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Original Paper

A Tablet-Based Interactive Movement Tool for Pediatric Rehabilitation: Development and Preliminary Usability Evaluation

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Abstract

Background: Motivating interactive tools may increase adherence to repetitive practice for children with disabilities, but many virtual reality and active video gaming systems are too challenging for children with significant needs.

Objective: The objective of this study was to develop and conduct a usability evaluation of the Fun, Interactive Therapy Board (FITBoard), a movement toy bridging digital and physical interactions for children with disabilities.

Methods: The FITBoard is a tablet app involving games controlled by hand, head, or foot touch of configurable, wired surfaces. Usability evaluation involved a cognitive walkthrough and think-aloud processes. Participants verbalized aloud while completing a series of 26 task actions involved in selecting a game and configuring the FITBoard to achieve the therapeutic goal. Therapists then responded to questions about usability perceptions. Unsuccessful actions were categorized as goal or action failures. Qualitative content analysis supported understanding of usability problems.

Results: Participants included 5 pediatric physical therapists and 2 occupational therapists from 2 clinical sites. Goal failure was experienced by all participants in 2 tasks, and action failure was experienced by all participants in 2 tasks. For 14 additional tasks, 1 or more patients experienced goal or action failure, with an overall failure rate of 69% (18 of 26 tasks). Content analysis revealed 4 main categories: hardware usability, software usability, facilitators of therapy goals, and improvement suggestions.

Conclusions: FITBoard hardware and software changes are needed to address goal and action failures to rectify identified usability issues. Results highlight potential FITBoard applications to address therapeutic goals and outline important practical considerations for product use by therapists. Subsequent research will evaluate therapist, parent, and child perspectives on FITBoard clinical utility when integrated within regular therapy interventions.

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KEYWORDS
equipment design; rehabilitation; pediatrics; tablets; software

Introduction

Children and adolescents with physical or developmental disabilities participate in rehabilitation to learn new motor skills, improve existing skills, and support capacity for self-care and independent living [1-3]. Motor learning requires abundant, challenging, progressive, varied, and feedback-rich practice opportunities to elicit meaningful change [4]. Providing these intervention characteristics is a major consideration in rehabilitation planning [5-7]. Therapists must select activities that are customizable to individual abilities and goals and that sustain children’s motivation to engage in challenging and repeated practice.

Enhancing and sustaining children’s motivation is important for rehabilitation because motivation is an affective state that may mediate the functional brain changes (ie, neuroplasticity)
that influence motor learning [8]. Motivation is a child characteristic thought to influence changes in motor ability for children with cerebral palsy [9], although no empirical link has been made between motivation and rehabilitation effectiveness in pediatric populations [10]. Therapists can enhance motivation by involving the child in selection of therapeutic tasks that are relevant to his or her interests and goals [11].

Interactive digital screens, including hand-held tablets, active video games (AVGs), and fully immersive 3D virtual reality (VR) systems, have recently become accessible, motivating therapeutic task options for children [12]. VR and AVGs encourage children to interact with onscreen simulations using body movements. The therapeutic advantages include repetitive practice, customized difficulty levels, metrics to track progress, and the potential for telerehabilitation [13-15]. Inexpensive, off-the-shelf AVGs, such as the Nintendo Wii or the Microsoft Kinect, however, may be too challenging for young children, children with perceptual or cognitive impairments, or children with more severe physical or cognitive limitations [16]. VR systems designed specifically for rehabilitation use can address some of these barriers but may have greater cost and training requirements.

In contrast to full body movement interaction, tablets are popular therapy tools used to stimulate fine motor movements and cognitive processes through a variety of games and apps [17]. These touch devices are portable, accessible, and fairly inexpensive. Children with disabilities, including preschoolers, can quickly become competent with these devices [18]. The body of evidence on whether the use of touch screens can support cognitive learning for children with disabilities is small, primarily focusing on children with autism spectrum disorder [18,19]. For children with fine or gross motor impairments, alternative interface modalities such as switches and push buttons are recommended to replace the swipe and touch movements requiring control and force regulation to interact with the screen [20].

In an attempt to build on the benefits and address the challenges of AVGs and tablet use in children with disabilities, we developed an alternative interface modality called the Fun, Interactive Therapy Board (FITBoard), a movement toy bridging digital and physical interactions. The FITBoard is a tablet app involving custom-designed games in which tablet screen touch is replaced by hand, head, or foot touch of configurable, wired surfaces. The FITBoard was designed to help children practice movement skills during physical or occupational therapy. Children reach and touch keys on the FITBoard panels to control the games on the tablet screen. The games are designed with the intent to meet the needs of children and youth at a variety of cognitive and physical abilities and provide challenging, progressive, varied, and feedback-rich practice opportunities to address therapeutic goals and elicit functional change.

Undertaking usability testing is important because many new interactive health care apps remain unused when they do not meet the needs of users [21]. Usability evaluation is part of a user-centered design process to understand effectiveness, efficiency, and appeal of a tool for users [22]. Usability testing provides the opportunity for individuals who will ultimately be users of the product to participate in its refinement [23]. The objective of this study was to describe development and preliminary usability evaluation of the FITBoard among physical and occupational therapists at 2 pediatric clinical sites.

**Methods**

**Research Design**

This usability study was approved by the institutional review board at the 2 clinical sites, Franciscan Children’s Hospital and Spaulding Rehabilitation Hospital, Boston, MA, USA.

**Participants**

Pediatric physical therapists (PTs) and occupational therapists (OTs) were recruited through volunteer sampling to participate in the usability evaluation. Therapists were invited to attend information sessions and were provided with a description of the project objectives, procedures, benefits, and risks. Therapists who were interested in taking part in the study provided written informed consent before participation. At 1 site, 5 of the 6 eligible therapists agreed to participate. At the second site, 2 of the 12 eligible therapists agreed to participate.

**Fun, Interactive Therapy Board Development**

Initial development of the FITBoard was informed by gathering perspectives on desired device characteristics from PTs and OTs through an informal needs assessment at the Spaulding Rehabilitation Institute before study initiation. Through informal discussion with the principal investigator (PI; DL), 5 therapists (3 PTs and 2 OTs) expressed the need for a device with the following characteristics: low cost; gaming-based; flexible to address varied physical and cognitive impairments; usable through hand, foot, or head movements; durable for energetic physical play; involving touch of different surfaces; constructed from easily sanitized materials; and capable of tracking patient progress.

A team of electrical, computer, and mechanical engineering undergraduate and graduate students at Northeastern University (Boston, MA, USA) was led by the project PIs to produce a prototype FITBoard. The individual PI’s experience included expertise with AVGs, considerable experience leading student groups in low-cost device construction for individuals with disabilities, or clinical expertise in pediatric rehabilitation. Over a 12-month period, various iterations were constructed and programmed to match the requested characteristics.

The resultant FITBoard (see Figure 1) is a physical interface running a tablet app that displays games controlled by hand, head, or foot touch. It operates via panels that have 3” × 5” keys with pressure switches and resistors that provide differing analog inputs to an Arduino microcontroller. The key covers hinge from 1 side allowing the pressure switch to be activated regardless of where on the panel covering it is pressed. Each panel also has a Velcro component to enable different materials representing cues for game actions or other sensory-stimulating touch surfaces to be attached.

The interface is a box-like design with folding panels that extend from a case resembling a hard-shell luggage product. Top folding panels are made of acrylic and friction hinges. Bottom
panels slide in and out using guide rails made from aluminum extrusions. The top panels are double-sided and fold out to keep the lid light, whereas the bottom panels slide for extra stability. Additional panels are arranged below the sliding path so that the device can be used with the bottom panels extended or kept inside the case. There are removable head and foot controls that can be positioned to accommodate user needs. The FITBoard rests on a wheelchair-accessible height-adjustable wheeled desk to accommodate users of different heights.

The app is displayed on a Microsoft surface tablet, chosen because it has a universal serial bus (USB) port for the Arduino to communicate button press signals into the game. The 7 custom-built games are built in Unity3D and scripted in C#. The games are appropriate for a variety of ages and children with varying cognitive abilities. For example, in the Paint a Picture game, key presses result in a splash of color on the screen. The user can try to cover the screen with paint splashes of varying colors within the preset time limit. In the Drive the Car game, users press keys corresponding to direction and speed to steer a car through a course of varying obstacles and difficulties. Each game incorporates visual and auditory effects; offers multiple challenge levels; can be played with head, foot, or hand controls; and provides feedback to the user about game play success.

To use the FITBoard, the therapist configures the physical device to the target therapy goal or goals (eg, positioning the panels, so the child has to reach across his or her body; using foot controls to facilitate stepping). The therapist then signs in to the app, selects an existing client or adds a new client, and selects a game to play (see Figure 2). Next, the therapist selects the specific FITBoard keys that he or she would like the child to use to play the game and adds a laminated paper (eg, arrows and colored circles) or other material as a cue to indicate that key’s action. Once at a game menu, settings such as game difficulty (eg, speed) and time can be selected or the user can choose to simply continue with previously used settings. Game play data are saved on the tablet.

**Figure 1.** The Fun, Interactive Therapy Board (FITBoard).
Usability Evaluation Methods

Usability evaluation was undertaken with cognitive walkthrough (CW) [22-24] and think-aloud (TA) [25] approaches. CW is a form of task analysis that enables evaluation of early prototypes to uncover possible errors in design that would interfere with the user's ability to learn how to use the system and conduct the required tasks [22]. CW involves a moderator observing users completing a walkthrough of tasks required to use the system predivided into single actions. In this study, users were required to set up a new therapist and client account; select, set up, and play a game; exit the application; identify a client goal and provide a rationale for FITBoard use; configure the FITBoard for the identified client; and select and implement a game for that client. Table 1 depicts the steps for each task. As the moderator observes the participant moving through the tasks, he or she records observations as to whether the user is successful or whether there are goal failures (the user accomplishes the wrong thing) or action failures (the user would like to perform the correct action but does not know how) [24].

The TA method is a widely used usability evaluation method often employed in conjunction with CW [25,26]. It involves asking potential users to think aloud as they interact with the product. TA is complementary to CW because it focuses on cognitive processes relevant to task completion. It is considered the gold standard because it supports greater understanding of the problems that users are having with interaction [25]. Sessions are audio-recorded, and the participant is encouraged to speak constantly as if alone in the room. He or she is given nonobtrusive reminders if they fall silent; otherwise, the moderator does not interfere.

Study Procedures

CW and TA procedures occurred during 1-hour individual audiotaped sessions led by 1 of 2 moderators (study investigators DL or HMD) in private testing rooms. Participants began by following a series of printed actions to set up a new therapist and client account, select and play a game, and close down the FITBoard app. They were then asked to describe a hypothetical or real client and a therapeutic goal for FITBoard use and subsequently complete a series of task actions involved in selecting a game and configuring the FITBoard to achieve the therapeutic goal. Moderators observed, documented, and categorized actions during the CW as goal failures (user tries to accomplish the wrong thing) or action failures (user would like to perform the correct action but does not know how). After completing the CW and TA, participants responded to 4 structured questions about FITBoard use. The 4 questions were specific to features therapists appreciated or found frustrating about FITBoard use as well as eliciting suggestions for FITBoard improvement and any other comments the therapist wished to share.
Table 1. Cognitive walkthrough results.

<table>
<thead>
<tr>
<th>Task and task description</th>
<th>Goal failures, n (%)</th>
<th>Action failures, n (%)</th>
<th>Successes, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Set up a new therapist and client account</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Turn on tablet</td>
<td>0 (0)</td>
<td>5 (71)</td>
<td>2 (29)</td>
</tr>
<tr>
<td>Attach keyboard and type in password</td>
<td>0 (0)</td>
<td>4 (57)</td>
<td>3 (33)</td>
</tr>
<tr>
<td>Plug in USB(^a)</td>
<td>0 (0)</td>
<td>2 (29)</td>
<td>5 (71)</td>
</tr>
<tr>
<td>Locate FITBoard(^b) icon</td>
<td>0 (0)</td>
<td>2 (29)</td>
<td>5 (71)</td>
</tr>
<tr>
<td>Sign up for new therapist account</td>
<td>3 (33)</td>
<td>0 (0)</td>
<td>4 (57)</td>
</tr>
<tr>
<td>Add a new client</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>7 (100)</td>
</tr>
<tr>
<td><strong>Game selection, set up, and play</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Use game descriptions to select a game</td>
<td>7 (100)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Use the interface to select 4 keys</td>
<td>0 (0)</td>
<td>7 (100)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Apply contact material to keys</td>
<td>0 (0)</td>
<td>4 (57)</td>
<td>3 (33)</td>
</tr>
<tr>
<td>Play game</td>
<td>0 (0)</td>
<td>2 (29)</td>
<td>5 (71)</td>
</tr>
<tr>
<td><strong>Exit the app</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Log-out of app</td>
<td>0 (0)</td>
<td>3 (33)</td>
<td>4 (57)</td>
</tr>
<tr>
<td>Remove contact material</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>7 (100)</td>
</tr>
<tr>
<td>Turn off tablet</td>
<td>0 (0)</td>
<td>3 (33)</td>
<td>4 (57)</td>
</tr>
<tr>
<td><strong>Identify a client(^c)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Identify a client</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>5 (100)</td>
</tr>
<tr>
<td>Identify a task or activity</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>5 (100)</td>
</tr>
<tr>
<td>Provide rationale for how FITBoard will assist in that task or activity</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>5 (100)</td>
</tr>
<tr>
<td><strong>Configure FITBoard for client(^c)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Log-in to FITBoard app using existing therapist and patient ID</td>
<td>0 (0)</td>
<td>1 (20)</td>
<td>4 (80)</td>
</tr>
<tr>
<td>Identify patient starting position</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>5 (100)</td>
</tr>
<tr>
<td>Open, close, or slide top or bottom panels</td>
<td>0 (0)</td>
<td>5 (100)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Add head or foot controls</td>
<td>0 (0)</td>
<td>4 (80)</td>
<td>1 (20)</td>
</tr>
<tr>
<td>Raise or lower the desk</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>5 (100)</td>
</tr>
<tr>
<td><strong>Select and implement game for client(^c)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Use game descriptions to select a suitable game</td>
<td>5 (100)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Use the interface to select 4 keys</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>5 (100)</td>
</tr>
<tr>
<td>Apply contact material to keys</td>
<td>0 (0)</td>
<td>2 (40)</td>
<td>3 (60)</td>
</tr>
<tr>
<td>Select appropriate game settings</td>
<td>2 (40)</td>
<td>3 (60)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Progress, modify, or change the activity</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>5 (110)</td>
</tr>
</tbody>
</table>

\(^a\)USB: universal serial bus.

\(^b\)FITBoard: Fun, Interactive Therapy Board.

\(^c\)Of 7 participants, 5 completed these tasks.

Analyses
Goal and action failures from the CW were summarized with descriptive statistics. TA process and interview question audio-recordings were transcribed. One PI (DL) undertook summative qualitative content analysis [27] focusing on words and content used by participants. Content was interpreted to specifically identify usability problems and to summarize suggestions for improvement.

Results
Participants
In this study, 5 pediatric PTs and 2 OTs (mean 19.3 years of clinical experience, range 3-33 years) participated from 2
in-patient pediatric rehabilitation clinical sites. Overall, 3 therapists (2 OTs and 1 PT) had participated in the previously described informal needs assessment.

**Cognitive Walkthrough**

Goal failure (user accomplishes the wrong thing) was experienced by all participants in 2 tasks (using game descriptions to select a game and select appropriate game settings), whereas action failure (user would like to perform the correct action but does not know how) was experienced by all participants in 3 tasks (select game keys, open or close or slide FITBoard panels, and select appropriate game settings). In total, 14 additional tasks experienced action failures by 1 or more participants. There was an overall rate of 31% tasks completed successfully by at least one participant (8/26 tasks), and 69% failed tasks (either goal or action failure) by at least two participants (18/26 tasks). Table 1 provides results of the CW process. Table 2 provides examples of goal and action failures experienced.

In total, 5 of the 7 therapist participants identified a hypothetical or real client to consider during the CW. Identified client impairments included reduced strength and altered muscle tone in 1 upper extremity (n=1), hemispatial neglect (n=1), or static and dynamic standing balance difficulties (n=3). Therapists provided rationales for FITBoard use, including increasing awareness and movement of the affected upper extremity, engaging the child while maintaining desired periods of static standing balance, and encouraging stepping outside of the base of support to improve dynamic standing balance. Therapists reported that they would position their hypothetical or real client in sitting (n=1), standing when using the 2 foot controls (n=2), and standing without the foot controls (n=2).

### Table 2. Examples of goal (user accomplishes the wrong thing) and action (user would like to perform correct action but does not know how) failures.

<table>
<thead>
<tr>
<th>Task</th>
<th>Goal or action failures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Using game descriptions to select a game</td>
<td>Goal: Participants did not long press on the game icon to bring up the game descriptions</td>
</tr>
<tr>
<td>Use the app interface to select game keys</td>
<td>Action: Participants were not able to understand how icons represented actions in the game</td>
</tr>
<tr>
<td>Open or close or slide FITBoard panels</td>
<td>Action: Participants were not sure how much force to use to move or slide the panels and in what direction</td>
</tr>
<tr>
<td>Select appropriate game settings</td>
<td>Goal: Participants missed the game settings option on the screen and did not select it</td>
</tr>
<tr>
<td>Attach keyboard and type in password</td>
<td>Action: Participants did not recognize magnetic interface to attach keyboard</td>
</tr>
<tr>
<td>Plug in USB</td>
<td>Action: Participants did not know where to plug in the USB</td>
</tr>
<tr>
<td>Locate FITBoard icon</td>
<td>Action: FITBoard icon was small and participants had difficulty locating it on the screen</td>
</tr>
<tr>
<td>Sign up for new therapist account</td>
<td>Goal: Participants tried to log-in without first signing up for a new account</td>
</tr>
<tr>
<td>Apply contact material to keys</td>
<td>Action: Participants were not clear where to find contact materials, which ones they should use</td>
</tr>
<tr>
<td>Play game</td>
<td>Action: Participants did not see results of key presses on screen because not pressing correct keys at correct time for the game interface</td>
</tr>
<tr>
<td>Log-out of app</td>
<td>Action: Participants quit without logging out</td>
</tr>
<tr>
<td>Turn off tablet</td>
<td>Action: Participants were not sure how to turn off the tablet</td>
</tr>
<tr>
<td>Log-in to FITBoard app using existing therapist and patient ID</td>
<td>Action: Participant tried to sign up instead of log-in</td>
</tr>
<tr>
<td>Add head or foot controls</td>
<td>Action: Participants were not sure where to plug in head or foot controls</td>
</tr>
</tbody>
</table>

**Think Aloud and Interviews**

Content analysis of the TA and interview transcripts revealed 4 categories: hardware usability (ie, FITBoard fragility), software usability (ie, key configuration and game settings), facilitators of therapy goals, and suggestions for improvement.

**Hardware Usability**

All therapists expressed concern about the physical appearance of the FITBoard, reporting they were apprehensive about its fragility and durability. Therapists reported being uncertain whether the force required to move and slide the FITBoard panels would cause the panels to break and were concerned that pediatric clients would pull the exposed wires. For example, one therapist said:

> …you know how when you’re working with technology and you have to guide people how hard they can hit without breaking the machine? So, I’m thinking at what point do I tell a kid “don’t hit that so hard”?…also how easily they [the panels] pop off…so my concern with this is with kids, no matter how much you tell them “I got you,” if they go to fall, they will grab onto this, and I just feel like this is something I wouldn’t want to pull on, so it almost like narrows who my population who I think would benefit from it.

Another therapist said:

> I know this is a prototype but I would hope that the permanent thing is a little sturdier...too many wires that a patient could inadvertently pull off, break off,
knock over...someone with strong tone or any sort of spasticity...it felt very fragile.

A third therapist commented:

I’m not sure about the durability and feasibility of it, meaning, putting it together, setting it up...I’d be afraid that it wasn’t going to hold up very well...sliding [the panels] in, sliding [the panels] out.

Additional hardware concerns expressed by the therapists related to the sensitivity of the panel keys:

It’s nice that you have that sensitivity [to touch the keys] but on the other hand we have a lot of kids that don’t have that controlled movement...

Finally, the inability to mount the tablet above the FITBoard to encourage children to raise their head to look at the screen was reported as problematic.

**Software Usability**

Software usability included challenges interacting with the FITBoard app interface on the tablet. Participants found aspects of the app interface confusing, particularly the game selection screen where they were not able to complete the task of viewing the game description. When shown this task action following the CW, participants expressed concern that without a picture of the game, it was difficult to understand the description. For example, with respect to the Whack a Mole game, 1 participant said:

Well I don’t know what the holes [where the Moles come up] look like...are they in a grid? Are they on top of each other, because of the up [and] down [buttons]? Without seeing the screen of what the holes look like, I don’t know what that means. I’m not sure for top and bottom [keys], what I’d choose.

In the key configuration screen where participants select specific keys on the FITBoard to interface with the game, participants disliked the incongruity between the visual representation of the key icons on the FITBoard panels and their actions in the game reporting it was very confusing to understand which key undertook which game action. Participants also reported challenges locating and then understanding how to set the game difficulty levels, including game duration and speed.

One participant was concerned that the games may not be visually appealing for her clients given the high-quality graphics of the media with which children typically interact:

...I would love to see what the kids think [about these games] because now video games have so many components to them and they are so animated and dynamic, and they have music and they have sounds and they can be more complex. So depending on the age of the kids and their cognitive abilities, I don’t know how they would like this [device]... it would really vary. Kids used to other games might not be thrilled with this [device] and then the older kids and teens might not like the games.

**Facilitators of Therapy Goals**

Participants appreciated the many options (eg, head switches, foot pedals, and panel positions) to elicit movement and the selection of tactile touch contact materials for interaction (eg, plastic arrows and toy animals) as well as the many opportunities to individualize the intervention. For example, one therapist said:

I think it would be good for kids that like video games...maybe they are working on gross movement...a child with hemiplegia – it would be a fun game to get reach to the side, and yet it’s not a lot of fine motor so you can get them to do some gross moves with their upper extremity.

Another therapist described potential use of the FITBoard with a particular child, stating:

I can make him reach out of his base of support, I could make him tap his foot and I think it would engage him as well because he loves video games.

Another therapist focused on the ability to interact with the game using only simple head movements, saying it would be appropriate for a current patient because:

...she has very poor head control so something we were trying to do today in rehab we were drawing tic-tac-toes and trying to get her to look up and get her head up. So this could be something for her that I use this for.

This was echoed by a second therapist, who said:

I like that you can...make it so specific to the patient you have...You do have something for even if it’s for something like head control...because we do get a significant amount of people that, that is a serious thing we are working on and it’s hard to make that fun sometimes.

**Suggestions for Improvement**

There were multiple specific suggestions for improving the FITBoard hardware and software interfaces. Hardware suggestions included increasing the stability of the head and foot controls, covering the microcontroller to protect it from exposure to cleaning fluids, and increasing the mobility of the top and side panels so they could be positioned higher and surround the user.

Software improvement suggestions included adding a pause feature to the games:

...I get so many interruptions at random times in the session...work with kids that need that closure...they want to make sure you can pause and finish that game and get that score, or like they won’t be able to listen to what a nurse has to say or take a medication, unless they can pause that game.

One therapist suggested a more intuitive way to access and store the touch materials, saying:

...they would benefit from being labeled so[it would be] easier to put your hands on stuff...
In addition, further touch materials were suggested, including materials to facilitate use by clients with limited fine motor control:

_I think that for her [the patient] I'd work on some grasp and I don't think she could get a good grasp and fall off of it. So, something she could rest her hand here and squeeze a little I mean depending on their hand skills._

Additional suggestions included having the games to provide more feedback about success or error rate and including games that required only 1 or 2 keys rather than 4 keys to play. Suggestions were also made to improve the user instructions with additional details, add a game description sheet to accompany the FITBoard, and round off sharp edges of the laminated paper pieces that attach to the keys.

Discussion

Principal Findings

The objective of this study was to develop and conduct a usability evaluation of the FITBoard, a movement toy bridging digital and physical interactions for children with disabilities. Usability was evaluated through CW and TA methods to enable identification of problematic tasks involved in using the FITBoard and identify areas for improvement.

The 69% overall goal and action failure rate in this study was similar to others in the literature. Peute et al [26] undertook a CW and TA evaluation of a new Web-based laboratory test ordering tool with 7 participants, finding that 16 of 25 (64%) actions resulted in goal or action failures. Valdes et al [28] used CW and TA to evaluate 2 newly developed motion-tracking rehabilitation therapeutic tools. They reported that 69.5% of the actions evaluated in their sample of 11 therapists had some element of failure but did not classify failures into goal or action components [28].

Our testing situation was unique because it focused on evaluating usability of both novel hardware and software interfaces, which differs, for example, from usability testing of a new website where users could be expected to be familiar with general layout and functioning of a keyboard, mouse, and monitor. The CW and TA processes illuminated usability problems and flaws in the process of using the FITBoard from the beginning to the end that led to errors for some or all participants. The primary usability problems included structural issues with the FITBoard that prevented users from being comfortable interacting with the device (ie, opening and closing panels and attaching foot and head controls). Other problems were related to lack of clarity in FITBoard software interactions (eg, how to select keys to play the game and how to find game descriptions before selecting a game). The results from CW and TA identified problematic tasks that must be addressed before therapists are able to test the FITBoard with children and families.

Despite these limitations, participants easily identified a client and functional goal that would be relevant to FITBoard use. In addition, they appreciated the diversity of options that the FITBoard provides to motivate and engage children in maintaining upright head control, which was identified as a priority in the informal needs assessment. Therapists appeared to view the FITBoard as relevant to the goals for the patients on their caseloads and provided valuable information to direct changes to the FITBoard before evaluation of its clinical utility.

Rehabilitation therapists have access to technological options, including VR, active video gaming, and other tablet apps that are commercially available and/or developed specifically for rehabilitation. As such, it is difficult for housemade systems and games to compete with commercially available choices in terms of aesthetic appeal or intuitive user interfaces. We know from barriers and facilitators assessments in the field of AVG use that the main barriers to introduction for these new technologies are practical difficulties such as cost, adequate space for use, and time to learn how to use, including how to choose specific games or apps most relevant to patients' goals [16,28,29]. Therapists wanted a tool that would work for children with more significant physical or cognitive impairments and for a younger age range than what is typical for AVG use.

The FITBoard has the potential for use with young children and children with significant needs. However, the current model is larger than initially desired, given our initial goal of a device that could fold down to be stored in a briefcase-like fashion. We emphasized durability of individual materials used in the design but the overall device is more fragile than originally anticipated.

Limitations

Although our development process began by soliciting input from therapists, it could have been more user-centered and iterative if it had taken place in close proximity to the therapists, allowing them to provide more regular input throughout the process. This did not occur because of the cost involved in transporting the FITBoard from the laboratory in which it was built to each clinical site as well as a reluctance to place an additional burden on therapists’ time. This limitation was evident, for example, in findings related to therapists’ recommendations about having panels extend higher and laterally to surround the participant, which might have been able to be implemented in early stages of construction.

The CW and TA processes were undertaken by authors DL and HMD, researchers known by therapists to be invested in FITBoard development. Despite assurances that all feedback was welcome, therapists may have felt uncomfortable expressing negative opinions about the device in their presence. In addition, the CW process has been criticized as being too rigid and, therefore, limiting the types of problems discovered [30]. The authors did not undertake traditional forms of qualitative data credibility analysis such as member checking or triangulation. Finally, the study is limited by a small sample, which may not have been sufficient to discover all usability problems and did not allow for comparisons between physical and occupational therapists in terms of their perspectives on the device. Although Bastien [23] suggests that 8 participants are sufficient for a TA process, there is no consensus on the number of participants required. In total, 2 of the 7 participants did not have time to complete the full CW. Moreover, there were only 2 OT participants. This is important because OTs may have different

http://rehab.jmir.org/2018/2/e10307/

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therapeutic rationale and interests in using this device. Including additional OTs might have led to the discovery of different usability problems [30].

Next Steps
Study results are guiding changes to the FITBoard to address hardware and software usability issues. Our next steps are to reintroduce the revised FITBoard to the clinical sites and undertake a clinical utility study with therapists, children, and families to determine how FITBoard use addresses relevant therapeutic goals. Therapists will use the FITBoard on several occasions, recording their functional goals and perceptions of how FITBoard use was able to address the goal; therapists, parents, and children, as able, will complete standardized measures evaluating satisfaction, engagement, and motivation. Finally, we will conduct interviews with children, parents, and therapists to further identify barriers to and facilitators for FITBoard use. On the basis of the results, we can approach industry partners with respect to making changes to the FITBoard interface and app to support creation of additional, improved devices with a larger budget for construction and game development. We would then undertake longer-term feasibility and effectiveness research in home or school settings to understand the potential role of the FITBoard in therapeutic programs.

Conclusions
The FITBoard is a newly developed, low-cost rehabilitation tool for movement skill practice that integrates the motivating attributes of video games with the functional, touch-based sensory input of traditional rehabilitation interventions. Usability testing methods (CW and TA) with a small sample of physical and occupational therapists revealed FITBoard hardware and software concerns, potential apps for therapy goals, and suggestions for improvement. FITBoard hardware and software changes are needed to address goal and action failures and respond to identified usability issues. Following these improvements, our goal is to produce an accessible, user-friendly, and low-cost product that can be integrated into school, home, or community programs to enhance practice dosage of functionally relevant movement skills for children and youth with disabilities.

Acknowledgments
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Conflicts of Interest
None declared.

References


Abbreviations

AVG: active video game
CW: cognitive walkthrough
Users’ Perspectives, Opportunities, and Barriers of the Strengthen Your Ankle App for Evidence-Based Ankle Sprain Prevention: Mixed-Methods Process Evaluation for a Randomized Controlled Trial

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Abstract

Background: The “Strengthen Your Ankle” neuromuscular training program has been thoroughly studied over the past 8 years. This process evaluation is a part of a randomized controlled trial that examined both the short- and long-term effectiveness of this particular program. Although it was shown previously that the program, available both in a printed booklet and as a mobile app, is able to effectively reduce the number of recurrent ankle sprains, participants’ compliance with the program is an ongoing challenge.

