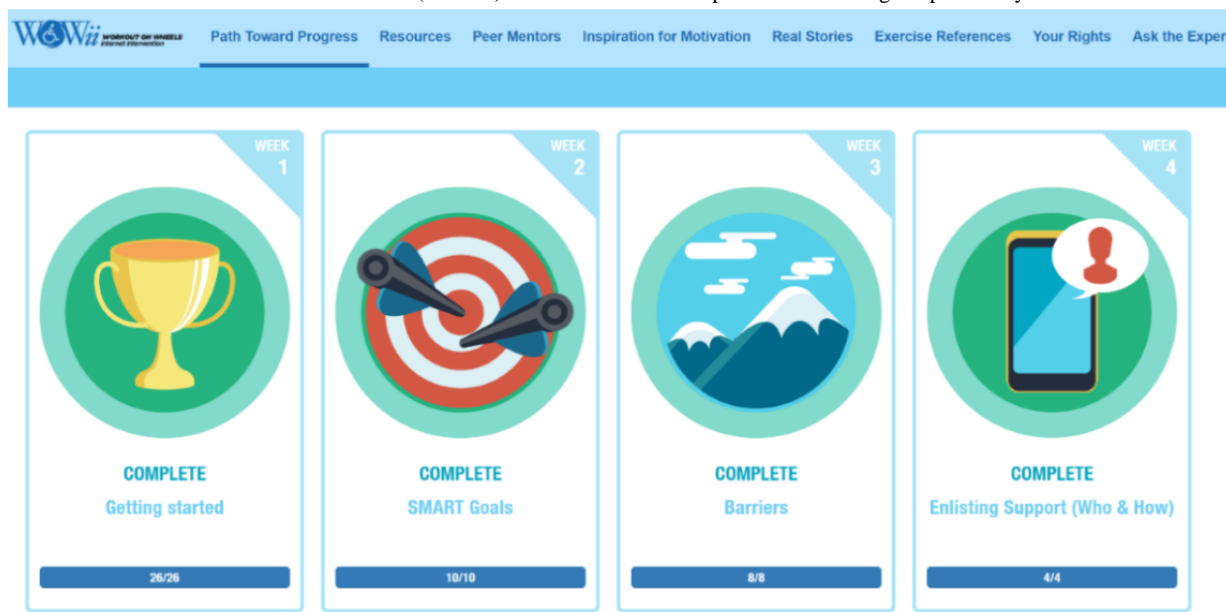
The starter package of exercise equipment included resistance bands, an aerobic exercise DVD, and a pedal exerciser. Participants were also given Polar A300 wristwatch activity monitors [29] and Polar H7 heart rate monitors [29] (Polar Electro Oy) for recording the frequency and intensity of exercise bouts. These devices operate with proprietary Polar software, Polar Flow [30], which tracks and displays its data on the watch that can be downloaded through a compatible smartphone app or a web browser directly from the Polar Flow website.

Weekly videoconference meetings conducted over Skype were facilitated by a study coordinator and/or the principal investigator. The content of these discussions was designed to reinforce the information covered during each weekly module from the website. The format of each session provided time for the leader to briefly review the key points of the web-based module while facilitating conversation among the group regarding their experiences with each module topic. At the end of each session, leaders prompted the participants to complete the weekly module activity that reinforced the material discussed and asked participants to share their activity responses with the group. Session leaders recorded weekly attendance in a web-based spreadsheet.

Analyses

Summary statistics were generated to describe the levels of individual and overall participant engagement as measured by percentage of sessions attended, percentage of weeks of exercise tracking via the Polar device, and percentage of website module activities completed. The data were summarized using SAS, version 9.4 (SAS Institute).

Results

A convenience sample of 10 people were enrolled in the pilot trial and provided engagement data for analysis. The sample was mostly male (6/10, 60%) and White (9/10, 90%) with an average age of 38.8 years (SD 16.6), and the participants had lived with their SCI for an average of 4.2 years (SD 2.6) (Table 1). A slight majority (6/10, 60%) were not currently employed, and most reported education levels of technical school/some college or a high school diploma (6/10, 60%). Of the 10 participants, 7 (70%) reported cervical-level injuries, with equal numbers of power and manual wheelchair users.

Table 1. Participant demographics (N=10).