Objective: This process evaluation explored participants’ opinions regarding both the methods of delivery, using RE-AIM (Reach Effectiveness Adoption Implementation Maintenance) Framework to identify barriers and challenges to program compliance. Although Reach, Effectiveness, and Adaptation were the focus of a previous study, this paper focuses on the implementation and maintenance phases.

Methods: Semistructured interviews and online questionnaires were analyzed using qualitative content analysis. Fisher exact, chi-square, and t tests assessed between-group differences in quantitative survey responses. Interviews were assessed by thematic analysis to identify key themes.

Results: While there were no significant differences in the perceived simplicity, usefulness, and liking of the exercise during the 8 weeks of the neuromuscular training program, semistructured interviews showed that 14 of 16 participants agreed that an app would be of additional benefits over a booklet. After the 12-month follow-up, when asked how they evaluated the overall use of the app or the booklet, the users of the app gave a mean score of 7.7 (SD 0.99) versus a mean score 7.1 (SD 1.23) for the users of the booklet. This difference in mean score was significant (P=.006).

Conclusions: Although both the app and booklet showed a high user satisfaction, the users of the app were significantly more satisfied. Semistructured questionnaires allowed users to address issues they would like to improve in future updates. Including
a possibility for feedback and postponement of exercises, an explanation of the use of specific exercises and possibly music were identified as features that might further improve the contentment of the program, probably leading to increased compliance.

**Trial Registration:** Netherlands Trial Register NTR4027; http://www.trialregister.nl/trialreg/admin/rctview.asp?TC=4027 (Archived by Website at http://www.webcitation.org/70MT09dMV)

**KEYWORDS**

injury prevention; ankle injury; eHealth; qualitative analysis; process evaluation

**Introduction**

Injuries, due to participation in sports and physical activities, are prevalent. Internationally, ankle sprains are one of the most common musculoskeletal injuries [1]. In particular, indoor and court sports have shown high incidences of ankle sprains with up to 7 injuries per 1000 hours of participation [2]. Generally considered a “minor” injury, ankle sprains pose a significant risk for long-term secondary complaints like instability and chronic pain [3]. For the prevention of acute lateral ankle sprains, numerous effective strategies have been developed and evaluated for their cost-effectiveness [2].

One of the many available interventions that has been shown to be effective in reducing the risk of recurrent ankle sprains, as well as protecting against secondary complaints, is neuromuscular training (NMT) [3-5]. Multiple variations of such training programs have been evaluated [6-8], including the “Strengthen Your Ankle” program. The “Strengthen Your Ankle” program consists of 6 exercises that are performed 3 times a week, over 8 weeks. Multiple trials have indicated that this program can be effective in reducing the injury incidence density [9,10] as well as being cost-effective [10,11]. Despite the proven value of the program in preventing recurrent injury risk, compliance with this and other NMT programs is an ongoing challenge [3]. Sufficient compliance with NMT programs is essential for successful prevention of ankle sprains [12]. Consequently, a free mobile app was developed as a novel and attractive means of providing athletes with the “Strengthen Your Ankle” program [13]. Details of the app have been described elsewhere [3]. A recent trial (NTR 4027) showed that the app neither increased compliance nor decreased recurrence of ankle sprains compared with a standard program administered via a paper booklet [3,4,13].

As with other preventive interventions, the translation of the evidence on ankle sprain prevention through NMT to the real-world context of sports remains a challenge, by which effective ankle sprain prevention in the community is lagging [14]. The success of introducing any intervention strategy in a practical context can be evaluated using the RE-AIM framework [15]. RE-AIM is a conceptual framework that was originally used to develop and evaluate health care programs. The goal of the RE-AIM framework is to “encourage program planners, evaluators, readers of journal articles, funders, and policy makers to pay more attention to essential program elements, including external validity, that can improve the sustainable adoption and implementation of effective, generalizable, evidence-based interventions” [16].

Although developed for use in health care settings, the RE-AIM framework has been previously used to evaluate the success of introducing strategies for sports injury prevention within a practical sports context [17,18]. Consequently, using the components of the RE-AIM framework, this study described the user experience of the “Strengthen Your Ankle” app and booklet to understand why compliance was challenged during program implementation.

**Methods**

**Design and Participants**

The full details of the “Strengthen Your Ankle” study have been described elsewhere [3,4,13]. In brief, 220 sports participants who experienced an ankle sprain during the past 2 months were included in this RCT. Participants were randomly assigned to either the app or booklet intervention group and were instructed to follow the embedded 8 week “Strengthen Your Ankle” NMT prevention program using either the app or the printed booklet.

**Outcome Measures**

The RE-AIM framework describes five dimensions to evaluate the practical feasibility of an intervention: “Reach,” “Effectiveness,” “Adoption,” “Implementation,” and “Maintenance” [16]. The dimensions “Reach” and “Adoption” are out of scope when describing the feasibility of an intervention within a controlled trial. As such, for this study, we focused on the dimensions “Effectiveness,” “Implementation,” and “Maintenance.”

**Effectiveness**

The “Effectiveness” dimension describes the clinical impact of the studied intervention. The short- and long-term effectiveness of the app compared with the booklet for preventing ankle sprain recurrences were assessed in a RCT. The full methods and results of this trial have been published elsewhere [3,4,13]. In order to put the outcomes of the “Implementation” and “Maintenance” dimensions in context, we will briefly summarize the “Effectiveness” outcomes.

**Implementation**

Implementation concerns the participants’ use of the intervention strategies. In this study, we quantified use as compliance with the 8-week NMT program in each of the study groups, measured as a percentage of the total program completed. In addition, the participants’ attitudes and perceptions toward the delivery of the NMT programs were assessed.

During the 8 weeks of the NMT program, participants received a weekly online questionnaire. The questionnaire registered
what percentage of the program was executed during the week, the amount of difficulty that was experienced while conducting each of the exercises, and the reason for a possible lack of compliance. For each of the 6 different exercises, participants indicated what percentage of the exercises they performed each week. Additionally, using a 5-point Likert scale, participants were asked how they perceived the exercises. When participants failed to complete the questionnaire, reminders were sent by email. The details on the questionnaire have been published previously [3].

After the 8-week training period, a more extensive evaluation questionnaire was completed, including closed and free-text questions on the subjectively-experienced value of the NMT program delivery mode, a subjective evaluation of the program, and the perceived disadvantages and advantages of the allocated intervention delivery mode. To measure satisfaction, all remaining participants (75 in the app group and 88 in the booklet group) were asked to give a 0-10 score for the app or booklet. An unpaired t test was performed to examine the difference in scores between the two groups.

Maintenance

“Maintenance” describes the long-term effectiveness of the intervention strategies. For this study, this dimension was defined as the percentage of participants still conducting the NMT program combined with the advantages the participants perceived related to the app or paper booklet use for intervention delivery.

After 12 months, semistructured interviews were conducted with individual participants to assess the perceived advantages of using the app over the paper booklet. All study participants were asked if they were willing to participate in a semistructured interview concerning the NMT program; 27% (32/119) of the remaining participants, evenly divided over the two study groups, responded positively. The interviews were structured using a preselected topic list on the individual experiences with the NMT program either through the booklet or app. All interviews were conducted and transcribed by one researcher (MA). Interviews were conducted via telephone until saturation was reached, that is, when interviews did not lead to new themes or information, within both study groups, resulting in 16 semistructured interviews with 8 randomly selected participants in the booklet group and 8 randomly selected participants in the app group. Multimedia Appendix 1 shows the question guide for the semistructured interviews, aimed at process evaluation, after finishing the 12-month intervention.

Data Analyses

Due to dropout during follow-up (n=57 after 8 weeks and a further n=44 after 12 months), sample sizes differed between questionnaires. The reasons for dropout were unknown. The participants’ answers on the 5-point Likert scales regarding attitudes and perceptions toward the program, as registered during the 8-week program, were averaged for each participant over the available follow-up moments. Independent sample t tests with assumed equal variances were conducted to assess for differences in the average Likert responses between the two study groups. The significance level was evaluated at P=.05. SPSS (version 22.0) and was used for all statistical analyses.

All semistructured interviews were audio-recorded and transcribed verbatim. In transcriptions, any personal information or information that was deducible to an individual was anonymized. Verbatim-transcribed interviews were thematically analyzed and fragmented on the basis of topical similarity using Atlas.ti [19]. Open, inductive coding was used line by line on the transcripts of the interviews and these codes were converged into subthemes [20]. Peer debriefing was used as an external check to the research process. This method of analysis was used after each interview and ended when no new codes arose and saturation was reached [19]. The final step in the analysis process was to submerge the subthemes to a limited number of main themes [19].

Results

Effectiveness

Previous studies that looked at the effectiveness of the “Strengthen Your Ankle” program provided further details on the (cost)-effectiveness of the program in the short and long term [3,4]. In short, during the 8 weeks of the NMT, there were 93 self-reported recurrent ankle sprains, which resulted in injury incidence densities of 25.3 per 1000 hours of sport (95% CI 18.0 to 32.7) in the app group and 25.6 per 1000 hours of sport (95% CI 18.3 to 32.9) in the booklet group. There was no significant difference in the incidence densities of self-reported recurrences (HR [hazard ratio] 3.07; 95% CI 0.62 to 15.20) [1].

During the 12-month follow-up, there were 139 recurrent ankle injuries, resulting in injury incidence densities of 15.59 per 1000 hours of sport (95% CI 11.94 to 19.24) in the app group and 15.84 (95% CI 12.10 to 19.58) in the booklet group. Over the long term, this difference in injury density was not significant (HR 1.06; 0.76 to 1.49) [4].

Implementation

The first study in this larger research project looked at compliance during the 8 weeks of the NMT intervention. It was shown that the average compliance to the exercise scheme was 73.3% (95% CI 67.7% to 78.1%) in the app group and 76.7% (95% CI 71.9 to 82.3%) in the booklet group. No significant difference in compliance was found between the groups [3].

The weekly questionnaires (Table 1) showed that participants in both the app and booklet groups gave comparable scores with regard to simplicity, usefulness, and subjective evaluation of the exercises. Table 1 shows the averaged responses of the participants over the 8 weeks.

After the 8-week intervention period, 35 participants using the app and 22 participants using the booklet discontinued the study for unknown reasons. The remaining 75 users of the app found this method of NMT program delivery more user friendly, easier, fun to use, and less annoying and thought that the videos were more helpful than the booklet (Table 2). The latter question should be interpreted with caution because online videos were available for the booklet users (n=88), but many of the participants stated that they were not aware of this possibility.
<table>
<thead>
<tr>
<th>The exercises are simple.</th>
<th>Mean (SD)(^a)</th>
<th>Mean difference(^b) (95% CI)</th>
<th>(P) value</th>
</tr>
</thead>
<tbody>
<tr>
<td>App</td>
<td>3.79 (0.86)</td>
<td>0.03 (−0.19 to 0.25)</td>
<td>.79</td>
</tr>
<tr>
<td>Booklet</td>
<td>3.76 (0.78)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Due to the variation in exercises I stay motivated.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>App</td>
<td>2.25 (0.82)</td>
<td>−0.16 (−0.36 to 0.05)</td>
<td>.13</td>
</tr>
<tr>
<td>Booklet</td>
<td>2.41 (0.71)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I find it easy to execute the exercises without help.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>App</td>
<td>3.72 (0.85)</td>
<td>0.05 (−0.16 to 0.26)</td>
<td>.65</td>
</tr>
<tr>
<td>Booklet</td>
<td>3.67 (0.75)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The exercises give me a sense of security.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>App</td>
<td>3.30 (0.94)</td>
<td>−0.01 (−0.25 to 0.23)</td>
<td>.96</td>
</tr>
<tr>
<td>Booklet</td>
<td>3.30 (0.87)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The exercises are painful.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>App</td>
<td>3.94 (0.68)</td>
<td>−0.04 (−0.22 to 0.14)</td>
<td>.64</td>
</tr>
<tr>
<td>Booklet</td>
<td>3.98 (0.67)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The exercises don’t fit with my regular schedule.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>App</td>
<td>3.42 (0.87)</td>
<td>0.09 (−0.14 to 0.32)</td>
<td>.47</td>
</tr>
<tr>
<td>Booklet</td>
<td>3.33 (0.88)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have too little time to do the exercises.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>App</td>
<td>3.29 (0.99)</td>
<td>−0.09 (−0.35 to 0.17)</td>
<td>.49</td>
</tr>
<tr>
<td>Booklet</td>
<td>3.38 (0.97)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I think the exercises take a long time.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>App</td>
<td>2.00 (0.58)</td>
<td>−0.15 (−0.32 to −0.01)</td>
<td>.07</td>
</tr>
<tr>
<td>Booklet</td>
<td>2.16 (0.67)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The exercises make me tired.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>App</td>
<td>3.87 (0.75)</td>
<td>−0.02 (−0.21 to 0.17)</td>
<td>.84</td>
</tr>
<tr>
<td>Booklet</td>
<td>3.89 (0.66)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I forget to execute the exercises.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>App</td>
<td>2.34 (0.68)</td>
<td>−0.06 (−0.24 to 0.11)</td>
<td>.49</td>
</tr>
<tr>
<td>Booklet</td>
<td>2.41 (0.64)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The exercises are not useful to prevent a recurrent injury.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>App</td>
<td>3.42 (0.88)</td>
<td>0.12 (−0.11 to 0.35)</td>
<td>.32</td>
</tr>
<tr>
<td>Booklet</td>
<td>3.31 (0.84)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The exercises won’t help me.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>App</td>
<td>2.66 (0.77)</td>
<td>0.07 (−0.13 to 0.26)</td>
<td>.50</td>
</tr>
<tr>
<td>Booklet</td>
<td>2.59 (0.71)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

\(^a\)Scores present means (SD) of 5-point Likert scales (1=strongly agree; 5=strongly disagree).

\(^b\)Differences in scores between groups were analyzed by independent \(t\) tests with equal variances assumed.
Table 2. The subjectively-experienced value of the NMT program and perceived disadvantages and advantages of the allocated intervention delivery mode assessed directly after the 8-week intervention.

<table>
<thead>
<tr>
<th>Participants’ opinions and method of delivery</th>
<th>Mean (SD)</th>
<th>Mean difference(^b) (95% CI)</th>
<th>(P) value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>The intervention is user friendly.</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>App</td>
<td>1.85 (0.98)</td>
<td>−0.43 (−0.75 to −0.11)</td>
<td>.009</td>
</tr>
<tr>
<td>Booklet</td>
<td>2.28 (1.10)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>The intervention is easy to use.</strong></td>
<td></td>
<td>−0.40 (−0.69 to −0.11)</td>
<td>.008</td>
</tr>
<tr>
<td>App</td>
<td>1.84 (0.92)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Booklet</td>
<td>2.24 (0.97)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>The intervention looks attractive.</strong></td>
<td></td>
<td>−0.06 (−0.35 to 0.23)</td>
<td>.68</td>
</tr>
<tr>
<td>App</td>
<td>2.12 (0.90)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Booklet</td>
<td>2.18 (0.97)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Navigation of the intervention is clear.</strong></td>
<td></td>
<td>−0.29 (−0.59 to 0.01)</td>
<td>.06</td>
</tr>
<tr>
<td>App</td>
<td>2.13 (0.95)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Booklet</td>
<td>2.42 (1.01)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>The intervention gives enough information.</strong></td>
<td></td>
<td>−0.29 (−0.59 to 0.01)</td>
<td>.06</td>
</tr>
<tr>
<td>App</td>
<td>2.19 (0.95)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Booklet</td>
<td>2.48 (0.97)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>I would advise others to use the intervention.</strong></td>
<td></td>
<td>−0.29 (−0.62 to 0.03)</td>
<td>.07</td>
</tr>
<tr>
<td>App</td>
<td>2.08 (1.03)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Booklet</td>
<td>2.38 (1.04)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>It is annoying to use the intervention.</strong></td>
<td></td>
<td>0.47 (0.12 to 0.81)</td>
<td>.008</td>
</tr>
<tr>
<td>App</td>
<td>4.09 (1.09)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Booklet</td>
<td>3.63 (1.13)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>I have used the intervention with pleasure.</strong></td>
<td></td>
<td>−0.18 (−0.48 to 0.12)</td>
<td>.23</td>
</tr>
<tr>
<td>App</td>
<td>2.25 (0.95)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Booklet</td>
<td>2.44 (0.97)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>The videos helped me (online for the Booklet).</strong></td>
<td></td>
<td>−0.99 (−1.31 to −0.68)</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>App</td>
<td>1.96 (1.07)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Booklet</td>
<td>2.95 (0.96)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>The written instructions helped me.</strong></td>
<td></td>
<td>−0.07 (−0.35 to 0.21)</td>
<td>.64</td>
</tr>
<tr>
<td>App</td>
<td>2.08 (0.98)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Booklet</td>
<td>2.15 (0.84)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>The schedule helped me.</strong></td>
<td></td>
<td>0.08 (−0.23 to 0.38)</td>
<td>.62</td>
</tr>
<tr>
<td>App</td>
<td>2.12 (1.10)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Booklet</td>
<td>2.05 (0.87)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>The intervention is boring.</strong></td>
<td></td>
<td>−0.05 (−0.36 to 0.26)</td>
<td>.73</td>
</tr>
<tr>
<td>App</td>
<td>3.48 (1.03)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Booklet</td>
<td>3.53 (0.97)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>The intervention makes it easier to do the exercises.</strong></td>
<td></td>
<td>−0.36 (−0.65 to −0.07)</td>
<td>.02</td>
</tr>
<tr>
<td>App</td>
<td>2.09 (0.94)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Booklet</td>
<td>2.45 (0.95)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Participants’ opinions and method of delivery | Mean (SD)a | Mean differenceb (95% CI) | P value
--- | --- | --- | ---
**The intervention makes it fun to do the exercises.** | | | .01
App | 2.68 (0.94) | −0.37 (−0.66 to −0.08) | 
Booklet | 3.06 (0.93) | 
**The intervention is informative.** | | | 0.26
App | 2.20 (0.74) | −0.14 (−0.39 to 0.11) | 
Booklet | 2.34 (0.84) | 
**The intervention is trustworthy.** | | | 0.13
App | 2.23 (0.84) | −0.17 (−0.42 to 0.09) | 
Booklet | 2.40 (0.87) | 
**The explanation of the exercises is clear.** | | | 0.17
App | 2.26 (1.07) | −0.22 (−0.52 to 0.10) | 
Booklet | 2.47 (0.91) | 

aScores present means (SD) of 5-point Likert scales (1=strongly agree; 5=strongly disagree).
bDifferences in scores between groups were analyzed through independent t tests with equal variances assumed.

Therefore, the answers of 53 of the booklet users were “neutral” when asked if the online videos were of help; this was in comparison with 5% (4/75) in the app group. Some participants failed to answer all the questions, the number of missing responses can be found in Table 2. Additional questions specifically related to possible improvements in the app, and not the booklet, (Multimedia Appendix 2) indicated that participants desired feedback after the exercises (44/75, 59%) and wanted the ability to postpone a training session (41/75, 55%). Overall, a t test showed that the users of the app were significantly more satisfied with the app (score 1 out of 10 with 10 referring to the highest score, mean±SD) compared with booklet users; 7.7 (SD 0.99) versus 7.1 (SD 1.23) P=.006.

Maintenance

At the end of the 12-month follow-up period, an additional 44 participants discontinued the study. These participants were asked if they were still doing (part of the) NMT program. Only 23% (28/122) of all participants still in the study responded affirmatively. We did not ask what amount of the program they were still doing. Two main themes arose from the semistructured interviews that related to the design of the app and possible additional benefits of the app. Fourteen out of 16 participants stated that an app would provide an additional benefit compared with a booklet. The main reasons given were that most of the participants always had their mobile phones with them and that the app provided visual support and had a reminder function. The two participants who did not feel that the app offered any benefit found the exercises too easy, which made the app redundant.

Errors in navigation and explanation, the lack of feedback and music, and lack of explanation of the purpose of the exercises were the main disadvantages experienced by the app users. The greatest perceived disadvantages of the booklet were the big size when folded out, small font, lack of robustness, and errors in explanation. Table 3 shows the individual responses during the semistructured interviews to illustrate the flavor of the original data and demonstrate the prevalence of the themes, as suggested by King [21].
Table 3. Individual responses from semistructured interviews.

<table>
<thead>
<tr>
<th>Method of delivery and respondent</th>
<th>Added benefit of the app?</th>
<th>Reason given</th>
<th>Pros (+) and suggestions for improvement (−) for the app</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>App</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>R1</td>
<td>Yes</td>
<td>You always have your phone with you</td>
<td>+ Easy to use</td>
</tr>
<tr>
<td></td>
<td></td>
<td>You forget the booklet</td>
<td>+ Agenda function</td>
</tr>
<tr>
<td>R2</td>
<td>No</td>
<td>The exercises are so easy, you don’t need an app</td>
<td>+ Videos with instructions</td>
</tr>
<tr>
<td>R3</td>
<td>Yes</td>
<td>You always have your phone with you</td>
<td>+ Videos with instructions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Seeing the app on my phone reminds you to do the exercises</td>
<td>+ Tick off done exercises</td>
</tr>
<tr>
<td>R4</td>
<td>Yes</td>
<td>The app gives visual support</td>
<td>− Show why you need to do an exercise</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>+ Easy to use</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>+ Videos with instructions</td>
</tr>
<tr>
<td>R5</td>
<td>Yes</td>
<td>You always have your phone with you</td>
<td>+ Easy to use</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>+ Easier navigation</td>
</tr>
<tr>
<td>R6</td>
<td>Yes</td>
<td>The app is smaller and thus easier to use</td>
<td>+ Videos with instructions</td>
</tr>
<tr>
<td>R7</td>
<td>Yes</td>
<td>The app gives visual support</td>
<td>+ Videos with instructions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Seeing the app on my phone motivates you to do the exercises</td>
<td>+ Counting down the number of exercises</td>
</tr>
<tr>
<td>R8</td>
<td>Yes</td>
<td>You always have your phone with you</td>
<td>+ Videos with instructions</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>+ Tick off done exercises</td>
</tr>
<tr>
<td><strong>Booklet</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>R9</td>
<td>Yes</td>
<td>You always have your phone with you</td>
<td>− Show why you need to do an exercise.</td>
</tr>
<tr>
<td>R10</td>
<td>No</td>
<td>The exercises are so easy, you don’t need an app</td>
<td>+ Reminder to do the exercises.</td>
</tr>
<tr>
<td>R11</td>
<td>Yes</td>
<td>The app gives visual support</td>
<td>− Stopwatch function</td>
</tr>
<tr>
<td>R12</td>
<td>Yes</td>
<td>You always have your phone with you</td>
<td>− Show why you need to do an exercise</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>− Possibility to postpone exercises</td>
</tr>
<tr>
<td>R13</td>
<td>Yes</td>
<td>The app gives visual support</td>
<td>+ Videos with instructions</td>
</tr>
<tr>
<td>R14</td>
<td>Yes</td>
<td>You always have your phone with you</td>
<td>− Direct translation of the app to a booklet</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Seeing the app on my phone would remind you to do the exercises</td>
<td>− More variation in the exercises</td>
</tr>
<tr>
<td>R15</td>
<td>Yes</td>
<td>You always have your phone with you</td>
<td>− Direct translation of the app to a booklet</td>
</tr>
<tr>
<td>R16</td>
<td>Yes</td>
<td>An agenda function would be easy</td>
<td></td>
</tr>
</tbody>
</table>

**Discussion**

**Principal Findings**

Previous studies [3,4] have shown that using an app or a booklet with a special NMT program to prevent recurrent ankle sprains has resulted in comparable injury densities during both short-(8 weeks) and long-term (12 months) follow-ups and comparable compliance rates with the program. During the execution of the program during the first 8 weeks, the app and booklet were given comparable scores for simplicity, usefulness, and liking of the exercises. After the 12-month follow-up, the users of the app were significantly more satisfied with the app compared with the users of the booklet. The users of the app evaluated the app as more patient friendly, easier to use, and less annoying and thought that the videos were helpful. With the help of semistructured interviews, 14 out of 16 participants agreed that an app would be of additional benefit over a booklet, mainly due to use of instructional videos, phone portability, and the agenda function. Further suggestions for improving the app that were mentioned by various participants were the ability to postpone exercises and the provision of exercise feedback.

Interventions for preventing sport injuries require high participant compliance [3]. Therefore, ways to increase compliance are a focus of many intervention studies [3]. The “Strengthen Your Ankle” program was developed in 2009. Since then, the program has been studied intensively [3,4,9-11,22]. It was shown that (1) the program was effective in reducing recurrent ankle sprains for those with high compliance [10], (2) the use of either the app or a booklet produced nonsignificant differences in injury densities in both the short and long term [3,4], and (3) both methods had comparable cost-effectiveness of implementation [23].

Over the years, compliance with the “Strengthen Your Ankle” program in RCTs has steadily increased from 23% [9] to 45%
Adherence can be seen as what happens in real-life conditions when individuals with an ankle sprain try to follow the program; compliance is studied in clinical settings. The extent to which the participant obeys the program instructions is measured by compliance rates [12,24]. Research, ideally performed in a more or less controlled setting, implicitly focuses on compliance, rather than on adherence. However, the “Strengthen Your Ankle” program is meant to increase adherence for all individuals at risk for an ankle sprain, not only for those who participate in the studies involved. This study has tried to explore the barriers and opportunities that participants experienced while using the training program via an app or booklet within a controlled study setting. However, because the interviews were held after follow-up, that is, months after the participants had finished the 8 weeks of the training program, we expected to gain insight as to program performance in real-life situations.

A further limitation of this study is the possibility of selection bias for the semistructured interviews. It is possible that only those participants that carried a strong negative or positive view of the program agreed to participate because the invitation for the interviews was made only after termination of the 12-month follow-up. Additionally, the (single) interviewer did not structure the interviews and continued to question the participants when needed. This may have affected the validity of the data analyses. However, it is recognized that this characteristic is inherent to the flexible nature of thematic analysis and does not threaten the depth of analysis [5].

Conclusions
With the use of semistructured interviews and online questionnaires, we were able to evaluate users’ opinions on both the app and booklet. The users of the app were significantly more satisfied with the app although there was no significant difference in the perceived simplicity, usefulness, and liking of the exercise during the 8 weeks of the NMT program. In the interviews, users acknowledged the need for improvements. Future updates should take the users’ suggestions into account because adherence with the NMT program remains an ongoing challenge.

Acknowledgments
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We would like to thank the following partners for their collaboration and recruitment of study participants: Royal Dutch Society for Physical Therapy (KNGF), Dutch Society for Physical Therapy in Sports (NVFS), Dutch College of General Practitioners (NHG), Dutch Sports Medicine Society (VSG), Dutch Olympic Committee (NOC*NSF), Zilveren Kruis Achmea (ZKA), and Disporta.

Conflicts of Interest
None declared.

Multimedia Appendix 1
Question guide for the process evaluation using semi-structured interviews after finishing the 12-month intervention period.

[PDF File (Adobe PDF File), 37KB - rehab_v5i2e13_app1.pdf ]
Multimedia Appendix 2
Responses to process evaluation of the neuromuscular training program after the intervention period.

References


Use of a Low-Cost, Chest-Mounted Accelerometer to Evaluate Transfer Skills of Wheelchair Users During Everyday Activities: Observational Study

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Abstract

Background: Transfers are an important skill for many wheelchair users (WU). However, they have also been related to the risk of falling or developing upper limb injuries. Transfer abilities are usually evaluated in clinical settings or biomechanics laboratories, and these methods of assessment are poorly suited to evaluation in real and unconstrained world settings where transfers take place.

Objective: The objective of this paper is to test the feasibility of a system based on a wearable low-cost sensor to monitor transfer skills in real-world settings.

Methods: We collected data from 9 WU wearing triaxial accelerometer on their chest while performing transfers to and from car seats and home furniture. We then extracted significant features from accelerometer data based on biomechanical considerations and previous relevant literature and used machine learning algorithms to evaluate the performance of wheelchair transfers and detect their occurrence from a continuous time series of data.

Results: Results show a good predictive accuracy of support vector machine classifiers when determining the use of head-hip relationship (75.9%) and smoothness of landing (79.6%) when the starting and ending of the transfer are known. Automatic transfer detection reaches performances that are similar to state of the art in this context (multinomial logistic regression accuracy 87.8%). However, we achieve these results using only a single sensor and collecting data in a more ecological manner.

Conclusions: The use of a single chest-placed accelerometer shows good predictive accuracy for algorithms applied independently to both transfer evaluation and monitoring. This points to the opportunity for designing ubiquitous-technology based personalized skill development interventions for WU. However, monitoring transfers still require the use of external inputs or extra sensors to identify the start and end of the transfer, which is needed to perform an accurate evaluation.

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KEYWORDS
wheelchair transfers; movement evaluation; machine learning; activity monitoring; accelerometer

Introduction

Globally, there are over 70 million wheelchair users (WU), and there is a growing need for wheelchairs to fill the mobility gap for people who are unable, or struggle, to walk [1]. This is a trend we can expect to continue as the population ages, and more people live longer with conditions that affect their ability to walk. Wheelchairs can be manual, electric or have “power assist,” which gives additional power with each push. Regardless of the type of wheelchair being used, the user needs to get into and out of the wheelchair. This process is called transferring.
Transfers are necessary for many daily activities and happen on average between 14 and 18 times a day [23]. Transfers occur between the wheelchair and other surfaces, and they are affected by a variety of factors such as height and stability of the surfaces and space available around them. Depending on the environment and the characteristics of the person, each transfer will have its challenges [4,5].