Variable	Value
Age (years), mean (SD)	38.8 (4.2)
Time with Injury (years), mean (SD)	16.6 (2.6)
Sex, n (%)	
Male	6 (60)
Female	4 (40)
Race, n (%)	
White	9 (90)
Other	1 (10)
Ethnicity, n (%)	
Non-Hispanic	10 (100)
Education level, n (%)	
Bachelor's degree or higher	4 (40)
High school or below	3 (30)
Technical school/some college	3 (30)
Employment status, n (%)	
Employed full- or part-time	4 (40)
Not currently working	6 (60)
Income level (US $), n (%)	
0-39,000	6 (60)
40,000-69,000	1 (10)
>100,000	3 (30)
Injury level, n (%)	
Cervical	7 (70)
Thoracic	3 (30)
Wheelchair type, n (%)	
Manual	5 (50)
Power	5 (50)

Tables 2 and 3 demonstrate the level of overall engagement across the 10 participants. A total of 2 participants had low program engagement in the key components (2/12, 17%, and 5/12, 42%, respectively), with the other 8 demonstrating engagement rates of 75% to 100%. All participants attended at least 2 sessions; average videoconference session attendance ranged from 80% to 90% over the first 3 weeks and dropped to 70% in the fourth week. Most participants (9/10, 90%) completed the weekly web-based activities; however, only 70% (7/10) completed the final week's activity. Of the total sample, 90% (9/10) synced their arm-based Polar activity monitors, with at least 60% (6/10) syncing the first 3 weeks; however, only 40% (4/10) synced the watch in the fourth week. The participants' overall engagement as an average of each component across the 4 weeks was 75%. One participant only attended 2 virtual videoconference sessions and did not engage with the other components, and one participant completed 100% of the activities.

Table 2. Participant engagement in key intervention components (N=12) over the 4-week pilot.

Participant #	Activities	Week 1	Week 2	Week 3	Week 4	Overall engagement, n (%)
201	Attended session	✓	✓	✓	✓	11 (92)
	Completed activity	✓	✓	✓	✓	
	Tracked exercise		✓	✓	✓	
202	Attended session	✓	✓	✓	✓	11 (92)
	Completed activity	✓	✓	✓	✓	
	Tracked exercise	✓	✓	✓		
203	Attended session	✓		✓		2 (17)
	Completed activity					
	Tracked exercise					
204	Attended session	✓	✓	✓	✓	12 (100)
	Completed activity	✓	✓	✓	✓	
	Tracked exercise	✓	✓	✓	✓	
205	Attended session		✓	✓		5 (42)
	Completed activity	✓	✓	✓		
	Tracked exercise					
206	Attended session	✓	✓	✓	✓	11 (92)
	Completed activity	✓	✓	✓	✓	
	Tracked exercise	✓	✓	✓		
207	Attended session	✓	✓		✓	10 (83)
	Completed activity	✓	✓	✓	✓	
	Tracked exercise	✓	✓	✓		
208	Attended session	✓	✓	✓	✓	10 (83)
	Completed activity	✓	✓	✓	✓	
	Tracked exercise			✓	✓	
209	Attended session	✓	✓	✓		9 (75)
	Completed activity	✓	✓	✓		
	Tracked exercise	✓	✓	✓		
210	Attended session	✓	✓		✓	9 (75)
	Completed activity	✓	✓	✓	✓	
	Tracked exercise	✓	✓			

Table 3. Average engagement for the 3 components of the intervention.

Component	Average engagement, n (%)				
	Week 1	Week 2	Week 3	Week 4	Overall
All components (total=30)	24 (80)	25 (83.3)	24 (80)	17 (56.7)	22.5 (75)
Session attendance	9 (90)	9 (90)	8 (80)	7 (70)	33 (82.5)
Online activity completion	9 (90)	9 (90)	9 (90)	7 (70)	34 (85)
Exercising tracking rate	6 (60)	7 (70)	6 (60)	4 (40)	23 (57.5)

Discussion

Principal Findings

Although individual participation levels varied from week to week, the participants demonstrated consistent engagement during the 4-week pilot, with an overall engagement rate among the sample of 75% for attending the weekly videoconference meetings, completing the web-based activities, and wearing and syncing the arm-based Polar activity monitor. The participants showed the highest rates of engagement for completing the web-based module activities (85%) and attending the videoconference sessions (83%). These activities offer participants the space to learn about behavioral skills critical to successful behavior change and to discuss with the group their plans and personal experiences implementing those plans. The rate of syncing the Polar activity monitors was lower at 56%, although 90% of participants synced the watch in at least 1 week. It was unclear whether participants had trouble syncing their watches or were not exercising each week.