Learning how to transfer correctly is a critical skill for WU. In order to maintain this independence WU must preserve the functioning in their upper limbs. However, due to the exceptionally high loads, and the repetitive nature of wheelchair transfers, WU frequently suffer from pain in the shoulders and wrists [6]. This pain is caused by musculoskeletal injuries, which can prevent people from using their wheelchair independently.

Wheelchair skills training helps to prevent such injuries by teaching WU correct techniques for everyday activities such as pushing over a variety of surfaces and transferring onto and from many surfaces. Clinicians mostly deliver wheelchair skills training [7] within rehabilitation clinics, but it can also be provided through charities that offer peer-to-peer training, or even remotely via online courses [8]. Regardless of how the training is provided, patients still need to rely on clinicians to evaluate their transfers, and this evaluation generally takes place in the clinic.

Indeed, there is no routine way for wheelchair transfers to be monitored remotely in everyday life settings. Furthermore, the provision of wheelchair skills training is not universal and can depend on geography (eg, more prevalent in more affluent countries), medical diagnosis (eg, spinal injury rehabilitation programs generally integrate wheelchair skills training whereas, for other conditions such as stroke, rehabilitation units might not), and funding [9]. The Web-based e-learning platform piloted by Worobey et al [8] shows the potential to improve the availability of transfer training through massive open online courses, but would benefit from a method for home/self-monitoring for WU that would ensure they did not need to depend on a clinician.

Wearable technologies offer the opportunity to provide monitoring and feedback to WU during their daily lives, particularly on activities and techniques which are known to cause injury. Research in this area has focused on automatically detecting different types of activities from one another (eg, resting, pushing the wheelchair, performing household activities) [10,11]. Most authors have focused on the use of a wrist-worn sensor for activity monitoring [12-14]. A few have linked energy expenditure to accelerometer data [14,15], and I has investigated the quality of pushes, identifying a good style of pushing from a poor one [12]. Very little attention has been dedicated to transfers.

There has only been 1 study which has evaluated the accuracy of classification algorithms for detecting the occurrence of wheelchair transfers, alongside other activities [11]. The researchers used 4 accelerometers located at the wrists, chest, and waist [11]. The experiment was highly successful, and transfer recognition reached 100% accuracy for both quadratic discriminant analysis (QDA) and support vector machine (SVM). However, the study consisted of a highly controlled experimental set-up and involved the performance of consecutive transfers for a set period, reducing movement differences between repetitions of the same activity. Also, the transfers were only executed between 2 surfaces of the same height (2 wheelchairs) rather than between different types of surfaces and different environmental real-life contexts. Therefore, it is not clear if the results generalize to real-life settings. Finally, despite the use of 4 sensors, only in-depth analysis of the contribution of the wrist-worn sensors is reported and it is not clear to what extent the other sensors contribute to the recognition. This is particularly critical given that trunk-worn sensors are, for example, useful for evaluating aspects of transfer quality [16] and WU do not always appreciate wrist-worn sensors as they can interfere with the wheel during pushing [17].

The primary aim of this study was to develop a strategy to enable the use of a single low-cost wearable sensor to evaluate the quality of wheelchair transfers across 3 common transfer scenarios. Body-worn sensors are often used to detect movement (ie, recognition). However, they are rarely used to evaluate the quality of body movement [18]. This is especially true for rehabilitation purposes, as the system needs to be able to capture clinical expertise in evaluating the movement. The secondary aim was to adapt current methods for the detection of wheelchair transfer occurrences through the same sensor in more ecologic settings with the long-term aims of continuously monitoring transfer skills.

Methods

Recruitment

The study was approved by the Internal Review Board at the Georgia Institute of Technology, United States. Calls for participants were made via a laboratory database, recruitment flyers, social media, and relevant online forums. Interested subjects were screened against the following criteria: (1) between 18-65 years of age, (2) use of a wheelchair as primary means of mobility for at least six months, and (3) ability to perform wheelchair transfers independently. Participants were excluded if they (1) were able to fully stand up when transferring, (2) reported the use of a transfer board when transferring, (3) were currently admitted to a hospital or a rehabilitation facility, and (4) reported having upper extremity pain or any medical condition that was likely to be exacerbated through the study protocol (eg, angina, exercise-induced asthma, uncontrolled hypertension).

Equipment

In this study, we consider the use of 1 accelerometer placed on the chest of the user to measure g-force acceleration. The accelerometer was secured to the upper third of the sternum of the participants using double-sided tape. The chest was chosen as it is the part of the body which dictates a good transfer (eg, turning the trunk to align a good head-hip relationship) and is helpful in detecting the start (eg, forward lean of the trunk) and end points of the transfer (eg, controlled descent). Also, the trunk is in motion throughout the wheelchair transfer cycle, whereas the arms are often stationary during key moments in the transfer [19,20]. Finally, the upper third of the sternum was chosen as the location as it guarantees good stability.
measurements [21]. The use of a single accelerometer was preferred to a multi-sensor system, as future applications for long term-monitoring will need to be as unobtrusive as possible in order to maximize the ease of use.

Trunk accelerations were recorded using a single wireless 3-axis accelerometer (range $\pm 16g$, resolution 16-bit, Gulf Coast Data Concepts, MS) sampling at 25Hz. The directions of the acceleration (see Figure 1) were measured in respect to the individual body axes (+ up – down; Y + left – right; Z + front – back). The accelerometer data were filtered using an 8th order low pass Butterworth filter with a cut off frequency of 10Hz to reduce noise. Two video cameras were used to record participants’ transfers, to label the recorded data for transferring quality performance and to determine exact seat-off (start) and landing time (end). Data processing was carried out on MATLAB R2015b, and the accuracy of various classifiers was calculated using WEKA 3.8 data mining suite.

Data Collection
For the data collection, a series of ecologically valid scenarios (see Figure 2) was used consisting of 3 common daily transfers: wheelchair-bed, wheelchair-toilet, and wheelchair-car. The first 2 represent necessary daily activities while car transfers are the most crucial skill for personal independence and social/working life [22]. The wheelchair-bed scenario was recreated in the research facility, and a real accessible bathroom in the building was used for the wheelchair-toilet scenario. The participant’s vehicle was used for the wheelchair-car scenario, as all participants reported ownership of a car.

Participants were asked to perform 2 return transfers (ie, to and from the wheelchair) for each scenario using their own wheelchair. Participants were asked to complete the transfers as they normally would in their everyday lives. The order of the 3 scenarios was randomized across participants. Also, between each transfer, the person was asked to move around the room to ensure variability between transfer executions. Participants were asked to rest for a minimum of one minute after each transfer. Additional resting time was granted to participants who requested it in order to avoid fatigue.

Accelerometer data were collected continuously for the duration of the experiment while the participant rested and moved between different scenarios. Each participant performed 12 transfers for an average of a forty-minute recording for each participant.

Data Analysis
Descriptive statistics, were determined for demographic data of participants.

Automatic Transfer Quality Evaluation
Following the method proposed by Hwang et al [23], the transfer assessment instrument (TAI) was reviewed to identify specific items that could be evaluated using an accelerometer. Only 3 of the 15 items listed in Part 1 of the TAI were considered (see Textbox 1). Part 2 of the TAI was excluded as the evaluator is asked to complete a series of Likert scales based on the overall evaluation of repeated transfers rather than the use of individual skills within a single transfer.

Figure 1. The orientation of the accelerometer’s axes relative to the body during wheelchair transfers and its position on the participant’s sternum.

Figure 2. Bed, car, and toilet transfer scenarios.
Textbox 1. Selected transfer assessment instrument items for the evaluation of transfers using a chest-placed accelerometer.

<table>
<thead>
<tr>
<th>Head-hip relationship (item 12)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subject moves the head in the opposite direction of the hips to make the transfer easier to perform</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Controlled flight (item 11)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transfer is smooth and uses coordinated movements</td>
</tr>
<tr>
<td>Person appears to be safe and able to complete the skill in a controlled manner</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Smooth landing (item 14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The landing phase of the transfer is smooth and well controlled</td>
</tr>
<tr>
<td>For example, hands are not flying off the support surface, and the subject is sitting safely on the target surface</td>
</tr>
</tbody>
</table>

Other evaluation items were excluded as they referred to the positioning of the wheelchair rather than the use of specific transferring skills (items 1, 2, 3, 4, 5), evaluated static body positioning rather than movement (items 6, 8, 9, 10, 13), or were only applicable to transfers performed with the assistance of a caregiver (item 15). Finally, item 7 was omitted as its clinical implications were unclear [24].

In keeping with the guidelines of the TAI 3.0, 2 trained physiotherapists, with at least four years of clinical experience and who were familiar with the use of the TAI, evaluated each transfer identified in the video by assigning a dichotomous score (ie, good or not good) for each item. Each physiotherapist evaluated the transfers independently, and any disagreements over different scores were resolved through consensus meetings.

In order to segment the transfer data from the full accelerometer recording sequence, accurate timestamps for start of lift (when the buttocks of the subject lose contact with the initial surface) and landing (when the buttocks of the subject contact the target surface) were obtained from the annotated videos. The accelerometer data were then partitioned in three time windows as shown by Nawoczenski et al [25]: head-hip relationship phase, flight phase, and landing phase. Time windows were defined within a reasonable interval from the marked start and end of the transfer to accommodate for potential imprecisions due to human error when detecting start and end of the transfer. Each window corresponded to a time epoch where the selected TAI items could be evaluated (see Textbox 2, Figure 3, and Multimedia Appendix 1).

Features for head-hip relationship and landing phases were selected based on the biomechanics characteristics of wheelchair transfers and confirmed by visual inspection of the data. The rationale for the feature selection of each transfer aspect evaluated is described in the following 3 sections.

Textbox 2. Time epochs for automatic transfer quality evaluation.

<table>
<thead>
<tr>
<th>Head-hip relationship phase</th>
</tr>
</thead>
<tbody>
<tr>
<td>±0.75s interval around the marked start lift timestamp</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Flight phase</th>
</tr>
</thead>
<tbody>
<tr>
<td>±0.5s interval around the marked timestamps for start lift and landing</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Landing phase</th>
</tr>
</thead>
<tbody>
<tr>
<td>±0.75s interval around the marked landing timestamp</td>
</tr>
</tbody>
</table>
**Head-Hip Relationship**

The performance of a transfer using a correct head-hip relationship requires the subject to perform a quick forward lean which causes a sharp decrease in the frontal acceleration (segment B: minimum frontal acceleration, minimum frontal jerk). A sudden trunk flexion is usually more effective in relieving weight from the buttocks (maximum total jerk). To gather more momentum, some people may move the trunk slightly backward before bending forward, leading to a greater range of frontal acceleration (segment A-B: range frontal acceleration). The direction along which the trunk moves can be represented by a line connecting the trunk with a point slightly ahead of the tip of the person’s feet. An approximation of the acceleration in that direction can be obtained from the sum of the acceleration values in the vertical direction and the inverse of the acceleration values in the frontal direction (segments A-B and C-D: maximum frontal-downward acceleration, range frontal-downward acceleration).

**Controlled Flight**

A controlled flight can be described as a smooth transition from starting to target surface, as the body follows a linear path without unexpected deviations. We, therefore, selected representative features according to preexisting literature focusing on measuring smoothness of movements during rehabilitation [26,27] (spectral length of acceleration, spectral length of velocity, dimensionless jerk, log dimensionless jerk).

**Smooth Landing**

The moment in which the subject’s buttocks land on the target surface is characterized by a sharp peak of acceleration in the vertical direction (segment E) combined with a smaller peak in the lateral direction (segment F: maximum vertical acceleration, maximum total acceleration). This would likely be reflected in higher average values of acceleration in the observed window of time (mean total acceleration, mean vertical acceleration, root mean square total acceleration). Hard landings will also likely cause large variations in the trunk accelerations, as the trunk moves to regain stability (range total acceleration).

**Feature Selection and Modeling**

The correlation-based feature subset selection method explained in Hall and Smith [28] was used to optimize the feature selection process (see Textbox 3). Only selected features were used to build the automatic transfer evaluation system. Random forest, SVM, Naïve Bayes, multinomial logistic regression (MLR) were used to build the classifiers as they are commonly used in the related literature. A leave-one-subject-out cross-validation method was used to calculate the accuracy of the models and test for generalization over unseen users.
Textbox 3. List of selected features calculated for automatic transfer quality evaluation.

<table>
<thead>
<tr>
<th>Feature Set</th>
<th>Features</th>
</tr>
</thead>
<tbody>
<tr>
<td>Head-hip relationship features</td>
<td>• Minimum frontal acceleration</td>
</tr>
<tr>
<td></td>
<td>• Range frontal acceleration</td>
</tr>
<tr>
<td></td>
<td>• Maximum frontal-downward acceleration</td>
</tr>
<tr>
<td></td>
<td>• Minimum frontal jerk</td>
</tr>
<tr>
<td>Smooth landing features</td>
<td>• Maximum total acceleration</td>
</tr>
<tr>
<td></td>
<td>• Range total acceleration</td>
</tr>
<tr>
<td></td>
<td>• Mean total acceleration</td>
</tr>
<tr>
<td></td>
<td>• Root mean square total acceleration</td>
</tr>
</tbody>
</table>

### Automatic Transfer Detection

Accelerometer data were divided into windows of 25 samples (1s at 25Hz) with a 50% overlap between neighboring windows. All windows were labeled for transfer occurrence according to the timestamps extracted from the videos. From each window, 59 features were extracted according to the procedure illustrated by Garcia-Masso et al [11]. Fourteen features were extracted for each accelerometer axis and the total acceleration vector including (1) SD, (2) variance, (3) 10th, 25th, 50th, 75th, and 90th percentiles, (4) interquartile range, (5) range between the 10th and the 90th percentiles, and (6) lag-one correlation of the counts in a period of 10 seconds as a measure of temporal dynamics [11,29]. Additionally, we used a two-level wavelet transform, with Daubechies 2 as mother wavelet [11,30] to calculate the Euclidean norm of the detail coefficients of the first and second level of resolution and the approximation coefficient of the second level. Finally, we calculated sample entropy for each axis (tolerance 0.3 standard deviations, pattern length 2) as shown in [11,31] and the cross-correlation between the 3 axes.

Although wheelchair transfers were only 1 of the activities classified by Garcia-Masso et al [11] the features used were found to be very informative to discriminate between discrete types of activities undertaken by WU. Even though these activities were quite different from each other, the use of the same features would allow for the integration of transfer detection within a more general activity detection framework for the WU.

As for the automatic transfer quality evaluation, the correlation-based feature subset selection method described by Hall and Smith [28] identified 25 relevant features across all participants that were used in the classifiers' list of attributes (see Textbox 4).

Textbox 4. List of selected features for the automatic transfer detection.

<table>
<thead>
<tr>
<th>Feature Set</th>
<th>Features</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time domain features</td>
<td>• Variance (Z, Total)</td>
</tr>
<tr>
<td></td>
<td>• SD (Total)</td>
</tr>
<tr>
<td></td>
<td>• 10th Percentile (Y, Z, Total)</td>
</tr>
<tr>
<td></td>
<td>• 25th Percentile (Z)</td>
</tr>
<tr>
<td></td>
<td>• 50th Percentile (Total)</td>
</tr>
<tr>
<td></td>
<td>• 75th Percentile (Total)</td>
</tr>
<tr>
<td></td>
<td>• 90th Percentile (Z, Total)</td>
</tr>
<tr>
<td></td>
<td>• Interquartile Range (X, Y, Z)</td>
</tr>
<tr>
<td></td>
<td>• Range between 10th and 90th percentiles (Y, Z, Total)</td>
</tr>
<tr>
<td></td>
<td>• Lag-one correlation (Z, Total)</td>
</tr>
<tr>
<td>Wavelet transform features</td>
<td>• Euclidean norm 1st level coefficient (Y)</td>
</tr>
<tr>
<td></td>
<td>• Euclidean norm 2nd level coefficient (Y, Z, Total)</td>
</tr>
<tr>
<td></td>
<td>• Approximation coefficient of the 2nd level (Z, Total)</td>
</tr>
</tbody>
</table>
Table 1. Number of instances labeled according the occurrence and nonoccurrence of transfers for each participant.

<table>
<thead>
<tr>
<th>Participant gender</th>
<th>Age (years)</th>
<th>Transfer (relative %)</th>
<th>No transfer (relative %)</th>
<th>Totalb</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>26</td>
<td>145 (3.1%)</td>
<td>4520 (96.9%)</td>
<td>4665</td>
</tr>
<tr>
<td>Male</td>
<td>26</td>
<td>100 (2.0%)</td>
<td>4937 (98.0%)</td>
<td>5037</td>
</tr>
<tr>
<td>Male</td>
<td>47</td>
<td>105 (1.4%)</td>
<td>7211 (98.6%)</td>
<td>7316</td>
</tr>
<tr>
<td>Male</td>
<td>25</td>
<td>108 (2.6%)</td>
<td>4005 (97.4%)</td>
<td>4113</td>
</tr>
<tr>
<td>Male</td>
<td>30</td>
<td>109 (2.1%)</td>
<td>5219 (97.9%)</td>
<td>5328</td>
</tr>
<tr>
<td>Male</td>
<td>35</td>
<td>108 (2.5%)</td>
<td>4273 (97.5%)</td>
<td>4381</td>
</tr>
<tr>
<td>Male</td>
<td>35</td>
<td>101 (1.7%)</td>
<td>5787 (98.3%)</td>
<td>5888</td>
</tr>
<tr>
<td>Male</td>
<td>46</td>
<td>117 (2.2%)</td>
<td>5104 (97.8%)</td>
<td>5221</td>
</tr>
<tr>
<td>Female</td>
<td>58</td>
<td>93 (1.0%)</td>
<td>9022 (99.0%)</td>
<td>9115</td>
</tr>
</tbody>
</table>

aRefers to the ratio between instances of transfer occurrence and the instances of no transfer occurrence.
bRefers to the total number of instances for each participant extracted from the accelerometer data.

Only selected features were used to build the automatic transfer detection system. Classification algorithms used for transfer monitoring were the same as the one used for automatic transfer quality evaluation. A leave-one-subject-out cross-validation strategy was to evaluate the performance and generalization of the models. Having the participant wear the accelerometer for the whole duration of the experiment minimized the disruption and resulted in the collection of a more realistic dataset. Accelerometer data were recorded continuously for approximately forty minutes for each participant. However, only 12 transfers lasting for a couple of seconds each were performed within the time frame. This resulted in a severe imbalance (See Table 1) between the transfer instances (986/51064, 1.9%) and no transfer instances (50078/51064, 98.1%). To reduce classifiers bias towards the majority class, random sampling with a 1:1 transfer/no transfer ratio was used for all participants.

Results

Participants

Nine manual WU (8 males, 1 female) were recruited for the study. Their mean age was 36.4 years (SD 11.5), mean height was 181.5 cm (SD 13.5), and mean weight was 88.4 kg (SD 17.6). All participants were successfully able to complete the 12 transfers and no missing data were found in the dataset (see Table 2).

Evaluation of Transfer Quality

After the physiotherapists’ evaluations, the dataset contained the following ratio of good/bad transfer instances for each evaluation item: (1) 59/49 for head-hip relationship, (2) 106/2 for controlled flight, and (3) 61/47 for smooth landing. Due to the unbalanced nature of the dataset for the controlled flight item, the automatic evaluation was not performed.

For both evaluation items, all classifiers exhibited similar average accuracies across all participants. For the evaluation of the head-hip relationship item average classifier accuracies across all participants were: (1) 75.9% (SD 13.5%) for SVM, (2) 72.2% (SD 15.6%) for random forest, (3) 75% (SD 13.8%) for Naïve Bayes, and (4) 75.9% (SD 14.1%) for MLR. For the evaluation of the smooth landing item average classifiers accuracies across all participants were: (1) 79.6% (SD 7.4%) for SVM, (2) 73.1% (SD 13.7%) for random forest, (3) 78.7% (SD 7.3%) for Naïve Bayes, and (4) 78.7% (SD 7.3%) for MLR. SVM was found to be the most accurate classifiers across all participants for the evaluation of both head-hip relationship use and smoothness of landing.

Accuracy and F1 scores displayed substantial variations across individual participants (see Table 3) while SVM classifiers achieved a balanced relative accuracy for both evaluation items (see Table 4).

Assessment of Automatic Transfer Detection

Average classifiers accuracies for automatic transfer detection were: (1) 86.8% (SD 10.1%) for SVM, (2) 83.2% (SD 10.1%) for random forest, (3) 91.9% (SD 4.9%) for Naïve Bayes, and (4) 87.8% (SD 4.9%) for MLR. Overall, Naïve Bayes classifiers obtained higher classification accuracies. Naïve Bayes classifiers displayed a considerably higher relative accuracy for no transfer occurrence instances. On the other hand, MLR classifiers achieved a more balanced relative accuracy between the 2 classes (Table 5 and Figure 4).
Table 2. Overview of participants’ characteristics.

<table>
<thead>
<tr>
<th>Participant gender</th>
<th>Age (years)</th>
<th>Medical condition</th>
<th>Wheelchair use (years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>26</td>
<td>SCI C6</td>
<td>2.1</td>
</tr>
<tr>
<td>Male</td>
<td>26</td>
<td>SCI C7</td>
<td>0.8</td>
</tr>
<tr>
<td>Male</td>
<td>47</td>
<td>SCI T4</td>
<td>8.5</td>
</tr>
<tr>
<td>Male</td>
<td>25</td>
<td>SCI T5</td>
<td>2.8</td>
</tr>
<tr>
<td>Male</td>
<td>30</td>
<td>SCI C6</td>
<td>12.0</td>
</tr>
<tr>
<td>Male</td>
<td>35</td>
<td>SCI T12</td>
<td>3.3</td>
</tr>
<tr>
<td>Male</td>
<td>35</td>
<td>SCI T1</td>
<td>7.8</td>
</tr>
<tr>
<td>Male</td>
<td>46</td>
<td>SCI T5</td>
<td>10.9</td>
</tr>
<tr>
<td>Female</td>
<td>58</td>
<td>TM</td>
<td>9.5</td>
</tr>
</tbody>
</table>

aSCI: spinal cord injury.
bC(n): Cervical spinal cord level of injury.
cT(n): Thoracic spinal cord level of injury.
dTM: transverse myelitis.

Table 3. Accuracy and weighted average score of support vector machine classifiers for the evaluation of head-hip relationship and smooth landing items.

<table>
<thead>
<tr>
<th>Participant gender</th>
<th>Age (years)</th>
<th>SVM accuracy (head-hip relationship)</th>
<th>F1 score</th>
<th>SVM accuracy (smooth landing)</th>
<th>F1 score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>26</td>
<td>66.7%</td>
<td>.667</td>
<td>75.0%</td>
<td>.739</td>
</tr>
<tr>
<td>Male</td>
<td>26</td>
<td>100.0%</td>
<td>1.00</td>
<td>83.3%</td>
<td>.838</td>
</tr>
<tr>
<td>Male</td>
<td>47</td>
<td>66.7%</td>
<td>.686</td>
<td>83.3%</td>
<td>.829</td>
</tr>
<tr>
<td>Male</td>
<td>25</td>
<td>91.7%</td>
<td>.923</td>
<td>75.0%</td>
<td>.755</td>
</tr>
<tr>
<td>Male</td>
<td>30</td>
<td>75.0%</td>
<td>.750</td>
<td>75.0%</td>
<td>.739</td>
</tr>
<tr>
<td>Male</td>
<td>35</td>
<td>66.7%</td>
<td>.663</td>
<td>66.7%</td>
<td>.667</td>
</tr>
<tr>
<td>Male</td>
<td>35</td>
<td>83.3%</td>
<td>.844</td>
<td>83.3%</td>
<td>.829</td>
</tr>
<tr>
<td>Male</td>
<td>46</td>
<td>75.0%</td>
<td>.767</td>
<td>83.3%</td>
<td>.833</td>
</tr>
<tr>
<td>Female</td>
<td>58</td>
<td>58.3%</td>
<td>.569</td>
<td>91.7%</td>
<td>.917</td>
</tr>
</tbody>
</table>

aSVM: support vector machine.
bF1: weighted average.

Table 4. Support vector machine global confusion matrices showing actual versus predicted classes (and relative percentages) for the evaluation of head-hip relationship use, and smoothness of landing for all wheelchair transfers.

<table>
<thead>
<tr>
<th>Actual class</th>
<th>Predicted class</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>HHa</td>
</tr>
<tr>
<td>HH</td>
<td>31 (63.3%)</td>
</tr>
<tr>
<td>No HH</td>
<td>8 (13.6%)</td>
</tr>
<tr>
<td>SL</td>
<td>—</td>
</tr>
<tr>
<td>No SL</td>
<td>—</td>
</tr>
</tbody>
</table>

aHH: head-hip relationship.
bSL: smooth landing.
Table 5. Global confusion matrices for automatic transfer detection using Naïve Bayes and multinomial logistic regression classifiers.

<table>
<thead>
<tr>
<th>Actual class</th>
<th>Predicted class</th>
<th>Naïve Bayes classifiers</th>
<th>MLR^a</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>TO^b</td>
<td>No TO</td>
<td>TO</td>
</tr>
<tr>
<td>TO</td>
<td>46160 (92.8%)</td>
<td>3558 (7.2%)</td>
<td>—</td>
</tr>
<tr>
<td>No TO</td>
<td>286 (27.5%)</td>
<td>754 (72.5%)</td>
<td>—</td>
</tr>
<tr>
<td>MLR</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TO</td>
<td>—</td>
<td>—</td>
<td>44293 (89.1%)</td>
</tr>
<tr>
<td>No TO</td>
<td>—</td>
<td>—</td>
<td>105 (15.3%)</td>
</tr>
</tbody>
</table>

^aMLR: multinomial logistic regression.
^bTO: transfer occurrence.

Figure 4. Classifiers accuracy for automatic transfer detection across all participants.

Discussion

Principal Findings

To our knowledge, this is the first paper that has attempted to use a body-worn accelerometer to both monitor the occurrence of wheelchair transfers and evaluate their quality. Using a single body-worn accelerometer located at the chest, we were able to evaluate 2 important elements of wheelchair transfers technique: head-hip relationship use, and smoothness of landing with a respective accuracy of 75.9% and 79.9%. These results are comparable to previous studies within the WU population, such as research which classifies wheelchair propulsion [32,33]. Unfortunately, we were unable to perform the automatic evaluation for the controlled flight item, as nearly all participants were able to control their movement during transferring. Participants in the current study were expert WU with good upper body strength. However, in a population of novice WU, this item could be particularly important in helping to identify difficulties and highlight the absence of postural control which can be linked to an increased risk of falling [34].

The choice of using a single chest-mounted accelerometer for the automatic transfer quality evaluation limited our assessment to 3 items of the TAI. However, this evaluation can have important clinical implications if extended to transfers performed in everyday settings. For example, the use of a head-hip relationship during wheelchair transfers has been shown to reduce muscular activity [35], shoulder forces [24], and increase stability [36]. Additionally, while a smooth landing is not necessarily linked with a reduction in the upper limb forces measured during wheelchair transfers, it offers an important indication of safety, as poor control in the final stage of the transfer can lead to an increased risk of falling [37].

Despite not reaching 100% accuracy, the current study shows the potential of using a single chest-mounted sensor to detect the occurrence of wheelchair transfers. Previous research by Garcia-Masso et al [11] included the chest sensor to increase the accuracy of classification when combined with
wrist-mounted sensors but failed to investigate the data from the chest alone. Our results show that such a sensor is as powerful as a pair of wrist sensors in detecting transfers.

The placement on the chest also allowed for the quality of movement to be evaluated. However, this sensor alone is not sufficient to measure the exact start and end of a transfer (or other items of TAI). Therefore, future work should investigate the use of an unobtrusive second sensor to aid with accurate detection (eg, a pressure switch on the wheelchair itself).

It should be noted that, even if the data from the current study are not directly comparable with [11], our dataset had increased complexity due to its higher ecological variability and to the continuous detection of such events. Indeed, we attempted to replicate a typical pattern of daily activities within a WU’s day by asking participants to wear the accelerometer while traveling and resting between scenario activities. This makes detecting transfers a more difficult task than when transfers are completed cyclically for up to a minute at a time between surfaces of a fixed height, and without any change in scenario.

The detection of transfers was more successful for some participants than others. The Naïve Bayes classifiers were the most accurate across all participants. However, it was unbalanced and overpredicted the number of transfers when no transfer was present. Despite this the Naïve Bayes classifiers were more robust, ensuring an accuracy of more than 80% for all participants. When the more balanced MLR was used the accuracy for participant 1 (male, 26 years of age) and 2 (male, 26 years of age) dropped below 70%. It is unclear why these participants were so affected. Future work should look to replicate our work in the wild and with a larger and more heterogeneous sample of WU, which we believe would begin to address the limitations of the current dataset. In fact, despite our efforts, the current set of participants included mainly males with SCI. Although the imbalance of genders and medical conditions among participants are not uncommon in wheelchair studies [38], it can limit the potential for generalization of results. Further research could also be carried out to identify alternative and additional locations for sensor positioning with the aim to maximize the accuracy of transfer detection.

Future Developments

Overall, the use of machine learning techniques to automatically detect and evaluate wheelchair transfers shows good potential for future clinical and well-being applications. A wearable system would allow people to self-monitor their transfers and seek additional medical help as and when required. Also, the system could be used to provide feedback to WU, helping them to identify potential weaknesses and providing suggestions for improvements. If paired with data concerning, for example—the environment, the emotional state of the WU, and time of day—a more complex picture of wheelchair transfers can be built, and better feedback and support mechanisms put in place. Therefore, the larger aim of our project is to develop a wearable system capable of continuously tracking and giving real-time feedback to WU on their transfer ability as they go about their life. Future developments should look into the possibility to combine the chest accelerometer with a portable surface electromyography system placed on the arm, as this could allow for a complete picture of the transfer skills to be captured. This information could then be used to provide more detailed feedback to the WU to help them train and practice the movement in real-life contexts.