This pilot study offers preliminary evidence that a web-based platform may be feasible for delivering a PA intervention program to meet the unique needs of people with SCI. Feedback from participants in this feasibility study was vital in implementing changes to the final website used during the RCT. For example, participants recommended incorporating a more robust peer mentoring component than we originally envisioned. The participants emphasized the importance of having individuals with SCI available to discuss their successes in increasing PA as a motivational piece for those starting the program. Additionally, participants advocated for adding cost-effective resources to the website, such as equipment and fitness programs, to best accommodate those whose disability may have limited access to disposable income. After conducting this initial feasibility study, the research team initiated testing the full 16-week theory- and evidence-based program in a randomized controlled trial with 168 total participants with SCI. That trial offered a more robust test of the effectiveness of the program in promoting increased moderate-intensity PA among a large SCI sample as well as the program's effects on the participants' self-reported self-efficacy and barriers to engaging in health promoting behaviors.

In contrast with the study by Kosma et al [25], which included a web-based message board that received only 6 postings over the course of the study, attendance at the virtual videoconference sessions was relatively high at 83%. During these weekly sessions, we observed that the participants were actively engaged in the conversation, and several reported that their favorite part of the program was connecting with other people with SCI. We believe that the high engagement we observed was due to participants being able to see one another and connect by videoconference, which mitigated any discomfort participants may have felt with sharing information on the web. Notably, a study published in 2019 that obtained qualitative feedback regarding a web-based portal aimed at increasing self-efficacy for exercise among a population with SCI reported that participants endorsed many of the features present in our program, such as self-regulation strategies, knowledge, and action planning [31].

Our observed attrition rate of 20% falls within an expected and acceptable range based on the previous WOW trial and research on weight loss and internet-based interventions. The WOW trial saw a 33% attrition rate [27], while a 2011 systematic review examining dropout among participants of intensive lifestyle weight loss interventions (61 total studies) found that the reported attrition rates among participants ranged from 9% to 90% depending on the length and type of the intervention [32]. Other systematic reviews examining participation in internet-based interventions for anxiety and depression found attrition rates of up to 83% [33,34].

Limitations

A potential study limitation was the lack of racial diversity among the participants despite good diversity in terms of education and income. Additionally, initial problems with Polar watch data exports limited our ability to accurately measure exercise in minutes. However, this pilot study yielded valuable knowledge that was implemented in the full RCT. For example, due to confusion regarding the difference between PA and exercise, more information was added to the first website module. Changes were also made to bolster the participants' interaction by having peer mentors with SCI join virtual sessions, content was conveyed by adding more informational videos, and other content was added about important disability-related legislation.

Conclusions

The WOW*ii* program incorporated the following three novel components to increase PA among people with SCI: (1) group videoconferencing to leverage social support, (2) a web-based portal for information related to increasing PA, and (3) provision of exercise equipment to facilitate PA while mitigating barriers. Our pilot study showed promise regarding the ability of WOW*ii* to engage participants. The pilot study also led to improvements that were made before implementing the full RCT to study the effectiveness of the intervention. Given the prevalence of transportation issues and computer use among people with SCI, this intervention may be a valuable contribution to address the scarcity of lifestyle interventions which are accessible to this population.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Screenshot of Module 1 (Getting Started) activity.
[PNG File , 107 KB - rehab_v8i2e24276_app1.png]

Multimedia Appendix 2
Screenshot of Module 2 (SMART Goals) activity.
[PNG File , 75 KB - rehab_v8i2e24276_app2.png]

Multimedia Appendix 3
Screenshot of Module 3 (Barriers) activity.
[PNG File , 31 KB - rehab_v8i2e24276_app3.png]

Multimedia Appendix 4
Screenshot of Module 4 (Enlisting Support) activity.
[PNG File , 40 KB - rehab_v8i2e24276_app4.png]

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Abbreviations

PA: physical activity
RCT: randomized controlled trial
SCI: spinal cord injury
WOW: Workout on Wheels
WOW*ii*: Workout on Wheels internet intervention

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