Finally, the ability to easily map transfer difficulties in the built environment could also allow WU to share their experiences and provide information about accessibility standards of various establishments (ie, hotel rooms, restaurant toilet). This could also be extended to lower- and middle-income countries, where the majority of disabled people live, who frequently do not have access to rehabilitation programs [39].

Conclusions

In this study, we investigated the use of a single chest-mounted accelerometer to monitor the occurrence of wheelchair transfers and evaluate their quality under three ecological settings. Using features extracted from the accelerometer we were able to improve the accuracy of detection of transfers for the ubiquitous computing literature in this area while also detecting key elements of the quality of movement at performance levels observed for other aspects of the movements. Results from this study open new possibilities for unobtrusive monitoring and evaluation of the performance of wheelchair transfers in the real world that could lead to important applications for wheelchair transfers training, upper limb injury prevention, and improved accessibility.

Acknowledgments

This work was partially supported by the Adaptive Assistive Rehabilitative Technology: Beyond the Clinic (AART-BC) grant (EP/M025543/1) and the UbiHealth project (MC-IRSES 316337). The authors wish to acknowledge Jason Ma, Austin Little, and Morris Huang for their help during data collection.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Clinical evaluation of wheelchair transfers.
References


Abbreviations

C(n): cervical spinal cord level of injury

F1: weighted average

HH: head-hip relationship
MLR: multinomial logistic regression
QDA: quadratic discriminant analysis
SCI: spinal cord injury
SL: smooth landing
SVM: support vector machine
TAI: transfer assessment instrument
TM: transverse myelitis
TO: transfer occurrence
T(n): thoracic spinal cord level of injury
WU: wheelchair user(s)

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A Web-Based Knowledge Translation Resource for Families and Service Providers (The “F-Words” in Childhood Disability Knowledge Hub): Developmental and Pilot Evaluation Study

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Abstract

Background: The “F-words in Childhood Disability” (Function, Family, Fitness, Fun, Friends, and Future) are an adaptation and an attempt to operationalize the World Health Organization’s (2001) International Classification of Functioning, Disability and Health (ICF) framework. Since the paper was published (November 2011), the “F-words” have attracted global attention (>12,000 downloads, January 2018). Internationally, people have adopted the “F-words” ideas, and many families and service providers have expressed a need for more information, tools, and resources on the “F-words”.

Objective: This paper reports on the development and pilot evaluation of a Web-based knowledge translation (KT) resource, the “F-words” Knowledge Hub that was created to inform people about the “F-words” and to provide action-oriented tools to support the use of the “F-words” in practice.

Methods: An integrated research team of families and researchers at CanChild Centre for Childhood Disability Research collaborated to develop, implement, and evaluate the Knowledge Hub. A pilot study design was chosen to assess the usability and utility of the Web-based hub before implementing a larger evaluation study. Data were collected using a brief anonymous Web-based survey that included both closed-ended and open-ended questions, with the closed-ended responses being based on a five-point Likert-type scale. We used descriptive statistics and a summary of key themes to report findings.

Results: From August to November 2017, the Knowledge Hub received >6,800 unique visitors. In 1 month (November 2017), 87 people completed the survey, of whom 63 completed the full survey and 24 completed 1 or 2 sections. The respondents included 42 clinicians and 30 family members or individuals with a disability. The majority of people visited the Knowledge Hub 1-5 times (n=63) and spent up to 45 minutes exploring (n=61) before providing feedback. Overall, 66 people provided information on the perceived usefulness of the Knowledge Hub, of which 92% (61/66) found the Knowledge Hub user-friendly and stated that they enjoyed exploring the hub, and a majority (n=52) reported that the Knowledge Hub would influence what they did when working with others. From the open-ended responses (n=48), the “F-words” videos (n=21) and the “F-words” tools (n=15) were rated as the best features on the Knowledge Hub.

Conclusions: The “F-words” Knowledge Hub is an evidence-informed Web-based KT resource that was useful for respondents, most of whom were seen as “early adopters” of the “F-words” concepts. Based on the findings, minor changes are to be made to improve the Knowledge Hub before completing a larger evaluation study on the impact at the family, clinician, and organizational levels with a wider group of users. Our hope is that the “F-words” Knowledge Hub will become a go-to resource for knowledge sharing and exchange for families and service providers.
Introduction

Background

It has been several years since the paper “The ‘F-words’ in Childhood Disability: I swear this is how we should think!” was published in Child: Care, Health and Development [1]. The “F-words” (Function, Family, Fitness, Fun, Friends, and Future) are an adaptation and operationalization of the World Health Organization’s International Classification of Functioning, Disability and Health (ICF) [2]. The initial aim of the “F-words” paper was to spread awareness of the ICF and to encourage people to apply these modern ways of thinking and developmental approaches to childhood disability [1]. Since it was first published (early November 2011) to December 2017, the paper has been cited over 140 times and downloaded over 12,000 times.

In 2014, based on considerable interest in the paper, we formed an integrated research team at CanChild Centre for Childhood Disability Research focused on disseminating the “F-words” into practice. At that time, several parents (ie, early adopters) had learned about the “F-words,” liked the ideas, and were interested in how to share the “F-words” message with more families. Recognizing the potential impact of an integrated approach to this work (ie, families and researchers working together), we partnered with family stakeholders to develop and evaluate knowledge translation (KT) strategies tailored to meet the families’ needs and preferences.

The first project involved the development, dissemination, and evaluation of a three-minute awareness video [3]. A video was chosen as an initial dissemination strategy as it was engaging, relatively easy to produce, and could be freely shared with a broad audience. At that time, the “F-words” paper was not yet open access and thus was reaching a limited audience in the scientific and clinical communities.

We evaluated the video by tracking its reach and asking viewers to complete an anonymous Web-based survey. In the first 2 months, there were 715 views and 137 survey responses. Overall, we learned that 97.8% (134/137) of people “extremely liked” the “F-words” video, and 87.5% (120/137) indicated they would share the video, and 92.7% (127/137) wanted to learn more. The CanChild website was identified by 65.7% of respondents (90/137) as the most popular strategy for sharing further information on the “F-words” concepts. A complete report of our findings and the lessons learned from this project are published [3].

The awareness video was only the first step toward moving the “F-words” into practice. By January 2015, we had given >30 international presentations and the “F-words” ideas had continued to spread over social media. We were gratified by the uptake of these ideas around the world and were excited to see the imaginative ways in which people were adapting and adopting the “F-words” to local contexts. We were also learning a great deal about the application of the “F-words” by connecting and working with families and other stakeholders such as service providers and health care administrators around the world. Therefore, as a research team, we were acting as “knowledge brokers” [4] by working with interested people to share and exchange knowledge on the “F-words” concepts.

From our conversations with the families and service providers, it was evident that there was significant interest in having more information on the “F-words” as well as action-oriented resources and tools to assist with the application of the “F-words” into practice. Furthermore, as the “F-words” ideas continued to spread, we recognized the need (and opportunity) to compile and share all that was being done on the “F-words” ideas by building a centralized Web-based community for knowledge sharing and exchange. Therefore, in 2015, our research team decided to develop, implement, and evaluate the usability and utility of a Web-based KT resource: a website called “The ‘F-words’ in Childhood Disability Knowledge Hub.”

The purpose of the “F-words” Knowledge Hub was to inform families and service providers about “F-words”/ICF concepts and to provide action-oriented tools to support the uptake and use of the “F-words” in practice. The Knowledge Hub is currently hosted on CanChild’s website [5] and is meant to be an ever-growing resource for knowledge sharing and exchange. The CanChild website is world-renowned in the field of childhood disability and receives over 12,000 unique visitors each month from over 205 countries [6].

Modern Approaches to Knowledge Translation

In the last several years, there has been increasing interest in using the internet as a platform for KT and the use of Web-based KT resources as a strategy for disseminating health research evidence in the field of childhood disability [7-10]. Levac et al [7] defined Web-based KT resources as “e-learning products that translate evidence-based knowledge to disseminate information that increases awareness, informs clinical practice, and stimulates practice change.” The Web-based KT resources include websites, educational modules, downloadable PDFs, blogs, and wikis [7,11]. Some of the advantages of Web-based resources are (1) the ability to be self-paced or self-directed; (2) accessibility and broad reach; (3) incorporation of engaging multimedia content; and (4) promotion of knowledge sharing and exchange [7,12].

While the current evidence base for Web-based KT strategies is limited, some studies have shown promising findings [12,13]; however, more research is needed to identify the most effective Web-based KT strategies and to understand their impact on behavior change and patient outcomes [13,14]. Research is also needed to explore the impact of Web-based KT resources as a single intervention compared with multifaceted interventions, such as a combination of Web-based KT resources and educational outreach [12,13].
This paper reports on the development process, usability, and utility of the Knowledge Hub. The Knowledge-to-Action (KTA) framework was used as the guiding theoretical underpinning for this research [15]. KT theories, models, and frameworks are recommended to guide the development, implementation, and evaluation of KT strategies [16-18]. The KTA framework provided a conceptual map of the KT process steps involved in transferring knowledge to practice [15]. For this study, we focused on the three steps of the action cycle: “select, tailor, and implement the intervention,” “monitor knowledge use,” and “evaluate outcomes.” This study was part of a larger research program that had already addressed the earlier stages of the action cycle [3].

Methods

Integrated Knowledge Translation Strategy

We implemented a formal integrated knowledge translation (iKT) strategy to develop, implement, and evaluate the Knowledge Hub. iKT involves the collaboration of researchers and knowledge users (eg, families and service providers) throughout all stages of the research or KT process [19] and has been found to increase the effectiveness and sustainability of KT interventions [20,21]. This project was led by an integrated team of children’s health researchers (PR, SB, JWG), family stakeholders (DG, JB, DK), and a doctoral student (AC), who coordinated the project.

All team members were involved in each stage of the project: (1) participating in initial planning stages; (2) providing feedback on the content and design of the Knowledge Hub; (3) creating and sharing tools/resources; (4) assisting with evaluation; and (5) disseminating the hub across their social networks. During the initial planning stages, team meetings were held by teleconference. We initially planned to develop an “F-words” Tool Kit as a paper-based resource designed to share knowledge and provide tools/resources to support the use of the “F-words” in practice; however, after extensive conversations with stakeholders and a review of the literature, we turned toward Web-based KT strategies (ie, the Knowledge Hub). AC led the development of the hub, but feedback was sought and received from all team members throughout the development process. Most team correspondence was done through email.

An area in which all three family stakeholders were heavily involved was the creation of the “F-words” tools; the “F-words” agreements, photo collage, goal sheet, and profile. Many of the ideas for the tools came from family stakeholders’ personal experiences of working with service providers and their perceptions of how the “F-words” could be used in practice. As an integrated research team, we discussed the purpose and goals for each tool, and then with the support of CanChild students we developed draft tool templates that could be distributed to all team members for feedback. When all team members had approved the tools, they were then posted on the Knowledge Hub.

Knowledge Hub Development Process

To help with the planning and development of the Knowledge Hub, we used Levac et al’s [7] best practice recommendations for designing Web-based KT resources. These were based on their experiences developing and evaluating Web-based KT resources, as well as a review of the KT and instructional design literature [7]. They identified four main recommendations: (1) develop evidence-based user-centered content; (2) tailor content to the Web-based format; (3) evaluate impact; and (4) share the results and disseminate knowledge. Each recommendation had several specific steps; the full description of the application of Levac et al’s [7] recommendations for this study is provided in Multimedia Appendix 1.

Description of Knowledge Hub

The purpose of the Knowledge Hub is to have a single site where people can go to learn about and share ideas for utilizing the “F-words” concepts in practice. The Web-based hub [22] includes tools and resources created by our research team, as well as materials that have been generously shared by stakeholders from around the world. Everything on the Knowledge Hub is freely available to share and adapt to localized practice settings. The Knowledge Hub has 6 main sections: (1) the F-words Homepage; (2) ICF Resources; (3) F-words Footprint; (4) Family & Clinician Voices; (5) F-words Tools; and (6) F-words Research Team. A full description of the Knowledge Hub is provided in Multimedia Appendix 2.

Knowledge Hub Evaluation

A pilot study design was used to assess the usability and utility of the Knowledge Hub, and to make any necessary changes, before implementing a larger evaluation study. Usability was measured with “usefulness” questions (ie, clear purpose, user-friendly, content meaningful or relevant) and utility was measured using “use” questions (ie, impact and use intent, change in knowledge, attitude, and behavior). Usability and utility testing is a critical component to the success of KT interventions [7,23]. Visitors to the Knowledge Hub were asked to review the hub and voluntarily provide feedback by completing a brief anonymous Web-based open survey through McMaster University’s LimeSurvey program. Participants were told that by completing the survey they were giving their consent to participate in the study. A survey link was posted on the Knowledge Hub, and a recruitment email and poster were distributed through CanChild’s social networks. The recruitment poster is provided in Multimedia Appendix 3.

The survey included both closed-ended and open-ended questions. The closed-ended responses had a five-point Likert-type scale that evaluated the visitors’ prior familiarity with the “F-words”, the perceived usefulness, and reported or intended use of the Knowledge Hub. Adaptive questioning was used (ie, some questions were conditionally displayed based on the responses to previous questions) to reduce the complexity of the survey. There were 37 questions in the survey. Google analytics evaluated the reach by tracking the number of visitors to the hub over a four-month period. Descriptive statistics were used to analyze the quantitative information, and descriptive content analysis was used to identify and synthesize the key
themes from the open-ended questions. Ethics approval was obtained from Hamilton Integrated Research Ethics Board (Project# 2017-0977).

Results

Google Analytic Data (Tracking the Reach)
Over the four-month evaluation period (August-November 2017), there were over 6,800 unique visitors to the Knowledge Hub, with the number of visitors increasing each month (Figure 1). This could correspond with KT strategies implemented by the research team (eg, conference presentations, educational outreach visits, monthly CanChild newsletters featuring the Knowledge Hub) and spread of the Knowledge Hub by people who liked and were sharing it within their communication channels and social networks.

Survey Responses

Survey Completion
The survey went live on November 3, 2017, and data were collected for 1 month. A total of 87 respondents provided information, with 63 completing the full survey and 24 partially completing the survey (ie, 1 or 2 sections), providing a completion rate of 72%. Most people visited the Knowledge Hub 1-5 times (n=63) and spent up to 45 minutes exploring the hub (n=61) prior to providing feedback. The following results were based on the survey data.

Respondent Demographics
Just under half the respondents that completed the survey lived in Canada (42/87, 48%). The only other country with >10 respondents was the United States (17/87, 20%). The remainder of respondents came from 13 countries. Respondents were asked to state the perspective from which they were viewing the Knowledge Hub (eg, family member, clinician etc). Of the 87 people who completed the survey, 42 were clinicians and 30 were family members (n=20) or individuals with a disability (n=10). There was a wide distribution of perspectives with many respondents (n=36) falling into >1 stakeholder category (Table 1).

Respondents’ Familiarity with the “F-words”
The majority of people (62/87, 71%) had heard of the “F-words” prior to visiting the Knowledge Hub and either “extremely liked the ideas” (38/62, 61%) or “liked the ideas” (21/62, 34%). Of the 62 people who were familiar with the “F-words”, 43 (69%) felt confident identifying and explaining the “F-words” ideas, 37 (60%) had shared them with others, and 35 (56%) indicated that they had used or applied them in practice prior to exploring the hub. To understand how people were using or applying the “F-words,” we asked for open-ended feedback. The majority of people who provided written responses were clinicians, researchers, people with disabilities, or family members. Depending on the stakeholder group, the use of the “F-words” concepts varied. Examples of how the “F-words” concepts have been used by each stakeholder group are shown in Table 2.

Perceived Usefulness of the Knowledge Hub
To evaluate the usefulness of the Knowledge Hub, respondents were asked to rate their overall satisfaction. Of the 87 people who started the survey, 66 people completed this section. Therefore, the following data are based on these 66 responses. Overall, 86% (57/66) of respondents felt the purpose was clear, 92% (61/66) found the Knowledge Hub user-friendly, and 92% (61/66) and 94% (62/66) perceived the content to be meaningful and relevant for families and service providers, respectively. The average scores ranged from 4.23 to 4.39 out of 5 for each category (Table 3).

Figure 1. Number of visits to the Knowledge Hub.
Table 1. Demographic characteristics of respondents (N=87).

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Country of residence</strong></td>
<td></td>
</tr>
<tr>
<td>Canada</td>
<td>42 (48)</td>
</tr>
<tr>
<td>United States</td>
<td>17 (20)</td>
</tr>
<tr>
<td>Australia</td>
<td>4 (5)</td>
</tr>
<tr>
<td>Spain</td>
<td>3 (3)</td>
</tr>
<tr>
<td>Brazil</td>
<td>3 (3)</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>2 (2)</td>
</tr>
<tr>
<td>Ethiopia</td>
<td>2 (2)</td>
</tr>
<tr>
<td>South Africa</td>
<td>2 (2)</td>
</tr>
<tr>
<td>No answer</td>
<td>5 (6)</td>
</tr>
<tr>
<td><strong>Type of stakeholder</strong></td>
<td></td>
</tr>
<tr>
<td>Clinician</td>
<td>42 (48)</td>
</tr>
<tr>
<td>Researcher</td>
<td>24 (28)</td>
</tr>
<tr>
<td>Family member</td>
<td>20 (23)</td>
</tr>
<tr>
<td>Educator</td>
<td>17 (20)</td>
</tr>
<tr>
<td>Friend of someone with a disability</td>
<td>17 (20)</td>
</tr>
<tr>
<td>Student</td>
<td>13 (15)</td>
</tr>
<tr>
<td>Person with a disability</td>
<td>10 (11)</td>
</tr>
<tr>
<td>No answer</td>
<td>2 (2)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>69 (79)</td>
</tr>
<tr>
<td>Male</td>
<td>13 (15)</td>
</tr>
<tr>
<td>No answer</td>
<td>5 (6)</td>
</tr>
<tr>
<td><strong>Previously aware of the “F-words”</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>62 (71)</td>
</tr>
<tr>
<td>No</td>
<td>19 (22)</td>
</tr>
<tr>
<td>No answer</td>
<td>6 (7)</td>
</tr>
</tbody>
</table>

*a*Includes countries with >1 respondent.

*b*Includes stakeholder groups with >5 respondents.

*c*Some respondents fit into >1 group (eg, clinician and educator).

*d*Primary target audience.
Table 2. Examples of use of the “F-words” concepts prior to exploring the hub.

<table>
<thead>
<tr>
<th>Level of uptake</th>
<th>Sample quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Family</strong></td>
<td></td>
</tr>
<tr>
<td>Applied the F-words to their own lives (n=5)</td>
<td>• “The F-words are very applicable to my own life. I’m happy to share them with others I feel could also benefit from this framework.” [Person with a disability, Canada]</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Used the F-words when speaking with therapists and teachers to assist with goal-setting and planning for their child (n=2)</td>
<td>• “When speaking to therapists and teachers in relation to goals for my child.” [Family member, Canada]</td>
</tr>
<tr>
<td><strong>Clinical</strong></td>
<td></td>
</tr>
<tr>
<td>Implemented the F-words to help with goal-setting with families, to frame conversations with families, and to help guide program planning and decision making (n=15)</td>
<td>• “When discussing outcomes and goal planning with the family, we discussed the ICF model and used the F-words as descriptors for the various categories.” [Clinician, USA]</td>
</tr>
<tr>
<td></td>
<td>• “Through discussion with families and creating goals that fit families’ lives.” [Clinician-researcher, Canada]</td>
</tr>
<tr>
<td><strong>Research or education</strong></td>
<td></td>
</tr>
<tr>
<td>Incorporated the F-words into training for students (n=3)</td>
<td>• “Especially in educational settings, such as the training of graduates in physiotherapy, multiprofessional residence in children’s health, as well as the master’s degree in collective health and PhD on rehabilitation sciences.” [Clinician-researcher/Educator, Brazil]</td>
</tr>
<tr>
<td></td>
<td>• “Used in talks to families and professional groups. Used in publications and in grant applications.” [Clinician-researcher, Australia]</td>
</tr>
<tr>
<td><strong>Health care organization</strong></td>
<td></td>
</tr>
<tr>
<td>The F-words are influencing organizations in items such as facility planning, departmental missions, and the development of programs (n=2)</td>
<td>• “Facility planning, restructuring.” [Administrator, USA]</td>
</tr>
<tr>
<td></td>
<td>• “Used them to guide collaborative goal-setting with families/clients; to focus our departmental mission; to develop programs.” [Clinician-researcher/Educator, USA]</td>
</tr>
</tbody>
</table>

Table 3. Overall satisfaction with the Knowledge Hub (n=66).

<table>
<thead>
<tr>
<th>Item</th>
<th>Strongly agree, n (%)</th>
<th>Agree, n (%)</th>
<th>Neutral, n (%)</th>
<th>Disagree, n (%)</th>
<th>Strongly disagree, n (%)</th>
<th>No answer, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The purpose is clear</td>
<td>32 (48)</td>
<td>25 (38)</td>
<td>5 (8)</td>
<td>4 (6)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>The hub is user-friendly</td>
<td>19 (29)</td>
<td>42 (64)</td>
<td>2 (3)</td>
<td>1 (2)</td>
<td>0 (0)</td>
<td>2 (3)</td>
</tr>
<tr>
<td>I enjoyed exploring the Knowledge Hub</td>
<td>26 (39)</td>
<td>35 (53)</td>
<td>3 (5)</td>
<td>0</td>
<td>0 (0)</td>
<td>2 (3)</td>
</tr>
<tr>
<td>The content is meaningful and relevant for families</td>
<td>32 (48)</td>
<td>29 (44)</td>
<td>4 (6)</td>
<td>1 (2)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>The content is meaningful and relevant for service providers</td>
<td>31 (47)</td>
<td>31 (47)</td>
<td>3 (5)</td>
<td>1 (2)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

Respondents were also asked to indicate which sections of the Knowledge Hub they liked and what could be improved. A total of 65 people answered this question, all of whom indicated they liked at least one section of the Knowledge Hub. 57% (37/65) indicated that they liked all sections and 45% (29/65) indicated they had no further suggestions for improvements. Table 4 shows the breakdown of the items respondents liked and the possible areas for improvement. The survey also collected open-ended feedback to gain a better understanding of what were perceived to be the best features of the Knowledge Hub (48 respondents) and which areas needed improvement (25 respondents). The best features and areas for improvement were categorized into two aspects: content and format or design of the Knowledge Hub. The key themes within these areas were then identified based on the number of responses. Table 5 shows the reported best features and Table 6 summarizes the reported main areas for improvement.
Table 4. The breakdown of what people liked and what can be improved (n=65).

<table>
<thead>
<tr>
<th>Item</th>
<th>Liked, n (%)</th>
<th>Areas for improvement, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Homepage</td>
<td>26 (40)</td>
<td>6 (9)</td>
</tr>
<tr>
<td>International Classification of Functioning, Disability and Health Resources</td>
<td>12 (18)</td>
<td>8 (12)</td>
</tr>
<tr>
<td>F-words Footprint</td>
<td>14 (22)</td>
<td>2 (3)</td>
</tr>
<tr>
<td>Family and Clinician Voices</td>
<td>17 (26)</td>
<td>4 (6)</td>
</tr>
<tr>
<td>F-words Tools</td>
<td>23 (35)</td>
<td>7 (11)</td>
</tr>
<tr>
<td>Research Team</td>
<td>10 (15)</td>
<td>3 (5)</td>
</tr>
<tr>
<td>All of the above</td>
<td>37 (57)</td>
<td>1 (2)</td>
</tr>
<tr>
<td>None of the above</td>
<td>0 (0)</td>
<td>29 (45)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (2)</td>
<td>9 (14)</td>
</tr>
</tbody>
</table>

*People could select >1 item.*

Table 5. Open-ended feedback on the best features of the Knowledge Hub.

<table>
<thead>
<tr>
<th>Category</th>
<th>Sample quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Content</strong></td>
<td></td>
</tr>
<tr>
<td>Overall, the videos (n=21) and “F-words” tools (n=15) were identified as the best features of the Knowledge Hub.</td>
<td>&quot;My favorite part of the Hub is the F-words Tools section! As an educator, access to tools and examples from children helps me to understand how the F-words come into practice in the classroom and at home.&quot; [Educator, Canada]</td>
</tr>
<tr>
<td>Many people also valued the stories and examples shared by families and clinicians on what the “F-words” meant to them and how they are using the “F-words” in practice (n=9).</td>
<td>&quot;The writing by families and therapists were also quite valuable in seeing how these principles are applied in many different situations. They are also very engaging to read.&quot; [Researcher, USA]</td>
</tr>
<tr>
<td><strong>Format or design</strong></td>
<td></td>
</tr>
<tr>
<td>Key design features were that the hub was easy to navigate (n=8), user-friendly (n=7), and interesting or engaging (n=7).</td>
<td>&quot;It's simple to use and navigate, visually interesting and love the video content.&quot; [Family member, friend, researcher, Canada]</td>
</tr>
<tr>
<td>The hub being publically available with sharable, downloadable content (n=5).</td>
<td>&quot;Sharing the information is great but also providing the tools and resources for families and providers alike is crucial to getting the word out and to helping these families.&quot; [Clinician, USA]</td>
</tr>
</tbody>
</table>

Table 6. Open-ended feedback on areas for improvement of the Knowledge Hub.

<table>
<thead>
<tr>
<th>Category</th>
<th>Sample quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Content</strong></td>
<td></td>
</tr>
<tr>
<td>More examples of the application of the F-words and the impact. This includes more case vignettes, as well as formal research studies implementing and evaluating the F-words tools (n=7).</td>
<td>&quot;I think it would be important to expand the dissemination of the six F-words by conducting studies on its application and results obtained.&quot; [Clinician-researcher, Brazil]</td>
</tr>
<tr>
<td>Also, extending the F-words to other populations, including teachers, young children, and increasing the diversity of representation (n=4).</td>
<td>&quot;Improve the representation of diverse (SES, racial, ethnic, disabilities) families and practitioners to discuss barriers and different strategies possible in a wide lens.&quot; [Person with a disability, family member, friend, student, researcher, educator, USA]</td>
</tr>
<tr>
<td><strong>Format or design</strong></td>
<td></td>
</tr>
<tr>
<td>Overall organization (eg, clearly identifying the different sections, resources, purpose of the hub, etc) (n=8).</td>
<td>&quot;The content is excellent, some of the formatting could be improved to make it more user-friendly (lots of scrolling currently and hard to orient to all the great materials with that format).&quot; [Student, researcher, support worker, Canada]</td>
</tr>
<tr>
<td>The need for better navigation from the homepage (n=5).</td>
<td>&quot;Better navigation. From the home page I would like a “how to use this site” section that will guide me to what I need to be looking at use - either as a parent, as a therapist, as a researcher.&quot; [Family member, Canada]</td>
</tr>
</tbody>
</table>
Table 7. Reported use of the Knowledge Hub (n=63).

<table>
<thead>
<tr>
<th>The Knowledge Hub…</th>
<th>Strongly agree, n (%)</th>
<th>Agree, n (%)</th>
<th>Neutral, n (%)</th>
<th>Disagree, n (%)</th>
<th>Strongly disagree, n (%)</th>
<th>No answer, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>...increased my understanding of the F-words concepts.</td>
<td>27 (43)</td>
<td>31 (49)</td>
<td>2 (3)</td>
<td>1 (2)</td>
<td>0 (0)</td>
<td>2 (3)</td>
</tr>
<tr>
<td>...influenced what I think about the F-words concepts.</td>
<td>20 (32)</td>
<td>29 (46)</td>
<td>11 (17)</td>
<td>1 (2)</td>
<td>0 (0)</td>
<td>2 (3)</td>
</tr>
<tr>
<td>...will be useful to me.</td>
<td>23 (37)</td>
<td>32 (51)</td>
<td>7 (11)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (2)</td>
</tr>
<tr>
<td>...will influence the things I do when I am working with others.</td>
<td>22 (35)</td>
<td>30 (48)</td>
<td>5 (8)</td>
<td>2 (3)</td>
<td>1 (2)</td>
<td>3 (5)</td>
</tr>
</tbody>
</table>

Reported Use

The final section of the survey explored the use or intended use of the Knowledge Hub and the “F-words” concepts. Among the people who started the survey, 72% (63/87) completed this final section. The following data are based on responses from these 63 people (Table 7).

Overall, 97% (61/63) people indicated that they either “extremely liked” (42/63, 67%) or “liked” (19/63, 30%) the “F-words” concepts, 92% (58/63) people reported that the hub increased their understanding of the “F-words”, and 78% (49/63) people reported that the hub influenced their thinking about the “F-words”. We were also interested in participants’ confidence in identifying and explaining the F-words after exploring the Knowledge Hub. Overall, 90% (57/63) people indicated that they were either “extremely confident” (19/63, 30%) or “confident” (38/63, 60%). When asked whether the Knowledge Hub would be useful to them, 83% (52/63) people reported that it would influence the way they did things when working with others.

Lastly, respondents were asked to rate the Knowledge Hub as a KT tool for sharing information with families and service providers. Overall, 90% (57/63) people rated it 4 or 5 (on the 5-point Likert scale) as a KT tool for families, 98% (60/63) people rated it as 4 or 5 as a KT tool for service providers, and 97% (58/63) people planned to share the Knowledge Hub.

Discussion

Reflections on the Development Process

From the beginning, it was important to us that the Knowledge Hub be cocreated with stakeholders. While our integrated team of families and researchers led the development process, many stakeholders outside of our research team were involved. For example, we worked with clinicians and health care administrators, who we knew were applying the “F-words” to share examples of how they were using the “F-words” in their organizations. These examples then served as examples of application for other service providers.

We believe early stakeholder involvement was crucial not only to the development of a meaningful and relevant resource but also to the dissemination of knowledge regarding the Knowledge Hub. Individuals interested in the Web-based hub were more likely to share it with their own communities, thus increasing its reach and potential impact as it was spread through broad communication channels and social networks [24]. The importance of involving stakeholders such as families and service providers in the development of the KT resources has been recognized by other children’s health researchers [25-27].

Another key feature of the Knowledge Hub was its promotion of knowledge sharing and exchange [28]. In comparison with other Web-based KT resources such as Web-based learning modules which are difficult to change after completion, as the Knowledge Hub is organic, it can be easily adapted and can grow over time. This not only encourages people to return to the Knowledge Hub but also inspires them to get involved and contribute to the conversation (ie, become “knowledge brokers” of the “F-words”) [4,29]. Having the Knowledge Hub freely available is crucial to supporting this global dissemination and uptake.

One common barrier reported in the literature was the time and resources needed to develop and implement KT interventions [3,25,30]. While our research team was responsible for developing and collating the content for the Knowledge Hub, we leveraged many of CanChild’s resources (eg, the CanChild website and CanChild KT staffs’ or students’ time) to design and maintain the Knowledge Hub. Creating and collating content for the Knowledge Hub also took a lot more time than initially expected. The development process involved iterative rounds of feedback from various stakeholders. We did not follow a structured system or timeline for collecting feedback, which led to a longer process. In the future, we would recommend the use of a structured process tailored to collecting feedback from a diverse group of stakeholders [7].

A key facilitator for this project was the use of theory and best practice guidelines to inform the KT intervention [18,31]. The KTA framework [15], the Diffusion of Innovation theory [24], and Levac et al’s [7] best practice guidelines for developing Web-based educational resources were all used to inform the development process. Specifically, the KTA framework [15] provided the “big picture” and was used as the overarching guide for the KT process. Levac et al’s [7] best practice guidelines for Web-based KT resources helped us with specific details and steps needed to design the Knowledge Hub. These guidelines were useful as they were specifically tailored to our chosen KT strategy. Lastly, the Diffusion of Innovation theory informed the design and implementation of the Knowledge Hub through consideration of the characteristics of the innovation that support adoption (ie, relative advantage, complexity, compatibility, trialability, and observability), as well as the key
factors that influence innovation dissemination (ie, time, social networks, and communication channels) [24].

Evaluation Reflections

The main aim of the Knowledge Hub is to inform families and service providers about the “F-words”/ICF concepts and to provide action-oriented tools to support the uptake and use of the “F-words” in practice. As such, the goal of this pilot evaluation was to evaluate the usability and utility of the Knowledge Hub. The findings from this study revealed that these self-assigned goals were attained. Overall, the respondents reported that the Knowledge Hub was informative and useful and the “F-words” tools were one of the best features of the Knowledge Hub.

In general, the hub received high ratings with regard to both its perceived usefulness and potential use. While mixed-model analyses between groups were not completed, the high ratings given by all participants implied that the Knowledge Hub was perceived to be a meaningful resource for both service providers and families. This finding was consistent with earlier research from CanChild that found that when educational materials were clearly written and user-friendly, they were useful and impactful for multiple target audiences (ie, families and service providers) [32,33]. Furthermore, while more structured research is still needed to evaluate the impact of the Knowledge Hub on family and service provider behavior, people’s reported intentions to use the hub were an encouraging preliminary finding. As outlined in behavior change literature, people’s attitudes have a significant influence on whether a change will happen [34,35].

We recognize that prior to exploring the Knowledge Hub, over 70% of people who completed the survey had previously heard of the “F-words.” Of these respondents, the majority felt confident identifying and explaining the “F-words” ideas, and about half of them indicated that they had used or applied the “F-words” in practice. Despite many respondents already being familiar with the “F-words” concepts, the majority stated that the Knowledge Hub increased their understanding of the “F-words” ideas. This is an important finding as it implies that the Knowledge Hub can increase perceived knowledge even if individuals have prior familiarity with the concepts. This probably occurred because the resources provide tangible materials that move beyond simple concept familiarity. Unfortunately, due to the low response rate from people for whom the “F-words” concept was new, it is not possible to say whether the Knowledge Hub is useful across all adopter categories (ie, from the early adopters—those who are already using the “F-words”—to the late adopters—those to whom the “F-words” are new) [24].

Conducting a pilot evaluation of the usability and utility of the Knowledge Hub is an important step toward ensuring its overall impact and sustainability [7,23]. This pilot evaluation helped us to understand what people liked about the Knowledge Hub (eg, the videos, “F-words” tools, families’ and clinicians’ voices, etc) and what changes were needed to improve it (eg, re-organizing the homepage to support navigation throughout the hub). The evaluation also helped us understand who was accessing the Knowledge Hub (ie, mostly the early adopters of the “F-words” concepts) and what was needed to broaden the applicability of the Knowledge Hub to a wider audience (eg, extending the “F-words” to other populations and conducting research on the impact of using the “F-words” tools). These findings will both inform and complement future evaluations of the Knowledge Hub. Recognizing that experimental evaluations only identify whether an intervention is effective, process evaluations such as this are recommended to understand the reasons why interventions are (or are not) effective [36,37].

Study Limitations and Future Directions

Based on the respondents’ positive feedback, we anticipate that the Knowledge Hub will be a useful resource for both families and service providers. A limitation to this work is that feedback was gained from only a small sample of the people who visited the hub during this period. It is important to remember that the majority of people who provided feedback were those who were already familiar with the “F-words” concepts and also liked the “F-words” ideas. Thus, their potential biases must be recognized.

In order to reach a broader audience, more time is needed to actively disseminate the Knowledge Hub. While the preliminary findings after a one-month evaluation were reported here, in order to overcome selection bias (ie, those who already like the “F-words” ideas), the evaluation will remain posted on the Knowledge Hub and further feedback will be monitored. The hope is that over time more people (including those who are not already familiar with the “F-words”) will complete the survey.

The next step is to evaluate the impact of the Knowledge Hub and “F-words” concepts at the family, clinician, and organizational levels. As active implementation strategies are useful in supporting the dissemination and uptake of educational materials, we plan to combine the Knowledge Hub intervention with tailored invitational outreach visits to local children’s treatment centers (CTCs). Once again, this is a stakeholder-driven strategy as CTCs have contacted us and expressed a need for in-person educational training on the “F-words” concepts. Based on our positive experiences of working with families and service providers to develop the Knowledge Hub, this project will continue to be informed by an iKT strategy.

Conclusions

Working with families and service providers, we designed a theory-informed and evidence-informed Web-based KT resource that was perceived to be relevant and meaningful to families raising children with disabilities and to service providers working in the field. To date, the Knowledge Hub has mainly reached early adopters (ie, people who like the “F-words” ideas and are seeking more information) [24]; therefore, to reach a wider audience (ie, the early majority), further active implementation strategies are needed.

KT is not only the doing but also the studying of the KT process and outcomes. From the evaluation of the usability and utility of the Knowledge Hub, we now have a good understanding of what was done well and what can be improved. Based on the findings from this pilot study, we intend to make minor changes to the Knowledge Hub before conducting a larger evaluation study of the impact at the family, clinician, and organizational
levels. Knowledge gained from this study is transferrable to other KT initiatives involving families and service providers. We hope that the findings and lessons learned from this integrated KT project will assist others in advancing iKT science and practice in other areas of childhood disability research.

Acknowledgments

We would like to thank all families, service providers, and researchers who were involved in this project. Developing and evaluating the Knowledge Hub was a collaborative effort, and we appreciate all the individuals’ time and contributions. We would like to specially thank the KT staff and students at CanChild who helped design the Knowledge Hub on the CanChild website. Finally, we thank everyone who shared with us how they adapted and used the “F-words” in practice and who provided permission to share their stories and resources on the Knowledge Hub. JWG holds the Scotiabank Chair in Child Health Research.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Application of Levac et al’s (2015) recommended best practices of Web-based knowledge translation resources.

[PDF File (Adobe PDF File), 45KB - rehab_v5i2e10439_app1.pdf]

Multimedia Appendix 2
Description of “F-words” Knowledge Hub.

[PDF File (Adobe PDF File), 28KB - rehab_v5i2e10439_app2.pdf]

Multimedia Appendix 3
“F-words” Knowledge Hub evaluation recruitment poster.

[JPG File, 109KB - rehab_v5i2e10439_app3.jpg]

References


**Abbreviations**

CTC: children’s treatment center  
ICF: International Classification of Functioning, Disability and Health  
iKT: integrated knowledge translation  
KT: knowledge translation  
KTA: Knowledge-to-Action

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Assistive Technology for the Upper Extremities After Stroke: Systematic Review of Users’ Needs

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Abstract

Background: Technical innovations have the potential to compensate for loss of upper-limb motor functions after stroke. However, majority of the designs do not completely meet the needs and preferences of the end users. User-centered design methods have shown that the attention to user perspectives during development of assistive technology leads to devices that better suit the needs of the users.

Objective: To get more insight into the factors that can bring the design of assistive technology to higher levels of satisfaction and acceptance, studies about user perspectives on assistive technology for the upper limb after stroke are systematically reviewed.

Methods: A database search was conducted in PubMed, EMBASE, CINAHL, PsycINFO, and Scopus from inception to August 2017, supplemented with a search of reference lists. Methodological quality of the included studies was appraised. User perspectives of stroke survivors, carers, and health care professionals were extracted. A total of 35 descriptive themes were identified, from which 5 overarching themes were derived.

Results: In total, 9 studies with information gathered from focus groups, questionnaires, and interviews were included. Barriers and enablers influencing the adoption of assistive technology for the upper limb after stroke emerged within 5 overarching but highly interdependent themes: (1) promoting hand and arm performance; (2) attitude toward technology; (3) decision process; (4) usability; and (5) practical applicability.

Conclusions: Expected use of an assistive technology is facilitated when it has a clear therapeutic base (expected benefit in enhancing function), its users (patients and health care professionals) have a positive attitude toward technology, sufficient information about the assistive technology is available, and usability and practical applicability have been addressed successfully in its design. The interdependency of the identified themes implies that all aspects influencing user perspectives of assistive technology need to be considered when developing assistive technology to enhance its chance of acceptance. The importance of each factor may vary depending on personal factors and the use context, either at home as an assistive aid or for rehabilitation at a clinic.

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KEYWORDS

user perspectives; stroke; upper limb; assistive technology; user-centered design
Introduction

Stroke is one of the main causes of permanent disability [1,2]. The risk of stroke increases substantially with age as the stroke incidence almost doubles with each decade after the age of 45 years [3]. As a result of the aging population, the number of people older than 65 years in the Netherlands is estimated to almost double (from 2.4 million–4.5 million) between 2008 and 2040 [4]. On the basis of the demographic trends alone, the incidence of stroke will rise in the coming decades. Besides, the number of deaths because of stroke decreased from 153 per 100,000 inhabitants in 2000 to 110 per 100,000 in 2016 [3], and the number of hospitalizations caused by stroke increased from 370 per 100,000 inhabitants in the year 2000 to 482 per 100,000 inhabitants in 2016 [3]. In addition, the stroke mortality rate is likely to decrease because of improvements in acute and long-term care [5]. The rising trend of stroke incidence and hospitalizations will place great strain on national health care services in the future [6].

The cause of stroke is an interrupted blood flow in the brain, either of hemorrhagic or ischemic cause, leading to disturbed generation and integration of neural commands. Depending on the area in which the interruption manifests, resulting impairments vary. Cognitive, emotional, and sensory disorders are often present after a first-time stroke; however, upper extremity weakness or hemiparesis are the most common impairments [7]. With regard to the arm, only 10% to 15% of stroke survivors regain complete functional use during activities of daily living (ADL) within 6 months after stroke, and approximately, another 40% will regain some dexterity in the paretic arm [8]. Recovery of upper extremity function is one of the primary goals of rehabilitation programs. About 40% of occupational therapy is directly targeted at improving ADL [9]. Several studies have shown that focusing on functional activities, with active contribution of the stroke survivor, is vital in stimulating motor recovery after stroke [10-12]. Loss of functional use of the hand and arm causes severe difficulties in personal care activities, especially when those activities involve handling of objects. This limits the independence of stroke survivors and significantly reduces their quality of life [13,14]. By the end of the first year post stroke, an estimated 40% of stroke survivors still need assistance in ADL [10].

Technical innovations, such as assistive technology (AT), provide the opportunity to compensate for loss of motor function by supporting the upper limb during the execution of ADL [13,15]. The definition of ATs used in this study is based on the definition proposed by Demain et al [16] and Hughes et al [5]. Assistive technology is defined as “Electrical or mechanical devices designed to help people recover movement by offering direct assistance to the movement of the upper extremity.” ATs have great potential to assist in promoting intensive use of the arm and hand, without any increase in clinical contact time in the case of a therapeutic application or help from formal or informal carers in case of assistive application. AT can increase the amount of motivational activities that stroke survivors perform, whether it be hobbies or gaming activities they enjoy or work and ADL-related tasks that might help them regain a sense of independence. AT can be used both inside and outside the clinic [5,17]. Remarkably, only 25% of the robotic devices for upper extremity rehabilitation have been tested clinically within the stroke population [18], suggesting limited implementation of robotic devices in practice [19]. The complexity of robotic devices and a mismatch between the needs and preferences of the end users and their environment regarding the design of the device are believed to be the main reasons for this low implementation rate [18,19]. This assumption is also expected to be applicable to AT in a more general sense.

User-centered design (UCD) methods have shown that including user perspectives during the design of AT enables development of devices that better suit the needs of the users [20]. The rationale for user involvement during the design process is to design a device that will be usable, comfortable, understandable, and, ultimately, acceptable for the users [21]. Currently, the design of robotic technology for stroke rehabilitation tends to be technology-driven [22]. Although an extensive list of existing technical solutions for physical therapy of the upper limb has been provided [13], few are clinically tested [18]. When AT was tested clinically, devices that were developed according to UCD showed acceptable to promising usability scores, although room for improvement was left, mainly with regard to usability aspects [23,24]. This supports the importance of taking the perspectives of the end users into account during the design and development of AT.

There is a clear need to bring assistive device design to higher levels of acceptance. Ideally, design projects should start with addressing user needs by collecting information about the target population through focus groups, interviews, questionnaires, or observation studies (Figure 1, adapted from Eger et al [25] and Martin et al [26]). Although some studies reported collection of needs and preferences of end users at the start of the design project [5,15,16,19,27-31], the questions asked to gather this information were often too generic.

This study, therefore, systematically reviews existing literature about user perspectives on AT for the upper extremity after stroke. The resulting insights could aid future developers in quickly determining essential user requirements that need to be addressed during the design of AT for the upper extremity after stroke to enhance its chances of acceptance by the users. The insights in this study can thus be used as a starting point for the first phase of AT development, from which developers can proceed to gather more in-depth information from their own use research, specific to their application and intended use. In the later stages of development, it remains important to involve users and incorporate UCD methods (Figure 1) to ensure the device will indeed meet the identified user requirements.
Methods

Literature Search
An electronic database search was conducted in PubMed, Scopus, CINAHL, Embase, and PsycINFO from inception to August 2017. The search strategy used in all these databases was a combination of the following keywords and related terms (see Multimedia Appendix 1 for the full syntax):

- Assistive technology, self-help devices, and assistive devices
- Rehabilitation robot, training devices, upper extremity rehabilitation equipment
- Robotics
- Upper extremity
- Cerebrovascular accident and stroke
- User requirements, a priori user perspectives, and patient preferences

Reference lists of potentially relevant papers were scanned to supplement the computerized search results. Furthermore, an internet search (Google Scholar) was performed with regard to factors that affect the use of upper extremity assistive devices in the rehabilitation setting and at home.

Study Selection
The following criteria were used for the inclusion of studies: (1) studies involving qualitative or quantitative research into user perspectives; (2) involvement of stroke survivors with upper extremity limitations, carers, or health care professionals (HCPs) of stroke survivors; (3) studies concerning upper extremity AT; (4) studies written in English; and (5) published, full-length, and peer-reviewed papers. The definition of ATs used in this review is “Electrical or mechanical devices designed to help people recover movement by offering direct assistance to the movement of the upper extremity,” without distinguishing between devices designed for therapeutic purposes or home use. The included studies needed to comply with all the inclusion criteria. Thus, case studies and studies including user perspectives with regard to a product that will be designed for one specific task were excluded. Moreover, studies evaluating a prototype or product were excluded. After the duplicate citations had been excluded, 2 reviewers (ALvO and GBPL) screened titles and abstracts. Full-text papers were read and summarized independently by 2 reviewers (ALvO and LCS) and discussed subsequently. A final list of papers to be included was created after consensus was reached. A third reviewer could be consulted if there was disagreement between the 2 principal reviewers (JHB in case of titles and abstracts and GBPL in case of full papers).

Methodological Research Quality Assessment
The Critical Appraisal Skills Program (CASP) checklist was used to appraise the methodological quality of the included studies as it can guide the evaluation of a wide range of methodologies [32,33]. This methodological assessment tool, endorsed by the Cochrane Collaboration, contains 10 items on aims, research design and methodology, participant selection and ethics, data collection and analysis, and the statement of findings, each of which was scored as positive (yes), negative (no), or unclear (cannot tell). Each positive score received 1 point, and each negative or unclear score received 0 points. Thus, the maximum possible methodological quality score was 10. Studies were not excluded based on the CASP score; rather, the CASP score was used as reference to serve as a guide during interpretation of the results.
### Table 1. Derivation and content of descriptive and analytical themes.

<table>
<thead>
<tr>
<th>Overarching themes and corresponding descriptive theme</th>
<th>Derived from</th>
<th>Example expressions and citations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Theme 1: Promoting hand and arm performance</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Goal-oriented exercises</td>
<td>[15,19,27-31]</td>
<td>Therapists stated that training should be oriented at a patient’s goal(s) and his/her ability to accomplish these goal(s). [29]</td>
</tr>
<tr>
<td>Repetition</td>
<td>[16,28,29,31]</td>
<td></td>
</tr>
<tr>
<td>Intensity</td>
<td>[16,29,30]</td>
<td></td>
</tr>
<tr>
<td>Active contribution</td>
<td>[15,19,28,31]</td>
<td></td>
</tr>
<tr>
<td>Focus on hand and arm</td>
<td>[5,16,27]</td>
<td></td>
</tr>
<tr>
<td><strong>Theme 2: Attitude toward technology</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Motivation</td>
<td>[5,16,27-29,31]</td>
<td>All participants believed that using home-based technology aimed at arm exercises would help them perform more arm exercises. It will motivate them to engage more in the exercise program. [27]</td>
</tr>
<tr>
<td>Familiarity and affinity with technology</td>
<td>[28,31]</td>
<td></td>
</tr>
<tr>
<td>Digital security and privacy</td>
<td>[29,31]</td>
<td></td>
</tr>
<tr>
<td><strong>Theme 3: Decision process</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knowledge</td>
<td>[5,16,31]</td>
<td>All patient participants were keen to self-manage. They were all actively engaged in looking for solutions to promote arm recovery and were prepared to spend time and, if necessary, money on potential solutions, including assistive technologies. [16]</td>
</tr>
<tr>
<td>Evidence-based practice</td>
<td>[5,16]</td>
<td></td>
</tr>
<tr>
<td>Advice</td>
<td>[5,16,28]</td>
<td></td>
</tr>
<tr>
<td>Time investment</td>
<td>[16]</td>
<td></td>
</tr>
<tr>
<td>Safety aspects regulations</td>
<td>[19,27]</td>
<td></td>
</tr>
<tr>
<td>Trust and expected usefulness</td>
<td>[5,16,27,28,31]</td>
<td></td>
</tr>
<tr>
<td>Money</td>
<td>[5,16,27,30,31]</td>
<td></td>
</tr>
<tr>
<td><strong>Theme 4: Usability</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Donning/doffing</td>
<td>[15,16,19]</td>
<td>For stroke survivors and families, the devices needed to be easy to get on and off a weak and/or contracted hand/arm...and to be intuitive in terms of correctly positioning the device. [16]</td>
</tr>
<tr>
<td>Setup</td>
<td>[5,16,27-29,31]</td>
<td></td>
</tr>
<tr>
<td>Initialization</td>
<td>[15,28,29,31]</td>
<td></td>
</tr>
<tr>
<td>Portable</td>
<td>[16,27,29,30]</td>
<td></td>
</tr>
<tr>
<td>Robustness</td>
<td>[5,27,29]</td>
<td></td>
</tr>
<tr>
<td>Instruction on exercises</td>
<td>[29,31]</td>
<td></td>
</tr>
<tr>
<td>Comfort</td>
<td>[5,15,19]</td>
<td></td>
</tr>
<tr>
<td>Lightweight</td>
<td>[15,19]</td>
<td></td>
</tr>
<tr>
<td>Ease of use</td>
<td>[5,15,16,27-29,31]</td>
<td></td>
</tr>
<tr>
<td>Compliant</td>
<td>[16,19,27,28,30,31]</td>
<td></td>
</tr>
<tr>
<td>Adjustment to patient</td>
<td>[16,19,28,29]</td>
<td></td>
</tr>
<tr>
<td>Technical support</td>
<td>[27]</td>
<td></td>
</tr>
<tr>
<td>Maintenance</td>
<td>[16,27]</td>
<td></td>
</tr>
<tr>
<td><strong>Theme 5: Applicability in practice</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Monitoring</td>
<td>[15,27,29,30]</td>
<td>Hardware and software design of technology should facilitate adaptation to individual stroke survivors or patient target groups and to patient progression over time. [29]</td>
</tr>
<tr>
<td>Feedback</td>
<td>[15,16,28-30]</td>
<td></td>
</tr>
<tr>
<td>Wrongly executed movements</td>
<td>[29,30]</td>
<td></td>
</tr>
<tr>
<td>Fatigue and overtraining</td>
<td>[30]</td>
<td></td>
</tr>
<tr>
<td>Adaptability (patient progression, task setting, and patient group diversity)</td>
<td>[15,19,27-31]</td>
<td></td>
</tr>
<tr>
<td>Physical comfort</td>
<td>[5,16,19,28,30]</td>
<td></td>
</tr>
</tbody>
</table>
Data Extraction
The content of the included studies was analyzed using a structured approach, scanning for information (where available) regarding descriptive features of the population involved and the type of AT and its purpose. Subsequently, factors related to the successful or unsuccessful use of AT were collected and used as input for the analysis of this review. Therefore, information and quotations from participants under the headings Results or Findings were retrieved from each study.

Data Synthesis
Meta-synthesis attempts to integrate results from interrelated qualitative studies. In contrast to meta-analysis, meta-synthesis has an interpretive rather than aggregating intent [34]. In this study, the data synthesis was based on the 3-phase process from Thomas and Harden’s thematic synthesis [35]. In the first phase of data synthesis, line-by-line coding of the findings of primary studies was performed by 2 reviewers (ALvO and LCS). Second, descriptive themes based on the expressions found in the first phase were developed. Examples of those descriptive themes can be found in Table 1. Third, the descriptive themes were presented to a multidisciplinary team experienced in the field of rehabilitation technology to develop consensus-based, analytical overarching themes that encompass all descriptive themes. The team consisted of a human movement scientist, electrical engineer, industrial design engineer, biomedical engineer, and a psychologist, of which the majority had not been involved in previous phases of this study. Each study was read several times by 2 reviewers (ALvO and LCS) to ensure that all the perspectives of the participants were captured.

Results

Study Selection
Initially, 935 references were retrieved from bibliographic databases. After removal of duplicates, 658 potentially relevant papers were screened for retrieval, of which 30 were retained for full-text review. After comparing with the selection criteria, 24 of the full-text papers were excluded. In total, 3 studies were included via additional reference searches of relevant publications. Therefore, the review includes 9 publications. The number of studies included and excluded at various stages of the review process is shown in Figure 2. In all cases, consensus between the 2 raters was reached. Consequently, there was no need to consult the third reviewer.
Figure 2. Flowchart of study inclusion.
Table 2. Characteristics of included studies.

<table>
<thead>
<tr>
<th>Source and aim of the paper (N=9)</th>
<th>Target population (number)</th>
<th>Method of data collection</th>
<th>Quality score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lam et al (2015) [31]; Aim: establish the current use and perceptions of gaming, social media, and robotics technologies for rehabilitative purposes from the perspective of adults with upper-limb impairments to identify barriers and enablers to their adoption and use</td>
<td>Stroke survivors (n=8)</td>
<td>Focus groups</td>
<td>9</td>
</tr>
<tr>
<td>Nasr et al (2015) [28]; Aim: examine stroke survivors’ experiences of living with stroke and technology to provide technology developers with insight into values, thoughts, and feelings of the potential users of a to-be-designed robotic technology for home-based rehabilitation of the hand and wrist</td>
<td>Stroke survivors (n=10) and caregivers (n=8)</td>
<td>In-depth interviews</td>
<td>8</td>
</tr>
<tr>
<td>Prange et al (2015) [19]; Aim: identify user requirements for development of an active assistive device to support hand opening during functional activities</td>
<td>Stroke survivors (n=5) and HCPs (n=6)</td>
<td>Interviews</td>
<td>5</td>
</tr>
<tr>
<td>Radder et al (2015) [15]; Aim: identify user requirements as input for the development of a wearable soft-robotic assistive device for the support of hand function of elderly and stroke survivors in a wide range of ADL</td>
<td>Stroke survivors (n=4) and HCPs (n=7)</td>
<td>Focus groups</td>
<td>7</td>
</tr>
<tr>
<td>Hughes et al (2014) [5]; Aim: understand HCPs’, stroke survivors’, and carers’ experience and views of upper-limb rehabilitation and ATs to identify barriers and opportunities critical to effective translation of ATs into clinical practice</td>
<td>Stroke survivors and carers (n=79) and HCPs (n=120)</td>
<td>Questionnaire</td>
<td>9</td>
</tr>
<tr>
<td>Sivan et al (2014) [27]; Aim: investigate if the ICF framework is a useful basis to ensure that the key user needs are identified in the development of a home-based arm rehabilitation system for stroke survivors</td>
<td>Stroke survivors (n=9) and HCPs (n=6)</td>
<td>Semistructured interviews</td>
<td>9</td>
</tr>
<tr>
<td>Demain et al (2013) [16]; Aim: investigate stroke survivors’, caregivers’, and stroke professionals’ experiences and perceptions of stroke upper-limb rehabilitation and AT use and identify the barriers and facilitators to their use in supporting stroke self-management</td>
<td>Stroke survivors (n=11), family caregivers (n=5), and HCPs (n=6)</td>
<td>Focus groups</td>
<td>8</td>
</tr>
<tr>
<td>Hochstenbach-Waelen and Seelen (2012) [29]; Aim: identify criteria and conditions technology should meet to facilitate (implementation of) technology-assisted arm-hand skills training in rehabilitation therapy of stroke survivors</td>
<td>HCPs (n=6)</td>
<td>Semistructured interviews</td>
<td>4</td>
</tr>
<tr>
<td>Lu et al (2011) [30]; Aim: discover the needs and preferences of therapists with respect to a robot that focuses on upper-limb rehabilitation</td>
<td>HCPs (n=233)</td>
<td>Questionnaire</td>
<td>9</td>
</tr>
</tbody>
</table>

\(a\)HCP: health care professional.

\(b\)ADL: activities of daily living.

\(c\)AT: assistive technology.

\(d\)ICF: International Classification of Functioning, Disability and Health.

Study Characteristics

In total, 9 studies covering 139 stroke survivors and carers and 384 HCPs were included for analysis [5,15,16,19,27-31]. The majority of the studies had at most 20 participants except for 2 studies that applied questionnaires involving over 100 participants [5,30]. The characteristics of the studies are shown in Table 2. All studies described end users’ experiences and perspectives regarding the design of AT for use after stroke. In total, 4 studies used interviews [19,27-29], 3 studies used focus groups [15,16,31], and 2 studies questionnaires [5,30] to elicit information from end users.

Methodological Quality

Quality scores retrieved from the CASP ranged from 4 to 9 points, with 7 studies having a score above 5 out of a possible score of 10 (Table 2). Scores per question of the CASP are shown in Table 3. Studies with lower scores tended to provide insufficient information about particularly the recruitment strategy, the relationship between researcher and participants, the ethical procedures, and the data analysis. A minority of the studies (2/9, approximately 22%) provided information about the role and potential bias of the researcher during the study. Nevertheless, studies with a low quality score were retained for inclusion because of their relevant contribution of data.
Table 3. Questions of the Critical Appraisal Skills Program and the number of studies that do or do not comply with each question.

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>Partially reported or No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Was there a clear statement of the aims of the research?</td>
<td>9</td>
<td>—a</td>
</tr>
<tr>
<td>Is a qualitative methodology appropriate?</td>
<td>9</td>
<td>—</td>
</tr>
<tr>
<td>Was the research design appropriate to address the aims of the research?</td>
<td>9</td>
<td>—</td>
</tr>
<tr>
<td>Was the recruitment strategy appropriate to the aims of the research?</td>
<td>5</td>
<td>4 [15,19,29,31]</td>
</tr>
<tr>
<td>Was the data collected in a way that addressed the research issue?</td>
<td>7</td>
<td>2 [19,29]</td>
</tr>
<tr>
<td>Has the relationship between researcher and participants been adequately considered?</td>
<td>2</td>
<td>7 [5,15,16,19,27-29]</td>
</tr>
<tr>
<td>Have the ethical issues been taken into consideration?</td>
<td>6</td>
<td>3 [19,29,30]</td>
</tr>
<tr>
<td>Was the data analysis sufficiently rigorous?</td>
<td>8</td>
<td>1 [29]</td>
</tr>
<tr>
<td>Is there a clear statement of findings?</td>
<td>4</td>
<td>5 [15,16,19,28,29]</td>
</tr>
<tr>
<td>How valuable is the research?</td>
<td>9</td>
<td>—</td>
</tr>
</tbody>
</table>

*aNot applicable.*

**Synthesis**

Statements and sentences from primary data were discussed and organized into 35 descriptive themes (Figure 3). On the basis of the descriptive themes, 5 overarching analytical themes were derived: (1) promoting hand and arm performance; (2) attitude toward technology; (3) decision-making process; (4) usability; and (5) applicability in practice, illustrated in Figure 3.

Table 1 provides illustrative quotations from included studies and the corresponding descriptive and overarching themes. During third-stage discussions (analytical theme identification) within the multidisciplinary expert group, underlying relationships between those themes were identified (Figure 3). For an AT to be considered for the support of the upper-limb function in stroke, the device should address a therapeutic base for promoting hand and arm performance (theme 1). A positive attitude toward technology (theme 2) is a prerequisite for starting the decision-making process (theme 3) on whether to use an AT. After it is decided to (consider to) use an AT, aspects determining the usability of the system (theme 4) play a crucial role in the level of user satisfaction. The applicability of an AT in practice (theme 5) depends on factors that may promote long-term use of the device, when properly implemented.

**Theme 1: Promoting Hand and Arm Performance**

*Repetition, Task Oriented, Active Contribution, Intensity, and Focus on Hand and Arm*

Therapeutic principles which are the foundation of motoric recovery should be addressed by AT. Stroke survivors and carers have remarked that intensive movement repetition needs to be promoted to regain any degree of function and to optimize recovery [16,28,31]. In their eyes, meaningful movements are preferred during training [28,31] as they want to improve their ability to use their affected limb in functional activities such as combing hair, washing, dressing, cooking, and eating with knife and fork [27]. HCPs in both qualitative [29] and quantitative studies (99%) [30] agree that the intensity and frequency of meaningful task-oriented movements should be enhanced. So training should be tailored to the individual goals, which involves training of the specific task to accomplish the goal, and also comprises components of the tasks that stroke survivors want to remaster [29]. When severely affected, active contribution and training of the severely affected side is preferred, to achieve the ability to use it as supporting hand in bimanual activities [15,19], as is wished by stroke survivors and carers. Tailored to the stroke survivors’ functional level, training should range from gross to fine manipulation and could be provided by games when these are used for rehabilitation purposes [28].

Technology aimed to be used to support the upper extremity should, therefore, offer variability in exercises and its functionality [29]. Computer exercises should enable (virtual) ADL-specific activities through meaningful and functionally relevant activities (88%) [30] based on the principles of motor relearning [27]. Normal movement patterns needed for daily activities, active participation of the hand and arm, and frequent movement repetition should be promoted and trained in the games [28]. Games functionality should be as close as possible to the functionality of real analog games [29].

Over 75% of the stroke survivors, carers, and HCPs mentioned that the current practice in therapy is insufficient [5], as there is therapeutic emphasis on the lower extremity [16,27], whereas additional therapy would enhance their upper extremity functioning [27]. All the end users thought that time efficiency of therapy could be improved with AT allowing additional time for upper extremity training [5].
Figure 3. Themes in use and implementation of assistive technology (AT) for the arm and hand according to health care professionals and stroke survivors.

**Theme 2: Attitude Toward Technology**

**Motivation, Familiarity and Affinity With Technology, and Digital Security and Privacy**

Before considering using an AT, the attitude toward technology in general can either play a facilitating role or form a barrier, for both the stroke survivor or end user and the HCP. Beside the before-mentioned factors to promote hand and arm performance, HCPs stress the importance of training to be motivating and challenging for stroke survivors. Motivation of stroke survivors to regain control over movements of their affected side is usually very strong [28]. Control over the affected side can be achieved by dividing large goals into smaller, achievable goals, but it can also be enhanced by including a gaming element in the case of therapeutic devices [29]. Games, either Web-based or offline as AT, are innovative means that can help to motivate stroke survivors to do their therapeutic exercises [28]. Stroke survivors, carers, and HCPs acknowledged the motivational aspect of AT as they were seen as an improvement on routine therapy because they are high-tech and more enjoyable [16]. All participants, stroke survivors and HCPs, in the study of Sivan et al [27] thought that using a home-based technology aimed at arm exercises would help them to perform more arm exercises. More independence [27,28] and regaining confidence in their own body are motivating aspects for stroke survivors to engage in the exercise program [28]. However, mixed feelings are expressed about the affinity with technology [28,31]. Feelings about AT are considerably influenced by the familiarity with technology; stroke survivors with technology experience before they suffered the stroke tend to be more positive toward new technologies [28]. Stroke survivors are willing to adopt new technologies if they are proven to be effective; however, a longer time is needed for learning to use the technology [31]—time that some stroke survivors find challenging [31].
survivors do not want to waste [31]. Participants had limited exposure to technology for rehabilitation. Aging has stopped stroke survivors from making full use of the benefits of technology [31].

Unlike the younger generation that grew up with the internet, stroke survivors are not keen on going online [31]. In fact, security and safety of personal information were primary concerns of stroke survivors when talking about connecting social networking websites to home-based rehabilitation technology [31]. Integration of social networking negatively influences the potential acceptance of such rehabilitation programs [31]. Therapists emphasized that a system should be able to save individual settings and data of a stroke survivor [29].

**Theme 3: Decision-Making Process**

*Knowledge, Evidence-Based Practice, Advice, Time Investment, Safety Aspects and Regulations, Trust and Expected Usefulness, Independence and Self-Management, and Money.*

The decision-making process for AT consists of factors important to both stroke survivors and their carers as well as HCPs. Stroke survivors are eager to function independently during ADL through self-management [16]. Stroke survivors expect that home-based technology would give them more independence in their rehabilitation program [27]. In addition, stroke survivors, carers, and their HCPs mentioned that an AT should be used independently at home [27,30], without the direct assistance and presence of an HCP (70%) [5]. Independent use of the AT is something that should be facilitated by the hardware and software design [16,29]. The design of the device in terms of safety, such as suitable solutions for emergency situations (back-drivable mechanism and quickly removable from the stroke survivor), electrical safety, and safety for the environment, plays a role in the decision-making process as well [19,27].

Some of the participants are actively engaged in the search for solutions to promote arm recovery [5,16], although there are many stroke survivors who have little to no exposure and knowledge about AT [16,31]. A majority of the HCPs, stroke survivors, and carers experience difficulties in accessing training and advice on AT, whereas stroke survivors and carers rely on the information given to them by HCPs. Ideally, they would like to seek advice from an HCP they know and trust [16]. However, stroke survivors feel that they receive too little information because HCPs lack knowledge and training about the availability of AT, HCPs are overworked, and because the therapists are reluctant to give information about devices that would not be state funded [16]. HCPs feel the tension about informing stroke survivors about the existence of a device, which may help, but which is not available from state-funded services [16]. HCPs prefer not to proactively inform stroke survivors about AT to prevent stroke survivors from purchasing an upper-limb AT for which insufficient research evidence is available [16]. For HCPs, scientific evidence is crucial [5,16,29], whereas stroke survivors and carers are less interested in the generic scientific evidence [5] and are more willing to accept risks [16]. Stroke survivors and carers point out that the evidence should be sought on a case-by-case basis because of the huge variety in the stroke population [16]. There is hope that AT could help stroke survivors to regain lost capabilities [28], and despite a potential lack of scientific evidence, HCPs believe that AT can enhance hands-on physiotherapy [27].

Although stroke survivors are willing to spend time and money on potential solutions [16], the decision-making process to invest in an AT largely depends on the financial commitment they have to make [31]. Concerns were raised by stroke survivors, carers, and HCPs about the current lack of financial support for AT and whether they will be cost-effective [5,16,27,31]. The amount of money HCPs, or their institution, would be willing to spend on an AT is less than US $10,000 for the majority (81%) of the respondents [30].

**Theme 4: Usability**

*Donning and Doffing, Setup, Initialization Time, Portable, Robustness, Instruction on Exercises, Comfort, Lightweight, Ease of Use, Compliant, Adjustment to Patient, Technical Support, and Maintenance*

When a device lacks in usability, using it will be less pleasant, which can ultimately lead to device abandonment. As previously mentioned, independence and self-management are very important to stroke survivors. Usability factors that can contribute to independent and pleasant use of the device are (1) easy to setup [5,16,27-29,31], (2) simple to apply [16], (3) easy to don and doff without the aid of others [15,16,19], (4) quickly initialized [15,28,29,31], (5) comfortable to use and wear [5,15,19], (6) portable [16,27,28,30], and (7) lightweight [15,19]. A common generic theme mentioned by stroke survivors, carers, and HCPs in almost every paper is the ease of use of an AT [5,15,16,27-29,31]. This theme comprises simplicity [28,31], easily programmable [16], intuitive in terms of positioning, easy to operate [15], and short familiarization time [29] of an AT.

To be usable for both stroke survivors and HCPs, adjustment to the stroke survivor must be straightforward. An AT must comply with both left- and right-side affected stroke survivors [28]; concerns are expressed about complex adjustment between stroke survivors [16]. Both hardware and software should facilitate adaptation between stroke survivors, but it should also be adaptable to the stroke survivor’s progression over time [19,29].

For an AT to be used at home, stroke survivors and their HCPs want the device to be compact enough to fit in the home environment [27,28,30]. The AT must be deployable in a living room, kitchen, or bedroom [27] and should not hinder during ADL [19]. Moreover, stroke survivors and HCPs should be able to rely on the AT; therefore, it should be durable [5,29]. As there is a chance of an AT breaking down, it is preferred that access to engineers and to HCPs who have knowledge about the technology is available at any time [27].
**Theme 5: Applicability in Practice**

*Monitoring, Feedback, Wrongly Executed Movements, Fatigue and Overtraining, Adaptability, and Physical Comfort*

Stroke survivors, carers, and HCPs acknowledge that ATs can potentially benefit functioning of stroke survivors by providing intensive therapy and a means of self-management [16]; however, factors influencing the implementation define the chances of user acceptance of AT in the long run. All respondents were of the view that ATs are efficient use of therapy time [5] and could be used to promote the usage of the hand and arm at home. Technology with the purpose of promoting hand and arm performance should first and foremost address the therapeutic principles mentioned in theme 1, that is, *promoting hand and arm performance*. Besides this, stroke survivors and HCPs want the possibility of an AT to be used unsupervised at home, which is why monitoring of their progression and provision of feedback are preferred. Among other reasons, monitoring and feedback are needed to halt or prevent wrongly executed movements, which can cause injury or inhibit recovery [29,30]. Compensatory movements are most likely to occur when fatigued, so an AT must monitor the state of fatigue of the stroke survivor [31]. The ability to monitor stroke survivor’s performance and quality of undertaken movements is seen as an important requirement to highlight possible problems [15,27,29]. Feedback not only plays a role for the HCP but also is key to support self-management [16]. Feedback on performance [15,16,28] and biofeedback were said to be of importance to stroke survivors and HCPs. However, stroke survivors do not necessarily wish for feedback from the system but rather prefer to receive feedback from the HCP [15]. Individual physical and cognitive impairments that limit the ability of a stroke survivor to perform tasks should be considered when applying a system in daily practice. HCPs are worried that different types of support are needed in ADL because of the individual impairments [15]; therefore, an AT must accommodate to the level of impairment and address movements that the stroke survivor needs to improve [28]. A modular system might not only fit into the individual needs of impairment level [15] but also technological familiarity [28]. Concerns are also expressed about the potential risk of harm such as secondary tissue changes, obstruction of blood vessels, sharp parts, and high forces that might cause injuries [5,19,28,30].

Besides adjustment between stroke survivors, an AT must be adaptable to the stroke survivor’s progression over time by adapting, for example, the level of difficulty [29], provided resistance and assistance [30,31], and the executed movements [28,30]. Automatic adaptation of task settings to account for the variation in impairment level is preferred as stroke survivors only want assist-as-needed: support only during (parts of) activities that need assistance [15,19].

**Relations Between Factors and Themes**

The previous paragraphs discussed the factors within each of the 5 overarching themes. From the included studies, it is clear that the factors can affect one another, and there are also relations between the overarching themes. The main relations between factors and themes are mapped in **Figure 4**.

**Use Context of Assistive Technology**

ATs are designed to be used either in the clinic or during daily life in a domestic situation. Although the definition of all themes and factors will differ to some extent between an AT used in the clinic or at home, the most pronounced differences are displayed in **Figure 5**.
Figure 4. Factors and themes influence one another. Connecting lines indicate relationships between factors. AT: assistive technology.
Discussion

Principal Findings

This review comprehensively investigated user needs, preferences, and expectations that are expected to be associated with acceptance and adoption of AT for promotion of hand and arm performance after stroke. Through a meta-synthesis, 5 overarching themes were identified from literature. Factors relevant to stakeholders who may purchase or decide to use AT are covered in the following themes: (1) promotion of hand and arm performance, (2) attitude toward technology, (3) decision-making process, (4) usability, and (5) applicability in practice. Although separately presented by themes, the findings of this review highlighted the diversity and interdependence of the numerous factors influencing the chances of acceptance and adoption of AT, as illustrated in Figure 4.

Interdependency of Themes and Factors

The potential of AT for the upper limb has been recognized by stroke survivors, carers, and HCPs [16]. Multiple stakeholders are directly or indirectly involved in the use of AT. Where stroke survivors and carers put more focus on self-management, HCPs put more focus on evidence-based practice. However, it is important to address the needs of every end user category during the design process [20] as involvement of both HCPs and stroke survivors will decrease the chance of discrepancy between expected and experienced usefulness. Unsatisfactory user interaction, or moreover, a lack of consideration of user needs, might lead to device abandonment [5,36].

Results from this systematic review suggested that adoption of AT depends on multiple organizational and psychosocial factors and can be influenced at any stage, ranging from attitude toward technology, to the practical applicability of AT designed to promote hand and arm performance after stroke. Previously, several general design criteria with a primary focus on usability have been developed [37]. The currently identified themes and underlying descriptive factors reflect many of those established design criteria. Moreover, several additional factors were identified in this review beyond those design criteria addressing predominantly usability, which are mainly represented by the themes attitude toward technology and decision process. Both themes affect the organizational process either by playing a facilitating role or by serving as a barrier. Besides that, factors such as age, gender, and voluntariness of use as described by the Unified Theory of Acceptance of Use of Technology influence the chances of adoption of technology [38].

To bring AT design to higher levels of user satisfaction and acceptance, the interdependency of user needs as revealed in this review must be considered in every stage of the design process. This means that addressing one particular aspect of the user perspective will not be sufficient to enhance user acceptance as, that aspect, for example, usability, is influenced by other
aspects as well, for example, the budget available to purchase the AT (which is in turn dependent on the use context, for instance). Therefore, when designing AT to promote hemiparetic arm and hand function, the complete spectre of themes encompassing the user perspective, as identified in this review, should be addressed.

Motivation to use AT for upper limb after stroke is driven by the wish for independence and self-management. Therefore, use of AT should have substantial added value for the performance of task-oriented activities with the upper limb. In particular, activities that the stroke survivor would normally not be able to perform without assistance should be supported by AT. ATs are seen as efficient use of therapy time [5] and could be used to promote the usage of the hand and arm at home. However, before AT can be applied efficiently, the time required to (learn to) use AT plays a crucial role in the acceptance of AT for stroke survivors as well as HCPs. The time it takes for acquaintance is highly dependent on usability aspects such as donning and doffing, initialization time, and time needed to setup the device. Additionally, the practical applicability in terms of time needed to adjust the settings between or within stroke survivors affects the chance of acceptance. However, if an AT is effective in supporting self-management, stroke survivors are willing to spend time, and if necessary, money, on it [16]. Naturally, their willingness is dependent on the financial commitment they have to make. Costs associated with AT, and a potential lack of funding, are seen as major factors influencing the decision on purchasing an AT. In terms of accessibility, concerns not only exist regarding purchasing the equipment and whether the time needed from staff can be billed at the insurance [29,39] but also with regard to informing stroke survivors about the existence of a device that may help but is not available from state-funded services [16].

Cost-effectiveness is seen as a determinant for the adoption of any new treatment [5]; it, however, does not automatically guarantee adoption into clinical practice or daily life [5,40]. Strength of scientific evidence has also been proposed to be an important factor influencing the translation of rehabilitation research into clinical practice, but there also appears to be a mismatch between the strength of the evidence and the clinical use of AT [5,41].

The decision-making process of HCPs to purchase or use an AT, or even inform stroke survivors about AT, is largely influenced by the level of knowledge about AT and the scientific evidence present. The decision-making process of stroke survivors is influenced by the HCPs as the primary source of information about AT is their HCP whom they trust. As only 25% of the devices have been tested in stroke [18], the clinical application and implementation remain low [39,42]. Currently, HCPs rely on their own experience with AT because of the absence of clear research evidence [5]. As proposed by Hughes et al [5], collaboration between clinical and developmental sites, health care providers, and the commercial sector would allow for a pragmatic approach for HCPs to learn about AT without awaiting publication, real dissemination, and reception of scientific evidence.

### Design Practice

Currently, the design of robotic technology for stroke rehabilitation tends to be technology-driven [22]. The focus on high-tech may jeopardize the consideration for (clinical) needs of the target population, which is a major reason why development can benefit from UCD methods. Unfortunately, manufacturers of medical devices in general can be hesitant in the involvement of users in the later stages of the design process because of perceived barriers in obtaining ethical approval and time constraints, among other reasons [43].

Cherry et al [44] reported on the perceived facilitators and barrier of stroke survivors after use of a hand telerehabilitation system for 3 months at home. Although many reported barriers and facilitators are in line with usability factors identified in this review, stroke survivors were able to point out the technical difficulties more specifically after actually using the device in their own homes. For example, unresponsiveness of the system that required rebooting, limited adhesiveness of the Velcro that was used, and incompatibility with existing furniture. New information about perceived facilitators and barriers as a result of prolonged use of a prototype or product highlights the importance of including user perspectives in the beginning of the design as well as later during evaluation of the prototype or product.

Developers should be aware that not only the prototype but the device itself can be evaluated with users. The instructions for use, commonly created in the wrap-up phase of development when all product details are known, can have great impact on usability. Quality of the user manual can be easily improved by giving several end users some assignments with the manual to determine whether the device can be successfully applied by following the instructions. In case of digital applications, it may be possible to collect user feedback after implementation to continue to improve the device through software updates, but developers need to seriously consider any privacy concerns users have, particularly in case of digital applications.

### Study Limitations

In this review, primary or secondary end users were not included during the sessions in which the overarching themes were defined. Instead, people who have experience in the design of assistive devices participated. Their backgrounds were diverse and with their different roles in device design, it was possible to combine the results into a complete framework that is useful to both developers of AT and those who evaluate or apply AT in practice. Inconsistent terminology about AT used among studies affected our ability to identify relevant studies. An iterative search strategy tailored to the databases was supplemented by scanning the reference lists of potentially relevant papers in an attempt to identify all relevant papers.

In addition, lack of distinction between AT used for therapeutic purposes and AT used during ADL in many studies made it difficult to design a framework for both purposes separately. Although the identified overarching themes are applicable in both situations, some factors may weigh heavier than others for either therapeutic or ADL purposes. For example, for a device that is to be used at home by only 1 stroke survivor, a low
adjustment time is not as crucial as when the device is intended to be used by several stroke survivors on 1 day at the clinic. In this review, both focus groups and interviews and user survey studies were included in the meta-synthesis. Although the diversity in methods to elicit user perspectives might have influenced the results or its interpretation, the aim of this review was to include all relevant information on user perspectives about AT for the upper extremity after stroke. Valuable authentic information was retrieved from user survey studies, extending the development of factors and themes with unique data from a large sample of potential users. It may be that the importance of factors varies between studies (or user-interaction methods), but weighing factors could not reliably be assigned in this review. Of the included studies, 2 studies had a methodological quality score below 5 [19,29]. Those studies particularly contained insufficient information about the recruitment strategy, data collection, relationship between researcher and participants, consideration of ethical issues, and provided an unclear statement of findings. Although rated low, those studies contained authentic information that contributed valuably to the comprehensive overview of themes related to user needs for AT for the upper limb as identified in this study. Another limitation is a potential selection bias in the reviewed studies where only participants who were already interested in the use of technology for the upper extremity were included in the study. This may have biased the views expressed by the participants in those studies. On the other hand, the various papers collectively included participants both with and without prior knowledge about and experience with AT.

Future Work

The 5 themes as identified in this study are relevant to aid future AT developers in quickly determining essential user requirements as a first step of a UCD process. As stated before, the factors identified in this review have interdependency, and the importance of a factor may change depending on the use context. Therefore, all factors need to be considered within the specific use context for which an AT is being developed. However, the reviewed studies did not indicate if certain user needs were more important than others. Therefore, insufficient information was present to rank the importance of the factors or themes, but it would be highly relevant to assess the weights that should be attributed to the identified factors and themes in future research. After identification of the user requirements, design solutions can be created and developed [20]. The results gained from the focus groups, interviews, and questionnaires of the studies included in this review primarily reflect the expectations about AT use before actual usage of technology. The chance of actual use of a device is probably related predominantly to the experienced ease of use and perceived usefulness of the system [19,45], which cannot always be predicted beforehand. Therefore, subsequent evaluation of the newly designed AT in terms of a priori user preferences and corresponding user acceptance might give new and more specific insights into the (key) user preferences for an AT.

Conclusions

This systematic review on user perspectives on AT identified several factors and themes that reflect user preferences for AT for the upper limb post stroke, before its development. The study identified barriers and enablers influencing the adoption of AT for the upper limb after stroke within the 5 overarching themes; (1) promoting hand and arm performance; (2) attitude toward technology; (3) decision process; (4) usability; and (5) practical applicability. Besides insights into relevant aspects for design of AT, this review showed that those aspects are highly interdependent. A potential purchaser of AT goes through a decision process. Prerequisite for entering the decision process is a sufficient positive attitude toward technology and the desire to increase independence and self-management of the stroke survivor. The stroke survivor and their carer(s) prefer to consult with a trusted HCP, who may or may not have experience with AT. By combining factors such as money, expected usefulness, and safety aspects, a decision can be reached to purchase AT. If AT incorporates therapeutic principles and can be used pleasantly in a time-efficient and safe manner, chances of acceptance increase. Time efficiency can be increased by usability factors such as setup time, clear and understandable instructions for use, easy donning or doffing, and adjustability. Features such as monitoring fatigue and detecting wrongly executed movements can contribute to safety. Depending on the use context, either at home for ADL purposes or for rehabilitation at a clinic, the importance of each factor may vary.

Due to this interdependency and a lack of weights attributed to the factors in the included studies, a ranking of most important themes could not be established within this review. Therefore, the current framework should be supplemented by future research evaluating the importance of the factors, while also considering differences in use contexts, such as clinical or domestic application of AT.

Acknowledgments

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Authors’ Contributions

ALvO, LCS, and GBPL conducted the literature search. ALvO and LCS drafted the manuscript. GBPL, JHB, PHV, and JSR reviewed and edited the manuscript and supervised the process in the roles of doctoral supervisor and promotor. All authors approved the final version of the manuscript.
Conflicts of Interest

None declared.

Multimedia Appendix 1

Search strategy.

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Abbreviations

ADL: activities of daily living
AT: assistive technology
CASP: Critical Appraisal Skills Program
HCP: health care professional
ICF: International Classification of Functioning, Disability and Health
UCD: user-centered design

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Capturing Expert Knowledge for the Personalization of Cognitive Rehabilitation: Study Combining Computational Modeling and a Participatory Design Strategy

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Abstract

Background: Cognitive impairments after stroke are not always given sufficient attention despite the critical limitations they impose on activities of daily living (ADLs). Although there is substantial evidence on cognitive rehabilitation benefits, its implementation is limited because of time and human resource’s demands. Moreover, many cognitive rehabilitation interventions lack a robust theoretical framework in the selection of paper-and-pencil tasks by the clinicians. In this endeavor, it would be useful to have a tool that could generate standardized paper-and-pencil tasks, parameterized according to patients’ needs.

Objective: In this study, we aimed to present a framework for the creation of personalized cognitive rehabilitation tasks based on a participatory design strategy.

Methods: We selected 11 paper-and-pencil tasks from standard clinical practice and parameterized them with multiple configurations. A total of 67 tasks were assessed according to their cognitive demands (attention, memory, language, and executive functions) and overall difficulty by 20 rehabilitation professionals.

Results: After assessing the internal consistency of the data—that is, alpha values from .918 to .997—we identified the parameters that significantly affected cognitive functions and proposed specific models for each task. Through computational modeling, we operationalized the tasks into their intrinsic parameters and developed a Web tool that generates personalized paper-and-pencil tasks—the Task Generator (TG).

Conclusions: Our framework proposes an objective and quantitative personalization strategy tailored to each patient in multiple cognitive domains (attention, memory, language, and executive functions) derived from expert knowledge and materialized in the TG app, a cognitive rehabilitation Web tool.

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KEYWORDS
stroke rehabilitation; attention; memory; executive function; language; cognition; community-based participatory research; patient-specific modeling

Introduction

Background

Stroke is one of the most common causes of adult disability, and because of the aging of the population, the number of people having a stroke continues to rise. According to the 2015 Global Burden of Disease study, the total number of stroke events in Europe is predicted to increase by 34% between 2015 and 2035. This increasing number of people living with the effects of stroke results in a growing burden on families, societies, and
Cognitive and Motor Impairments After Stroke

Poststroke impairments impact the individual’s ability to safely and independently carry out activities of daily living (ADLs) and to restart prestroke personal, social, and vocational activities. Stroke survivors often express that they feel like a different person, not because of the typical motor sequelae but because of changes they suffer in cognitive functions underlying their capacity for language, attention, executive functions, and memory [2].

Currently, rehabilitation following stroke routinely takes a bottom-up approach, with the primary focus placed on motor gait retraining, followed by upper limb rehabilitation and speech and language therapy [3]. Consequently, cognitive impairments are not always systematically assessed and treated. Moreover, current rehabilitation entails a high demand for human resources, making them time consuming and expensive. As a result, there is a high number of patients per therapist that makes it challenging to deliver a rehabilitation program with the appropriate intensity and training, hampering the recovery potential for some patients [4]. It is known that inappropriate cognitive rehabilitation limits patients’ capacity of living independently. In fact, it has been shown that the level of cognitive impairment correlates with the length of inpatient stay and the number and frequency of referrals for outpatient and home therapies [5].

In a recent James Lind Alliance study, 799 stroke survivors were interviewed about their unmet needs following a stroke, and they reported problems with concentration (45%), memory (43%), and reading (23%) [6]. A high proportion felt that issues such as memory and concentration had not been addressed appropriately, especially when compared with other issues such as mobility. Similarly, when caregivers and health professionals were consulted, the main conclusion of the study was that investigating ways to improve cognition after stroke should be a research priority [7]. There is, therefore, an avoidable psychosocial and economic cost derived from the currently limited cognitive rehabilitation, which contributes to the patient’s increased dependency on relatives, professionals, and health care systems and their premature placement at nursing homes [8].

Cognitive Rehabilitation and What Are We Missing?

Rehabilitation refers to the act of relearning a previously learned behavior that has been disrupted by brain damage. It involves re-establishing connection weights or synapses within the network, diverting the information by building new connection weights or synapses or activating the neurons that were not previously used [9]. Ben-Yishay and Prigatano defined cognitive rehabilitation as “the amelioration of deficits in problem-solving abilities to improve functional competence in everyday situations” [10]. The main point about this definition is the understanding that cognitive rehabilitation should focus on real-life functional problems. In rehabilitation, models and theories are useful to conceptualize processes and think about treatments. Especially, cognitive rehabilitation methodologies urge a comprehensive theoretical framework that incorporates theories and models from different fields. The working memory model [11], the dual route model of reading [12], and the face recognition model [13] are examples of models that helped planning treatment for people with cognitive impairments. Nevertheless, until now, there is no single model or integrative cognitive rehabilitation framework that addresses the multiple aspects of cognitive functions involved in real life [14].

Although paper-and-pencil tasks are reliable tools to assess multiple domains of cognitive functioning (specific task scores can be used to evaluate the capacities of a patient in multiple cognitive domains) [15], there are few solutions to the inverse problem: a set of paper-and-pencil tasks that are specifically adapted to the results of different assessments of cognitive functioning of a patient [16,17]. Cognitive rehabilitation approaches have been relatively successful for focal cortical deficits (eg, neglect and aphasia) but less so for more generalized cognitive impairment (eg, slowed information processing and executive dysfunction) [5]. Additional research is needed to investigate the patient characteristics that influence treatment effectiveness [18]. Consequently, cognitive rehabilitation is still mostly planned and delivered based on the experience of the health professional and based on a subjective selection of paper-and-pencil cognitive tests or conventional games, which are generally not adjusted to or validated for the specific cognitive needs of the patient [19]. Although we know that stroke-related cognitive problems are weighted more toward attention executive dysfunction than memory dysfunction and that there are marked deficits in abstraction, executive function, and processing speed [20], the cognitive impairment profile of each patient is highly variable and depends on the characteristics of his lesion.

The Impact of Cognitive Rehabilitation on the Improvement of Cognitive Performance in Everyday Life

The American Congress of Rehabilitation Medicine conducted systematic reviews on a total of 370 studies about cognitive rehabilitation for people with traumatic brain injury (TBI) or stroke, published from 1971 through 2008 [21,22,18]. Cognitive rehabilitation was shown to be of greater benefit than conventional rehabilitation in 94.1% of the comparison studies. According to this evidence, there is a clear indication that cognitive rehabilitation is the best available form of treatment for people who exhibit cognitive impairments and functional limitations after TBI or stroke [18]. However, Paiva et al performed a meta-analysis on cognitive rehabilitation in stroke, and the results suggested a lack of sufficient evidence to support or refute the efficacy of cognitive interventions in stroke patients [23]. These divergent results should be interpreted with caution because in this meta-analysis, 304 of 507 studies were excluded because of low quality, and only 3 were considered by the authors. Additional research, using standardized assessment instruments and well-structured training programs, is needed to elucidate the mechanisms of change underlying the efficacy of cognitive rehabilitation.

The primary difficulty in determining the impact of cognitive interventions on the everyday functioning of healthy older adults...
is that most trials do not include functional outcome measures [24,25]. A review about the impact of cognitive training and mental stimulation on the cognitive and everyday functioning of healthy older adults from Kelly et al’s study (2014) found only 2 studies that examined the effects of cognitive training on everyday function [26]. One of them concluded that 6 months of memory training did not significantly improve everyday functioning for older adults at a 2-year follow-up [27], and the other study similarly reported no training effects on everyday functioning after 6 weeks of memory, reasoning, or processing speed training at a 2-year follow-up [28]. Interestingly, the later authors conducted a 5-year follow-up and concluded that successful performance in everyday tasks is critically dependent on executive cognitive function [29], which is supported by prior research that shows that the ability to perform independent living skills is dependent on intact executive function [30].

**Information and Communication Technologies**

Over the past few years, several computer-based solutions have been proposed to increase the availability and quality of cognitive training, flooding the marketplace with commercial brain exercise programs that claim to improve cognition and have diagnostic abilities [31] such as the CogWeb [16,32,33] and the Gutmann Neuro Personal Trainer [34,35], for instance. There is also an increasing number of research projects focused in using a task modeling approach in poststroke rehabilitation, as the CogWatch, that developed intelligent common objects to help retraining Apraxia or action disorganization syndrome patients on how to carry out ADLs by providing persistent multimodal feedback to them [36]. Preliminary results involving 12 patients interacting with this system validated the ability of the system to assist stroke survivors in tea making. CogWatch was very beneficial to the patients who had difficulties performing the tasks alone, and when patients had access to the output retrieved by the system, their success rate was higher, and they made fewer errors than when they could not interact with the system.

Despite the proliferation of information and communication technologies (ICTs) in cognitive rehabilitation, only 5% to 15% of people with disabilities have access to technological devices that can assist in the rehabilitation process [37]. In addition, many health care providers are unfamiliar or uncomfortable with technology, and only about 27% of these professionals refer to use these computer-assisted technologies in their rehabilitation interventions [38]. Moreover, technological interventions are subject to continuous maintenance and technical support, eventually resulting in delayed interventions or the need to reschedule. Such complications speak to the challenges of implementing interventions dependent on technology within inpatient and outpatient rehabilitation settings. Any delays in these fast-paced settings, requiring the coordination of various professionals, can be disruptive [19].

To maximize the benefits of ICTs and to address the above-stated limitations, we developed a new Web-based tool, the Task Generator (TG). This Web tool capitalizes on the solid aspects of existing computerized training protocols for cognitive rehabilitation [17,32,39] and integrates existing theories and models [15]. The TG addresses multiple domains of cognitive functioning systematically and quantitatively, generating a profile of cognitive demands for each task and enabling the clinician to efficiently deliver a highly adapted training program to each patient’s deficits. The TG ultimately generates paper-and-pencil training tasks, making its application low cost and compatible with the current practice and existing limitations of clinical settings, and at the same time, it integrates most of the essential advantages of ICT-based interventions.

**Objectives**

The objective of this research was to propose a systematic and objective design framework that can guide us on the methodology for the development of training tasks capable of addressing multiple domains of cognitive functioning, yet delivering a highly adaptive training program to each patient’s assessed deficits, and showcase its use in a Web-based app for cognitive rehabilitation.

**Methods**

**Development Process**

We have based our methodology on a participatory design strategy involving rehabilitation experts interworking with the research and development team through interviews, meetings, and questionnaires. In Figure 1, we describe the process we followed to identify and develop a set of highly personalized cognitive training tasks for a specific clinical group, in this case, stroke patients. It involved 3 main participatory steps: task selection, modeling, and application. However, the process followed is not unique to stroke rehabilitation and generalizes to any application area and target group where personalization of training is of importance.

**Figure 1.** Methodology development process. ADLs: activities of daily living.
**Task Selection**

As a first step toward the creation of a repertoire of cognitive training tasks, 3 rehabilitation experts (2 neuropsychologists with experience in cognitive assessment and interventions in stroke and dementia and an experienced rehabilitation technology researcher) documented the currently used methodologies in clinical rehabilitation settings (public hospitals, private clinics, and senior houses) and collected the most commonly used training tasks, some of them being available as published training material [40]. Of this search, 20 distinct paper-and-pencil task types were identified and analyzed.

As stated previously, no clear or comprehensive cognitive rehabilitation framework can provide us with general guidelines for cognitive training task selection. In the education field, however, there are multiple frameworks, the Bloom Taxonomy is one of the most relevant ones [41]. Hence, we have chosen and categorized the 20 tasks according to Bloom learning objectives as described below:

- **Knowledge (lower level):** memory of stories; cancellation; questions of general knowledge; find locations; image pairs
- **Comprehension:** differences between similar scenarios; categorization; synonyms and antonyms; association
- **Application:** mazes; problem resolution; tangram; numeric sequences; navigation
- **Analysis:** action sequencing; visual memory; puzzles; word search
- **Evaluation (higher level):** differentiation between coherent and incoherent situations; comprehension of contexts

After the identification and organization of the 20 tasks according to their learning objectives, the 3 rehabilitation experts proceeded to a ranking of the 20 available cognitive tasks according to its relevance in the successful performance of ADLs. This Task Selection process, according to the learning objective’s representativeness and the relevance for ADLs performance, resulted in the selection of the following 11 tasks: word search, problem resolution, numeric sequences, action sequencing, association, cancellation, categorization, comprehension of contexts, image pairs, mazes, and memory of stories.

**Modeling**

It is necessary to identify the relevant tasks to train a specific cognitive deficit (such as attention and memory) to define a proper rehabilitation program, but that is not sufficient. It is imperative also to consider the learner characteristics to design adapted training capable of providing as best as possible a personalized rehabilitation. In our case, the learners are stroke patients with different deficits that need to be rehabilitated through intensive and continuous training. There is then, no one-fits-all training program. There should be a uniquely adapted rehabilitation program for patients according to their assessment of the multiple domains of cognitive functioning. Currently, this adaptation process is generated through tacit knowledge based on the clinicians’ subjective experience—which is essential and results from years of training—but there is no explicit formulation of such knowledge. This implicit knowledge is valid and necessary; however, to generalize, we should be able to transform it in a set of objective guidelines that support the personalization of training to the characteristics of each patient. To obtain such a set of guidelines and an objective way of operationalizing the adaptation in the different cognitive tasks, we followed a participatory design strategy with the main stakeholders.

### Table 1. List of training tasks, their objectives, and parameters subject to personalization.

<table>
<thead>
<tr>
<th>Training task</th>
<th>Objective</th>
<th>Parameters</th>
</tr>
</thead>
<tbody>
<tr>
<td>Word search</td>
<td>A number of words can be found up, down, forward, or diagonally in a pool of randomized letters.</td>
<td>Words number; clue words; and clue pictures</td>
</tr>
<tr>
<td>Problem resolution</td>
<td>Two types of problems are presented, numeric calculations or calculations based on textual descriptions of daily activities.</td>
<td>Type; operations number; ones; and tens</td>
</tr>
<tr>
<td>Numeric sequences</td>
<td>A numeric sequence is given, and the subject has to come up with the missing numbers.</td>
<td>Step; ascending; and missing; position</td>
</tr>
<tr>
<td>Action sequencing</td>
<td>A list of randomized actions needed for the execution of several activities of daily living is presented.</td>
<td>Actions number and task goal</td>
</tr>
<tr>
<td>Association</td>
<td>A number of randomized pairs of items need to be paired correctly.</td>
<td>Pairs number</td>
</tr>
<tr>
<td>Cancellation</td>
<td>Find a target stimulus in a pool of distractors.</td>
<td>Distractors; letters; numbers; targets; and arrangement</td>
</tr>
<tr>
<td>Categorization</td>
<td>Grouping items into their underlying categories. The categories must be guessed from the items.</td>
<td>Categories number and items number</td>
</tr>
<tr>
<td>Comprehension of contexts</td>
<td>Some images are given with some descriptions. Correct descriptions need to be identified.</td>
<td>Descriptions number</td>
</tr>
<tr>
<td>Image pairs</td>
<td>A number of pairs of images to be memorized are presented. They must be recalled after 30 min.</td>
<td>Number of pairs</td>
</tr>
<tr>
<td>Mazes</td>
<td>Finding the way out of a labyrinth.</td>
<td>Size</td>
</tr>
<tr>
<td>Memory of stories</td>
<td>Recalling information about a read story or a picture by answering questions about it.</td>
<td>Type; size; and questions</td>
</tr>
</tbody>
</table>
Task Parameterization

This step had as primary objective to break down each of the 11 previously selected cognitive training tasks and identify their main parameters or variables to quantify their effects regarding demands in different domains of cognitive functioning. For that, we operationalized all tasks into their task parameters (independent variables; IVs) to study their demands in 4 cognitive domains (attention, memory, language, and executive functions) and for their overall difficulty (dependent variables; DVs). The breakdown of the tasks is as follows and is summarized in Table 1:

1. Word search: A predetermined number of words can be found up, down, forward, or diagonally in a pool of randomized letters. Words can overlap so that a letter can be part of 2 or more words. This task was operationalized according to the number of words to find and the existence of clues provided to identify words (pictures, words, or none).

2. Problem resolution: Here, 2 types of problems are presented, numeric calculations or calculations based on a textual description of daily activities. Problems vary according to the number of operations involved and the use of numbers with ones or tens.

3. Numeric sequences: A numeric sequence is given as a finite sequence of numbers, and the subject must come up with the missing numbers. The task can be operationalized according to the number of missing numbers (1, 2, or 3) in the sequence, their position in the sequence, and the step size between numbers.

4. Action sequencing: In this task, a list of randomized steps needed for the execution of several ADLs is presented. The task can be defined by the number of steps to be ordered and whether the goal of the task is explicitly mentioned or must be guessed.

5. Association: The task comprehends a number of randomized pairs of items. These items need to be paired correctly according to a logical relationship between them.

6. Cancellation: The purpose of cancellation tasks is to find predetermined target stimulus in a pool of distractor stimulus. Thus, we operationalized this task according to the type of stimulus (letters, black or colored symbols, or numbers), the pool size, and their arrangement (randomly organized or in a grid structure).

7. Categorization: This task consists of organizing different items into their underlying categories. The names of the categories are not given, it must be guessed from the item’s or object’s relationships. The task can be defined according to the number of categories and the number of items.

8. Comprehension of contexts: In this task, some images are given with some descriptions, with some being incorrect descriptions.

9. Image pairs: In this task, a number of pairs of images are presented to be memorized. They are recalled after 30 min.

10. Mazes: The task consists of a labyrinth type of puzzle through which one must find the way out. The task can be operationalized according to the maze size.

11. Memory of stories: The task consists of recalling information about a read story or a pictorial scenario by answering questions about it. Stories can be textual or pictorial (type) and can have several descriptive elements (size) and a variable number of questions.

Task Permutation

After the operationalization of the previously mentioned 11 tasks and the identification of their underlying parameters, multiple variants of each task were created to explore all parameter space. Because it is not feasible to study the complete permutation of all combinations of task parameters for all tasks (a minimum of 134), task parameters were selected and combined according to what was feasible to implement and could be mathematically modeled. Table 1 describes the parameter combinations that were selected. Overall, we created 67 variants of the above 11 tasks.

Assessment

Subsequently, we further involved in this study a total of 20 external rehabilitation experts (3 physiatrists, 5 neuropsychologists, and 12 rehabilitation therapists) from the private and public sectors in the autonomous region of Madeira and mainland Portugal. None of them was involved in the previous steps of the design process. The age range of participants was from 26 to 56 years (mean=40.05, SD=10.26), and the experts’ experience range was from 2 to 32 years (mean=16.40, SD=10.54). Participants were 85% (17/20) female.

Each of the 20 study participants rated each of the 67 task variants in a 1 to 10 Likert scale according to their assessment of the tasks’ demands on attention, memory, language, executive functions domains, and difficulty. Participants were provided with the questionnaires to be completed within a week and the order in which participants rated the variants, and the amount of time required to complete the 67 of them was not controlled.

Results

Internal Consistency

The internal consistency of each questionnaire was assessed through the Cronbach alpha, which reported consistency in the experts’ responses for all tasks (Multimedia Appendix 1).

Quantification of the Cognitive Profile of the Tasks

An analysis of the ratings of the 20 rehabilitation experts’ answers was performed to proceed to the identification of the relevant task parameters and the quantification of their impact regarding cognitive demands via a computational modeling approach. We have used this computational approach because traditional multiple regression techniques treat the units of analysis as independent observations, which is not the case in our study. The computational modeling was performed with the R 3.1.1 software (Bell Labs), through the multilevel analysis package, which provides tools to estimate a wide variety of within-group agreement and reliability measures and provides data manipulation functions to facilitate multilevel analyses such as the one presented here [42]. A descriptive analysis per cognitive domain and overall difficulty (Table 2) was performed with the Statistical Package for the Social Sciences 20 (IBM SPSS Statistics 20).
By assessing the minimum and maximum ratings per task variant in each domain, we can create a profile for every task, which is graphically represented in Figure 2, which determines each task’s training range. These profiles allow us to quickly judge the demands of each task and their adaptability in each cognitive domain. For instance, in the word search task, the demands range from 5.05 to 6.20 for memory, from 5.60 to 6.55 for the executive functions, from 6.50 to 7.60 for attention, and from 5.25 to 6 for language.

### Multilevel Analysis and Modeling

The above-reported ranges correspond to the ranges of the tested task variants, which are limited to the parameters described in Table 1. Through computational approaches, it is possible to further generalize these profiles by modeling the effect of untested parameters and combinations. Multilevel analysis was selected to accommodate the specificity of the data collected with partial observations (not all parameter combinations were assessed). The objective of the modeling approach was to quantitatively determine how the IVs (task parameters) impact each of the DVs (memory, executive functions, attention, language, and difficulty). To model this relationship, the parameters of each task (IVs) were used as predictors of the demands in each cognitive domain (DVs). A multilevel model of the following type was computed for each task:

\[ DV = \text{intercept} + C_1 \times IV_1 + C_2 \times IV_2 + \ldots + C_i \times IV_i \]

where \( C_i \) indicates the contribution of each IV to the DV. These models considered a linear relationship with the order that the tasks were analyzed, allowed the slopes of these relationships to randomly vary, and incorporated an autoregressive structure with serial correlations in the error structures.

The basic procedure started by examining the nature of the outcome (task difficulty or cognitive load). First, we estimated the intraclass correlation coefficient and determined whether the outcome or DV (task difficulty or cognitive load) did not randomly vary among rehabilitation professionals. Thereafter, we considered only the significant IVs of the model. Second, we examined the form of the relationship between the order of the rated cognitive tasks and the outcome task difficulty or cognitive load. We wanted to know whether there was an order effect of the task’s rating. Third, we attempted to determine whether the relationship between the task order and the outcome or DVs is constant among individuals or whether it varies on an individual-by-individual basis. Fourth, we modeled the error structures such as autocorrelation [42].

The model quality was quantified, after each iteration, through the Akaike Information Criterion (AIC), Bayesian Information Criterion (BIC), and \( P \) values. AIC is an estimate of a constant plus the relative distance between the unknown true likelihood function of the data and the fitted likelihood function of the model so that a lower AIC means a model is considered to be closer to the truth. AIC does not provide a test of a model in the sense of testing a null hypothesis; therefore, it can tell nothing about the quality of the model in an absolute sense. BIC is an estimate of a function of the posterior probability of a model being true, under a specific Bayesian setup, so that a lower BIC means that a model is more likely to be the true model. Both criteria are based on various assumptions and asymptotic approximations. Hence, AIC and BIC provide a means for model selection. Each, despite its heuristic usefulness, has also been criticized as having questionable validity for real-world data. Our modeling process stopped at the step where the best model was generated according to AIC.

Through the computational analysis, we quantified how the manipulation of the IV impacted the DV. In some tasks and for some specific cognitive domains, it was not possible to model the relationship between IV and DV, which means that some parameter manipulations had no significant effects on the DV. In those cases, the mean rating is assumed in that domain. Task parameters that do not have a significant contribution to either of the cognitive domains or overall difficulty are omitted in the guidelines below. In the following, we present the detailed guidelines for the customization of training. Multimedia Appendices 2-10 and Tables 3-6 contain the mathematical models together with the AIC and BIC values, which helped us to determine if we should perform the third (Order) and fourth (AutoCorr) steps of the modeling process.
**Figure 2.** Task adaptation profiles represented as radar plots. Each plot has 4 axes—memory, executive functions, attention, and language—and the area between the blue (minimum) and the red line (maximum) represents the range interval in which the task varied depending on the selected task parameters in the study.

**Table 3.** Problem resolution task models for language and difficulty.

<table>
<thead>
<tr>
<th>Problem resolution task</th>
<th>Language</th>
<th>Difficulty</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Coefficient value</td>
<td>SE</td>
</tr>
<tr>
<td>Intercept</td>
<td>4.65</td>
<td>0.562</td>
</tr>
<tr>
<td>Type</td>
<td>1.10</td>
<td>0.242</td>
</tr>
<tr>
<td>Operations number</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Tens</td>
<td>—</td>
<td>—</td>
</tr>
</tbody>
</table>

*Not applicable.*
Table 4. Problem resolution task models quality for language and difficulty.

<table>
<thead>
<tr>
<th>Model Quality</th>
<th>Language</th>
<th>Difficulty</th>
</tr>
</thead>
<tbody>
<tr>
<td>Akaike Information Criterion</td>
<td>645.2693</td>
<td>794.0537</td>
</tr>
<tr>
<td>Bayesian Information Criterion</td>
<td>668.2871</td>
<td>813.7529</td>
</tr>
<tr>
<td>Order</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Autocorrelation</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Table 5. Comprehension of contexts task models for executive functions, language and difficulty.

<table>
<thead>
<tr>
<th>Comprehension of contexts task</th>
<th>Executive functions</th>
<th>Language</th>
<th>Difficulty</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Coefficient value</td>
<td>SE</td>
<td>t value</td>
</tr>
<tr>
<td>Intercept</td>
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<td>1.235</td>
<td>0.202</td>
</tr>
<tr>
<td>Descriptions number</td>
<td>1.20</td>
<td>0.457</td>
<td>2.629</td>
</tr>
</tbody>
</table>

Table 6. Comprehension of contexts task models quality for executive functions, language and difficulty.

<table>
<thead>
<tr>
<th>Model quality</th>
<th>Executive functions</th>
<th>Language</th>
<th>Difficulty</th>
</tr>
</thead>
<tbody>
<tr>
<td>Akaike Information Criterion</td>
<td>177.3641</td>
<td>184.2205</td>
<td>144.2994</td>
</tr>
<tr>
<td>Bayesian Information Criterion</td>
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<td>190.7708</td>
<td>150.8498</td>
</tr>
<tr>
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<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Autocorrelation</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

Word Search (Impact Memory, Attention, and Executive Functions)

Through raising the number of words, it is possible to increase overall difficulty, memory, attention, and executive functions’ demands. In addition, if clues are given in images, it is more difficult and demanding for memory, attention, and executive functions (Multimedia Appendix 2).

Problem Resolution (Impact Language)

The task allows the training of language by presenting the problems through real daily living situations. A higher number of operations and number of digits increase the general difficulty of this task (Tables 3 and 4).

Numeric Sequences (Impact Memory, Attention, Executive Functions, and Language)

The higher the demands for training memory, attention, executive functions, and language, the more the missing numbers, and yet higher if they are omitted at the beginning of the sequence. Concerning overall difficulty, the task is more laborious if the sequence is in descending order and the higher the step size between the sequence numbers is (Multimedia Appendix 3).

Action Sequencing (Impact Memory, Attention, Executive Functions, and Language)

A higher number of steps are needed to increase the cognitive demands. Also, it is possible to make the training more demanding for attention and language if the task goal is not explicitly mentioned (Multimedia Appendix 4).

Association (Impact Memory, Attention, Executive Functions, and Language)

Augmenting the number of pairs will increase the difficulty as well as the training of memory, attention, executive functions, and language (Multimedia Appendix 5).

Cancellation (Impact Memory, Attention, Executive Functions, and Language)

Memory and attention demands can be increased by using symbols and letters instead of numbers and by having more distractors and targets. For training in the language domain, we should use symbols and increase the number of distractors. By increasing both targets and distractors and using symbols, the task gets more difficult and more demanding in executive functions (Multimedia Appendix 6).

Categorization (Impact Memory, Attention, Executive Functions, and Language)

Augmenting the number of categories will increase the difficulty of the task as well as the training of memory, executive functions, and language. Concerning attention, besides augmenting the number of categories, we need to have more items per category (Multimedia Appendix 7).

Comprehension of Contexts (Impact Executive Functions and Language)

The higher the number of descriptions per context, the higher the demands for executive functions, language, and difficulty (Tables 5 and 6).
**Image Pairs (Impact Memory, Attention, Executive Functions, and Language)**

Increasing the number of images to pair will increase the difficulty of the task and the training of memory, attention, executive functions, and language (Multimedia Appendix 8).

**Mazes (Impact Memory, Attention, Executive Functions, and Language)**

They can be used to train memory, attention, executive functions, and language. By augmenting the size of the mazes, the cognitive demands and general difficulty are increased (Multimedia Appendix 9).

**Memory of Stories (Impact Memory, Attention, Executive Functions, and Language)**

To increase demands for memory, attention, and general difficulty, we need to increase the length of the story and the number of questions about it. To train executive functions and language, increasing the story length is enough (Multimedia Appendix 10).

The above modeling effort of the selected cognitive training tasks—selected for their high impact in the realization of ADLs—enables us to create a cognitive rehabilitation program that is precisely adjusted to each individual cognitive domain depending on the specific profile of each patient in terms of memory, attention, executive functions, language demands, and overall difficulty. Our computational approach, thus, captures the implicit rehabilitation experts’ experience and knowledge quantitatively; thus, providing us with explicit models to create an adaptation engine capable of personalizing cognitive training.

**App: the Task Generator**

Still today, paper-and-pencil tasks are the most widely used means of cognitive rehabilitation [43] because of their acceptance, clinical validity, and reduced cost [44]. However, one of their limitations is that they lack flexibility and personalization. Consequently, it would be advantageous to have a tool that could generate standard, accepted, and validated paper-and-pencil tasks, yet customized according to any patient profile. This approach would mitigate some of the most critical limitations of paper-and-pencil tasks. For this reason, we have created a free and world-accessible Web-based tool, the TG, for the generation of personalized cognitive training tasks (see Multimedia Appendix 11). The TG is a Web-based app and does not require to be installed on the computer; the only software required is a PDF reader to open the downloaded files. Through this tool, clinicians can define appropriate parameters of training for memory, attention, executive functions, language, and difficulty, and it automatically generates the requested personalized cognitive training tasks based on the task adaptation profiles represented as radar plots in Figure 2 (the area between the minimum and the maximum line represents the range interval in which each task can vary).

Tasks can be created either individually by directly specifying the values of their parameters (Figure 3) or as a full cognitive training program containing the whole set of 11 personalized training tasks. Tasks are created procedurally; 2 training tasks are never the same, allowing for the repeated use of this tool. Besides, the generated tasks have a task profile (Figure 4)—a graphical representation of their demands in each cognitive domain and difficulty—enabling clinicians to efficiently and continuously adapt the training to the patient’s needs (Figure 5).

**Training Adaptation Over Time**

When the patient finishes a set of tasks, the clinician may use one of these 2 procedures:

1. **From training session to training session:** By scoring the TG task’s performance using a 0% to 100% scale and computing the mean performance of the whole task’s set. If the mean performance is higher than a specific threshold (for instance, assuming an optimal performance from 70% to 100% [45]), the clinician should increase by 0.5 only the difficulty parameter while keeping the ones related to memory, attention, executive functions, and language constant. Alternatively, if performance is from 0% to 50%, the difficulty parameter should be reduced by 0.5.

2. **After a progress evaluation point:** By performing a new assessment of the patient profile. A new set of training tasks is generated with the new assessment following the same procedure stated in the Cognitive Training Program Generation section.

**Full Cognitive Training Program Generation**

Once a patient is assessed, and the patient’s deficits and cognitive profile are known, the clinician’s challenge is that of adapting the available training tasks to this patient. TG solves that problem by allowing clinicians to quickly generate a complete cognitive training program, containing the whole set of 11 tasks by simply specifying the cognitive profile for a patient in 4 cognitive domains (memory, attention, executive functions, and language), and the overall task difficulty in a 1 to 10 scale. This can be easily done through the characterization of the patient with validated instruments such as the Montreal Cognitive Assessment (MoCA) [46]. The TG Attention parameter can be defined from MoCA’s attention component score (0-6); the delayed recall and orientation scores (0-11) can be used to parameterize memory; executive functions can be parameterized through the sum of the visuospatial, executive, and abstraction MoCA subscores (0-7); MoCA’s naming and language scores (0-6) can be used to parameterize language; and the total score (0-30) can be used to parameterize the overall difficulty. After the characterization of a patient, through the normalization of these assessment results on a 1 to 0 scale, a full training program is generated by pressing the Generate Training button and then can be downloaded as a PDF file by pressing the Download PDF button. In addition, there is an optional check box in the patient profile page that when selected only generates tasks closely matching the chosen profile. Tasks that would differ substantially from the selected profile can then be filtered out as they can represent nonoptimal task parameter choices. Nonetheless, the user can disable this feature by unchecking the selection box and the TG will generate the complete set of 11 tasks, with the best possible personalization allowed by their parameters.
Figure 3. Individual tasks can also be generated by specifying the value of their parameters (cancellation task example).

Figure 4. A cognitive training program can be generated by specifying the intended training intensity in each cognitive domain. Each training task contains a visual task profile, indicating its demands in attention, memory, executive functions, language, and difficulty.
Discussion

Principal Findings

We developed a design framework where we borrowed concepts from educational psychology and a participatory design strategy with stakeholders to support the development process. Through this process, we were able to identify a representative group of well-established standard paper-and-pencil tasks currently used for cognitive rehabilitation, and we operationalized them with respect to their parameters. To that end, the expert knowledge of 20 rehabilitation experts was used to model each task for its difficulty and impact on cognitive functions. The task models obtained provide us with valuable guidelines toward the development of personalized cognitive rehabilitation tools. Furthermore, we demonstrated the proposed methodology with an example case: a Web-based tool for the generation of customized paper-and-pencil cognitive training tasks, the TG. We believe that the TG contributes toward the definition of objective procedures for the application of adaptive cognitive rehabilitation through the use of ICTs. The use of TG has virtually zero cost associated, and it is available in English, Portuguese, and Italian.

Comparison With Prior Work

Recent technological advances have allowed improved apps for cognitive rehabilitation, and it has been shown that they can be effective rehabilitation tools for health professionals [33]. However, the lack of a precise design methodology that can guide the development of ICT’s applications, applied to rehabilitation, still remains one of the main limitations in this field. Data mining techniques have been applied to predict the outcomes of cognitive rehabilitation in patients with acquired brain injury; however, rehabilitation experts’ input should also be included [47]. As an answer to this need, the primary goal of this study was to propose a general framework to guide in the design of future cognitive rehabilitation tools, with objective and expert-based guidelines.

The app here presented guidelines in a Web-based tool as the TG also addresses the accessibility limitations because it can be widely deployed at health care centers and home. This new approach does not interfere with current clinical practices because it produces printable paper-and-pencil tasks. By enabling the adaptation of task parameters and difficulty levels according to patient performance, this tool provides a comprehensive and highly personalized cognitive training.

Limitations

Despite the valuable guidelines obtained, via computational modeling, from our participatory design strategy, some limitations of our study must be considered. First, there is a considerable variety of paper-and-pencil tasks being used in cognitive rehabilitation and stimulation practice, and we have selected a small subset of 11 tasks to be possible to parameterize and present them in a questionnaire; however, we are aware it is a small number. Second, concerning the sample of rehabilitation experts, 20 participants can be considered a small number although we managed to include different professionals: physicians, psychologists, and therapists. Third and last, our...
participatory design strategy was limited in the sense that we did not include subjective and qualitative feedback from the rehabilitation experts, except for one of the physiatrists who was involved in the task selection phase.

**Developments of This Study**

Although paper-and-pencil tasks are widely used in cognitive rehabilitation, these tools mostly focus on isolated components of cognitive functioning, which have been reported to disagree with everyday life tasks [44,48]. It has been shown that virtual reality (VR), as a tool, has a significant potential for enhancing the reliability and specificity of cognitive assessment and rehabilitation [19,49]. Due to all the VR advantages, the logical next step is the integration of the computational models obtained through the participatory design study in a cognitive VR rehabilitation environment presented here. In this context, we integrated the findings from our models and transformed the original paper-and-pencil tasks in virtual ADL's tasks within a simulation of a city with streets, sidewalks, realistic buildings, several parks, and moving vehicles—the Reh@City [50]. The activities in the Reh@City are organized in parameterized difficulty levels and target the cognitive domains addressed in the guidelines presented here: memory, attention, executive functions, and language. As an illustrative example, in terms of attention, Reh@City incorporates relevant ADL's, implementation of which helps bridge paper-and-pencil cancellation tasks. More specifically, targets and distractors are embedded in a pharmacy, a supermarket, or a post-office shelf. This kind of implementation allows the operationalization of the training difficulty by changing the number and nature of targets and distractors, their sizes, and their spatial arrangement.

Currently, we are running a 1-month longitudinal randomized controlled trial comparing both TG and Reh@City v2.0 interventions. This study entails a comprehensive neuropsychological assessment not only pre- and post intervention but also at follow-up, with the aim of comparing the impact of a personalized paper-and-pencil program (TG), a personalized and integrative VR-based program (Reh@City v2.0), and conventional therapy. The main objective of this study was to assess the neuropsychological and functional impact of a paper-and-pencil task and a VR intervention, having the same tasks and parameterization guidelines for comparison. In addition, in this study, we are also addressing the usability of the tool through interviews and questionnaires so that we can improve both tools regarding the patients’ perspective.

**Future Work**

Many health care providers are unfamiliar with ICTs and, as a consequence, a very small percentage of people with disabilities have access to technological devices that can assist them in the rehabilitation process. To mitigate this issue, it would be valuable to improve the usability of both the TG and the Reh@City by interviewing the health care providers after using them as complementary tools for their work.

Moreover, as future work, we are also planning to upgrade the TG app by creating a tablet version that allows remote monitoring by the health care providers and automatic personalization through artificial intelligence and machine learning algorithms.

**Acknowledgments**

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**Authors' Contributions**

ALF and SBiB designed the study and performed the data analysis. MSP provided methodology guidelines. ALF performed the data collection. ALF, MSP, and SBiB wrote the paper for publication.

**Conflicts of Interest**

None declared.

**Multimedia Appendix 1**

Questionnaire’s internal consistency.

[PDF File (Adobe PDF File), 14KB - rehab_v5i2e10714_app1.pdf]

**Multimedia Appendix 2**

Word search task models for memory, attention, executive functions and difficulty.

[PDF File (Adobe PDF File), 49KB - rehab_v5i2e10714_app2.pdf]
Multimedia Appendix 3
Numeric sequences task models for memory, attention, executive functions, language, and difficulty.

[PDF File (Adobe PDF File), 21KB - rehab_v5i2e10714_app3.pdf]

Multimedia Appendix 4
Action sequencing task models for memory, attention, executive functions, language, and difficulty.

[PDF File (Adobe PDF File), 21KB - rehab_v5i2e10714_app4.pdf]

Multimedia Appendix 5
Association task models for memory, attention, executive functions, language, and difficulty.

[PDF File (Adobe PDF File), 21KB - rehab_v5i2e10714_app5.pdf]

Multimedia Appendix 6
Cancellation task models for memory, attention, executive functions, language, and difficulty.

[PDF File (Adobe PDF File), 22KB - rehab_v5i2e10714_app6.pdf]

Multimedia Appendix 7
Categorization task models for memory, attention, executive functions, language, and difficulty.

[PDF File (Adobe PDF File), 21KB - rehab_v5i2e10714_app7.pdf]

Multimedia Appendix 8
Image pairs task models for memory, attention, executive functions, language, and difficulty.

[PDF File (Adobe PDF File), 21KB - rehab_v5i2e10714_app8.pdf]

Multimedia Appendix 9
Mazes task models for memory, attention, executive functions, language, and difficulty.

[PDF File (Adobe PDF File), 21KB - rehab_v5i2e10714_app9.pdf]

Multimedia Appendix 10
Memory of stories and images task models for memory, attention, executive functions, language and difficulty.

[PDF File (Adobe PDF File), 24KB - rehab_v5i2e10714_app10.pdf]

Multimedia Appendix 11
Task Generator video.

[MP4 File (MP4 Video), 129MB - rehab_v5i2e10714_app11.mp4]

References


Abbreviations

ADL: activity of daily living
AIC: Akaike Information Criterion
**BIC**: Bayesian Information Criterion

**DV**: dependent variable

**ICT**: information and communication technology

**IV**: independent variable

**MoCA**: Montreal Cognitive Assessment

**TBI**: traumatic brain injury

**TG**: Task Generator

**VR**: virtual reality

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Adoption of Stroke Rehabilitation Technologies by the User Community: Qualitative Study

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Abstract

Background: Using technology in stroke rehabilitation is attractive. Devices such as robots or smartphones can help deliver evidence-based levels of practice intensity and automated feedback without additional labor costs. Currently, however, few technologies have been adopted into everyday rehabilitation.

Objective: This project aimed to identify stakeholder (therapists, patients, and caregivers) priorities for stroke rehabilitation technologies and to generate user-centered solutions for enhancing everyday adoption.

Methods: We invited stakeholders (n=60), comprising stroke survivors (20/60, 33%), therapists (20/60, 33%), caregivers, and technology developers (including researchers; 20/60, 33%), to attend 2 facilitated workshops. Workshop 1 was preceded by a national survey of stroke survivors and therapists (n=177) to generate an initial list of priorities. The subsequent workshop focused on identifying practical solutions to enhance adoption.

Results: A total of 25 priorities were generated from the survey; these were reduced to 10 nonranked priorities through discussion, consensus activities, and voting at Workshop 1: access to technologies, ease of use, awareness of available technologies, technologies focused on function, supports self-management, user training, evidence of effectiveness, value for money, knowledgeable staff, and performance feedback. The second workshop provided recommendations for improving the adoption of technologies in stroke rehabilitation: an annual exhibition of commercially available and developing technologies, an online consumer-rating website of available technologies, and a user network to inspire and test new technologies.

Conclusions: The key outcomes from this series of stakeholder workshops provides a starting point for an integrated approach to promoting greater adoption of technologies in stroke rehabilitation. Bringing technology developers and users together to shape future and evaluate current technologies is critical to achieving evidence-based stroke rehabilitation.

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KEYWORDS
stroke; rehabilitation; technology; priorities
Introduction

Background

Stroke has been a priority for the National Health Service (NHS) in Scotland for the last 15 years. In that time, there has been a 21% decrease in incidence and a 41% improvement in survival rates [1]. These figures represent an enormous success for public health and acute care but have created a new challenge: to provide rehabilitation and care to the increasing number of survivors, currently estimated at 117,500 in Scotland [2]. This challenge is not confined to Scotland; worldwide, an estimated 15 million people suffer from stroke every year, a third of whom are estimated to be left with persistent disability [3].

There is good evidence that rehabilitation can improve recovery from stroke [4]. The recovery of specific functions such as walking and upper limb activities are improved through repetitive, task-specific practice with performance feedback [5], all delivered, typically, by rehabilitation professionals. While rationing access to such a resource is understandable in the context of health budget constraints, this is likely to limit the recovery of some individuals.

In response to this need, technology has been used to increase rehabilitation practice intensity [6,7], enhance health professionals’ efficiency [8], and provide objective feedback on progress [9]. Technology can also support independent practice, which is critical to achieving the levels of intensity associated with improved outcomes [8]. Technologies are developing rapidly, and global advances in digital healthcare mean that a greater reliance on technology is inevitable. In Scotland, this is compounded by the drive to reduce the length of hospital stay [10], which will, by necessity, require greater integration of care in the community and promotion of self-management [11]. Technologies designed to promote patient-centered functional recovery after stroke can play a critical role, particularly in those aspects prioritized by patients and healthcare professionals (eg, mobility, speech, cognition, and confidence) [12]. Currently, few of these technologies are being embedded into everyday practice. This may relate to technology developers focusing on impairment, and not on the functional needs of the individual [13], as well as a general lack of collaboration across the stakeholders, (ie, users, technology developers including researchers, and policymakers) [14].

A perceived mismatch between research and patient priorities for life after stroke motivated a Priority Setting Partnership (PSP) that produced a list of agreed priorities for future research [12] that has been widely adopted by the research community. This was considered a sensible first step to resolving the poor adoption of technologies in stroke rehabilitation.

Our aim was to identify stakeholder priorities for stroke rehabilitation technologies using an adapted version of the James Lind Alliance approach to priority setting [15] and then use these priorities to generate user-centered solutions to enhance the everyday adoption of technologies by users, therapists, patients, and caregivers.

Objectives

The objectives were (1) to gather stakeholder priorities for the development of technologies in stroke rehabilitation, (2) to produce a top 10 list of priorities through a process of consensus across stakeholders, and (3) to generate new ideas from stakeholders on ways to improve the adoption of technology in stroke rehabilitation.

Methods

To achieve our aim, we planned a consensus-building process that emulated the James Lind PSP [15]. This consisted of a national survey of stakeholders to gather a long list of priorities followed by two one-day workshops inviting local, national, and international stakeholders. While Workshop 1 followed the James Lind process to reach consensus on the top 10 priorities, Workshop 2 aimed to generate new ideas using the top 10 list as a framework. An organizing committee consisting of 2 stroke survivors, 2 NHS therapists, 2 researchers, and 1 representative from the third sector, the charitable organization Chest Heart and Stroke Scotland (CHSS), agreed with the overall aim of the project, the design of the survey, and the structure of the two workshops. The study was ethically approved by the University Ethics Committee of University of Strathclyde (UEC16/02).

Results

Stakeholder Survey

Surveys were sent to stroke survivors, caregivers, and rehabilitation professionals working in stroke to generate a long list of priorities from the broad community. These surveys were distributed electronically and manually through professional (Scottish Allied Health Professions Forum) and patient support networks (CHSS) to reach as broad a population as possible. As the survey was designed with the single purpose of generating a long list of priorities, only 6 questions were posed. These included background information on the use of rehabilitation technologies and a request to state their perceived priorities for stroke rehabilitation technologies. A copy of the survey can be found in Multimedia Appendix 1. The response to the request for priorities provided 137 individual priorities. These were checked for duplication, and a list of priorities was assembled and ranked by popularity. To be included on the final list, a priority had to be stated by at least two individuals. In this way, a list of 25 ranked priorities was produced from the survey.

Stakeholder Workshop 1: Consensus Agreement

Workshop 1 was located at a neutral (ie, not a hospital or university), city center venue with good public transport links and disabled access. The workshop lasted 7 hours with breaks for lunch and refreshments. Sixty delegates representing the three stakeholder groups (users, technology developers including researchers, and policymakers) attended the workshop. Delegates were recruited through general invitations sent out to members of the Scottish Allied Health Professions Forum (therapists), CHSS patient networks (patients and caregivers), and individuals known to the committee as being active and experienced in this area (policymakers, researchers, and...
technology developers). The final delegate list was agreed upon by the organizing committee to ensure an even proportion from each group. Delegates were placed at 7 tables so that each table had at least 2 individuals from each of the stakeholder groups and a facilitator. Facilitators experienced in working with stroke survivors and therapists were supplied by CHSS.

The workshop included presentations of different models of rehabilitation provision including community therapy delivered according to the current NHS model, private rehabilitation delivered in the patient’s home, and a third sector (charitable organization) service based around a gym and activity center, which made use of technologies such as virtual reality. There were also short demonstrations of rehabilitation technologies designed for mobility and communication impairments. These presentations and demonstrations were intended to help participants engage with the subject matter and were arranged by the organizing committee. After these presentations, the long list of priorities (n=25) generated by the survey were graphically presented to the group and placed as individual pieces of paper, in no particular order, on each table. The short-listing process consisted of each table reducing their list from 25 to 15 priorities through consensus discussions, which they subsequently presented and justified to the whole group for broader discussion.

A final selection of 10 priorities was then agreed through discussion by the whole group with a consensus on the inclusion of each priority reached by voting (raising a colored card for yes and no).

The following priorities were agreed at the end of the workshop. A short description is appended to each priority because the group felt that these clarifications were important to avoid ambiguity. They were initially ranked (based on the group vote) in the order set below. However, the workshop delegates requested the list should not be ranked, as the level of priority may differ according to the context and role of the individual, but they were happy that these were the 10 most important priorities. To encapsulate this lack of hierarchy, the final list was expressed as a circle (Figure 1).

The priorities for rehabilitation technology were as follows:

1. **Access to equipment**: This referred to users being able to access specific pieces of equipment without too much trouble and being able to use them within NHS facilities. The latter was particularly relevant to healthcare professionals using software apps that were blocked by NHS IT systems.
2. **Ease of use**: Although considered largely self-explanatory, there was a specific desire for devices to be operable with one hand and for all devices to be easy to use by all end users (ie, healthcare staff, stroke survivors, and their caregivers).
3. **Awareness**: This referred to the awareness of what technologies were actually available to the users in their local area as well as how they could access them.
4. **Functional**: Workshop delegates felt that any technology should be clearly focused on improving functional outcomes (ie, those that enhance activities of daily living whether related to mobility, speech, or cognition or memory).
5. **Supported self-management**: This was a priority identified as overlapping with other priorities (eg, access, ease of use, etc), but the consensus was that it should have its own position on the list. Technologies should, therefore, be designed with the ambition that they can be used to assist the user to manage their own condition by enabling them to practice rehabilitation activities.
6. **Training**: For all end users, training should available in accessible formats.
7. **Evidence of effectiveness**: This was widely debated as it was felt that definitive proof is unlikely to be achieved for technologies in the near future. The group felt that while a lack of research evidence on efficacy should not pose a barrier to a technology being adopted, the stakeholder community (users, policymakers, and technology developers) should work together to provide this evidence. Initially, this may be collated experiential evidence but should progress toward definitive evidence suitable for inclusion in practice guidelines.
8. **Value for money**: This term was originally described as “cost” but was altered so that the benefit of the technology, at both individual and societal levels, was considered relative to its monetary cost.
9. **Knowledgeable staff**: Stroke survivor end users felt that a technology was more likely to be used and be effective if their healthcare professional was knowledgeable (practically and theoretically) in its use.
10. **Feedback**: Where possible, technologies should provide information on general rehabilitation progress to users (therapists and patients) as well as detailed information on the performance of the specific activity. It was recognized that this was not always possible, for example, when using resistance bands. This information should be presented in an accessible format that takes into consideration the potential visual, cognitive, and communication impairments that people with stroke may be dealing with and should be available to healthcare professionals, provided this was agreed.

**Stakeholder Workshop 2: Generating New Ideas to Promote Rehabilitation Technology in Stroke**

The second workshop took place in a neighboring city to broaden the stakeholder representation. Delegates (n=60) were recruited in the same manner as Workshop 1, with the organizing committee again deciding on the final delegate list to ensure an even distribution across the three stakeholder groups (users, technology developers, and policymakers). It is worth noting that 40 of the delegates attended Workshop 1. This was a deliberate decision to maintain some consistency. The aim of this workshop was to develop practical ideas for improving technology adoption considering the outcomes from the first workshop. To facilitate discussion, innovative rehabilitation practices (both models and use of technologies) were presented by local (Scotland and United Kingdom) and international (Italy and the Netherlands) speakers. The structure of the workshop, including presentation topics and speakers, was agreed by the organizing committee.
Following these presentations, delegates were organized into 7 tables of approximately 8 individuals with a mix of backgrounds (as per Workshop 1) to discuss the following question: “What practical steps could be taken to progress the aim of improving adoption of stroke rehabilitation technologies?”

The discussions from each table were summarized by a facilitator and presented to the whole group for further discussion. This process continued until clear outcomes, with consensus from the whole group, emerged. An agreement was finally reached on three practical steps to promote greater adoption of technologies in stroke rehabilitation: (1) an annual exhibition of rehabilitation technologies for all stakeholders, (2) formation of a network consisting of users, technology developers, and policymakers with the ambition of creating a road map for rehabilitation technologies, and (3) development of a consumer rater website inspired by websites such as TripAdvisor with the objectives of enhancing awareness of rehabilitation technologies, providing clear access to available research findings on the efficacy of these technologies, and allowing consumers to rate technologies on key attributes such as ease of use, value for money, and provision of feedback.

**Discussion**

**Principal Findings**

By providing the means to increase engagement with rehabilitation, technology has been shown to improve outcomes after stroke [6]. Despite growing evidence of efficacy, the adoption of these technologies by users (rehabilitation professionals, patients, and caregivers) is suboptimal [13]. A more integrated approach to technology development is required to ensure that this valuable resource is fully exploited [16]. Our study aimed to identify user priorities for rehabilitation technology and user-centered solutions to enhance the everyday adoption of these technologies by users: therapists, patients, and caregivers.

The 10 priorities identified by users through our survey and consensus workshops were similar to those reported by Hughes et al [17] and the Cumberland Consensus Working Group [18]. In particular, ease of use, evidence of effectiveness, access, and value for money have all been reported previously using questionnaire methodologies. Focus groups of pediatric and adult hemiplegic participants further confirm these enabling factors, adding motivation as a therapy “enabler” [19]. This is consistent with the feedback priority expressed by our stakeholder group.

**Strengths and Limitations**

The use of facilitated workshops to develop a consensus among stakeholders was the strength of our approach since it provided the opportunity for broad face-to-face discussions among individuals with real and often contrasting experiences of using rehabilitation technologies. This open discourse was deemed necessary to reveal the range of factors involved and has been used successfully in similar priority setting exercises [12]. Furthermore, our inclusion of a second workshop that incorporated new delegates both confirmed the outcomes from the first workshop and generated practical steps to improve technology adoption. This information can be used to assist the industry to overcome the poor adoption of rehabilitation technologies.
The limitations of our study are similar to other approaches that depend on engagement with users, namely that the users responding to the survey and attending the workshops may not be typical of the entire user group in that they are likely to have a pre-existing interest in the area. Furthermore, there may be some social desirability bias, particularly from arranging therapists and patients around the same table [18].

Conclusion

A series of workshops and surveys focusing on the adoption of technologies in stroke rehabilitation identified 10 key priorities by users (access to equipment, ease of use, awareness, functional, supported self-management, training, evidence of effectiveness, value for money, knowledgeable staff, and feedback). To improve adoption, practical steps including organization of an annual rehabilitation technology exhibition, formation of a network consisting of users, technology developers, and policymakers, and development of a consumer website were recommended.

Acknowledgments

We would like to acknowledge the Scottish Universities Insight Institute for funding this work and CHSS for providing facilitators and helping to distribute the survey and workshop invitations.

Multimedia Appendix 1

Survey questions for stroke survivors, carers, and therapists.

References


Abbreviations

- CHSS: Chest Heart and Stroke Scotland
- NHS: National Health Service
- PSP: Priority Setting Partnership

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Abstract

Background: Physical therapy is an essential component of multidisciplinary treatment in amyotrophic lateral sclerosis (ALS). However, the meaning of physical therapy beside preservation of muscular strength and functional maintenance is not fully understood.

Objective: The purpose of this study was to examine patients’ perception of physical therapy during symptom progression using an internet assessment approach.

Methods: A prospective, longitudinal, observational study was performed. Recruitment took place in an ALS center in Berlin, Germany. Online self-assessment was established on a case management platform over 6 months. Participants self-assessed the progression of the disease with the ALS Functional Rating Scale-Revised (ALSFRS-R) and tracked the efficacy of targeted physical therapy using Measure Yourself Medical Outcome Profile (MYMOP). We used the net promoter score (NPS) to inquire into recommendation levels of physical therapy.

Results: Forty-five participants with ALS were included in the study. Twenty-seven (60.0%) started the online assessment. The mean duration of physical therapy sessions per week was 142.7 minutes (SD 60.4) with a mean frequency of 2.9 (SD 1.2) per week. As defined by MYMOP input, the most concerning symptoms were reported in the legs (62.2%), arms (31.1%), and less frequently in the torso (6.7%). As expected for a progressive disease, there was a functional decline of 3 points in the ALSFRS-R at the end of the observation period (n=20). Furthermore, the MYMOP showed a significant loss of 0.8 in the composite score, 0.9 in the activity score and 0.8 in the targeted symptom. In spite of functional decline, the recommendation for physical therapy jumped from a baseline value of 20 NPS points to a very high 50 points at the end of study (P=.05).

Conclusions: Physical therapy is perceived as an important treatment method by patients with ALS. Despite functional deterioration, patients are satisfied with physical therapy and recommend this intervention. The results also underline how the meaning of physical therapy changes throughout the disease. Physical therapy in ALS has to be regarded as a supportive and palliative health care intervention beyond functional outcome parameters.

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KEYWORDS
ALS; amyotrophic lateral sclerosis; physical therapy; MYMOP; net promoter score; NPS; online self-assessment
Introduction

Amyotrophic lateral sclerosis (ALS) is a fatal neurodegenerative disease. The disease is characterized by a loss of motor neurons in the cortex, brain stem, and spinal cord resulting in progressive motor deficits and paralysis of the muscles that control limb movement, swallowing, and breathing [1]. As the disease progresses, muscles responsible for fine and gross motor functions are affected, leading to a decline in motor skills. As there is no current curative treatment for ALS, managing these complex symptoms depends on multidisciplinary care. Symptomatic, rehabilitative, and palliative therapy are typically delivered by a multiprofessional team that consists of neurologists, nurses, and therapists working in a coordinated and organized manner [2]. An important part of this multidisciplinary treatment is physical therapy, which is widely prescribed and applied in the treatment of ALS. A European survey has shown that 83% of ALS patients receive physical therapy [3]. Physiotherapists play an essential role on the multidisciplinary care team as they emphasize improving the function and quality of life in patients who require physical and functional dimensions of palliative care [4].

Experimental data [5-7] and several randomized clinical trials showed moderate effects and benefits of submaximal resistive exercises, especially in the early stages of the disease [8,9]. The neuromuscular mechanism was thought to prevent disuse atrophy and more efficient motor unit recruitment. Excessive or high resistance exercises have been associated with overwork damage and thus are not recommended in ALS treatment [8]. The key focus for physical therapists is to delay the decline of muscular strength by submaximal resistance exercise, which has been shown to be safe and efficacious. Additionally, because pain and spasticity worsen the burden of ALS, physical therapy also addresses these symptoms. Along with other service providers, physical therapists support the provision and adjustment of adaptive equipment and mobility aids [10]. However, there is still uncertainty about best practices concerning the manner, duration, and frequency of physical therapy. This lack of defined treatment guidelines arises from the large clinical heterogeneity of ALS syndromes, the different therapeutic approaches, and the individual expectations of patients and therapists.

Thus, this study aimed to:

1. Evaluate the frequency and duration of physical therapy sessions among ALS patients
2. Determine the most bothersome motor symptoms
3. Identify recommendation levels for physical therapy and the Net Promoter Score (NPS) at the beginning and end of the study

We investigated the recommendation of physical therapy to symptom progression in ALS. Furthermore, we explored whether the recommendation of physical therapy is related to the most concerning motor symptom, disease severity, duration, or the frequency of physical therapy sessions for ALS patients.

Methods

Study Design and Recruitment

This was a prospective, longitudinal, observational study that recruited a consecutive cohort of participants from the ALS outpatient department at Charité-Universitätsmedizin Berlin, Germany. A baseline assessment of epidemiological data, symptoms, type and amount of physical therapy was performed with 45 individuals, 20 of whom completed online surveys over a 6-months period, tracking symptom severity, restriction of activity, and recommendation for physical therapy.

Setting

The digital and internet-supported case management network Ambulanzpartner Soziotechnologie (APST) was used for online self-assessment and evaluation of physical therapy [11]. APST encompasses the services of case management coordinators, a tailored digital management platform and assessment tools for self-evaluation, services, therapy and assistive devices [12]. Patients and their caregivers were granted access to the APST platform through personalized accounts.

Participants

Inclusion criteria for this study involved a possible, probable or definitive diagnosis of ALS following the revised El Escorial criteria [13], a stage of a disease where at least one motor function was restricted, and participation in physical therapy. Patients with other severe life-limiting diseases or who showed clinically significant cognitive impairment were not eligible for this trial. For online assessment, participants used the digital case management program provided by APST [11].

Variables and Data Sources

Physical Therapy

Physical therapy was prescribed by a neurologist specializing in ALS and undertaken by physical therapists trained in the treatment of neurological disorders including ALS. In addition to physical therapy, patients received special treatments such as massages, lymphatic drainage, thermal treatment, and breathing therapy if needed. The overall time and frequency of individual physical therapy sessions per week were documented, as were additional special treatments.

Amyotrophic Lateral Sclerosis Functional Rating Scale-Revised

We evaluated the functional impairment of participants using the ALS Functional Rating Scale-Revised (ALSFRS-R), through online self-assessment [14]. This scale is a validated and widely used instrument that gauges the fine and gross motor functions of the arms and legs, bulbar functions, and breathing abilities. It comprises 12 short, clear questions with 5 anchor points (0-4) for response options. Hence, the total range of the scale spans 0 to 48 points, with fewer points representing poorer functioning and higher disease severity. The loss of ALSFRS-R value per month, or delta ALSFRS-R, indicates the rate of deterioration and predicts survival [15].
Measure Yourself Medical Outcome Profile

To focus on specific bothersome or disabling motor symptoms we employed the Measure Yourself Medical Outcome Profile (MYMOP) [16,17]. This instrument has not been used in patients with ALS before but has been suggested as an individualized patient-reported outcome measure in primary care physical therapy [18]. The MYMOP is a brief, patient-generated, problem-specific questionnaire, which requires participants to specify a symptom that concerns them most. Subsequently, participants evaluate the severity of this symptom on a 7-point Likert scale (eg, weakness of the right leg could score 0 for “as good as it could be” to 6 for “as bad as it could be”) as compared to the previous week. Participants also rate general well-being. Follow-up questionnaires address the original concerns. All domains (symptom severity, restriction of activity, and well-being) can be analyzed individually or as a total score, the profile score, that equals the mean of the subscores recorded (score 0-6).

Net Promoter Score

To evaluate the overall recommendation of physical therapy, we used a numeric rating scale (NRS) that derives from the Net Promoter Score (NPS) [19,20], which is used in customer relation management and has recently been introduced to clinical assessment [21,22]. The NPS is an easy-to-use, one-item questionnaire that is based on the question “How likely is it, that you would recommend the service to a friend or colleague?” Participants were asked to score on a 0 to 10 NRS, with 10 being extremely likely to recommend the therapy. The percentage of participants whose response was between 0-6 was subtracted from the percentage of those whose scores were 9-10 (Figure 1) to calculate the NPS. Participants with the values 7 and 8 were assumed to be indifferent or passive. Therefore, the NPS can be as low as –100 if everybody is a detractor, or as high as +100 if everybody is a promoter. A positive NPS is regarded as good, and an NPS of more than 50 is considered excellent. Alternatively, to avoid problems of NPS categorization, it is possible to refrain from calculating the NPS and only report the average NRS which reflects the recommendation [20].

Data Analysis

Data were analyzed with IBM SPSS Statistics (Version 24.0) for Microsoft Windows. Results were expressed as mean (SD) if normally distributed and medians (maximum/minimum) if the distribution was non-Gaussian. Correlational analysis was performed with the Spearman rho (ρ) because of the ordinal nature of the scales. A statistically significant difference of paired samples was analyzed with a t test. The recommendation was tested with the Wilcoxon test for related samples. A P value of <.05 (two-tailed) was considered significant. Due to the observational design of the study, the data has not been adjusted for multiple comparisons.

Protocol Approvals and Registrations

The study protocol was approved by the Medical Ethics Committee of the Charitè-Universitätsmedizin Berlin, Germany. A data safety and monitoring board supervised the study. Signed patient information and informed consent forms were obtained from all participating patients.

Results

Descriptive Data

Forty-five participants were included in this study and performed the baseline assessment. Sixty percent (27/45) also consented to online assessment through MYMOP and the recommendation of physical therapy for 20 weeks. Twenty of the 45 (44%) participants finished the 20-week online assessment providing complete data sets (Figure 2).

The mean age of all participants at baseline was 59.2 years (SD 10.6) with a relatively long disease duration of 27 months (median min/max 3/203) due to a higher percentage of long-term survivors in our trial. The mean duration of physical therapy was 142.7 minutes per week (SD 60.4) and mean frequency was 2.9 sessions per week (SD 1.2). Occupational therapy and speech and language therapy are not included in these values. The demographics and baseline characteristics of the participants are presented in Table 1.
Figure 2. Flowchart of participants.

Table 1. Baseline characteristics of participants.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>All patients, (N=45)</th>
<th>Online patients, (n=27)</th>
<th>Online patients-dropouts, (n=7)</th>
<th>Online patients-no dropouts, (n=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years), mean (SD)</td>
<td>59.2 (10.6)</td>
<td>59.4 (11.1)</td>
<td>58.0 (5.6)</td>
<td>59.9 (12.5)</td>
</tr>
<tr>
<td>Gender, n (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>16 (36)</td>
<td>7 (35)</td>
<td>3 (43)</td>
<td>4 (20)</td>
</tr>
<tr>
<td>Male</td>
<td>29 (64)</td>
<td>20 (65)</td>
<td>4 (57)</td>
<td>16 (80)</td>
</tr>
<tr>
<td>ALSFRS-R &lt;sup&gt;a&lt;/sup&gt; baseline, mean (SD)</td>
<td>36.9 (6.9)</td>
<td>38.5 (4.8)</td>
<td>36.1 (5.0)</td>
<td>39.4 (1.0)</td>
</tr>
<tr>
<td>Delta ALSFRS-R &lt;sup&gt;b&lt;/sup&gt;, mean (SD)</td>
<td>0.57 (0.51)</td>
<td>0.61 (0.57)</td>
<td>0.86 (0.27)</td>
<td>0.53 (0.11)</td>
</tr>
<tr>
<td>Disease duration (months), median (min/max)</td>
<td>27.0 (3/203)</td>
<td>25.0 (3/194)</td>
<td>16.0 (9/87)</td>
<td>26.5 (3/195)</td>
</tr>
<tr>
<td>Total MYMOP &lt;sup&gt;c&lt;/sup&gt; baseline, mean (SD)</td>
<td>3.0 (0.9)</td>
<td>3.0 (0.9)</td>
<td>3.1 (1.1)</td>
<td>2.9 (0.9)</td>
</tr>
<tr>
<td>PT &lt;sup&gt;d&lt;/sup&gt; time per week (minutes), mean (SD)</td>
<td>142.7 (60.4)</td>
<td>151.1 (63.5)</td>
<td>157.1 (70.4)</td>
<td>149.0 (62.7)</td>
</tr>
<tr>
<td>Overall time prescribed (minutes), mean (SD)</td>
<td>269.3 (138.6)</td>
<td>263.6 (110.7)</td>
<td>216.6 (58.5)</td>
<td>280.1 (120.7)</td>
</tr>
<tr>
<td>PT frequency per week, mean (SD)</td>
<td>2.9 (1.2)</td>
<td>2.9 (1.2)</td>
<td>2.9 (1.5)</td>
<td>3.0 (1.2)</td>
</tr>
</tbody>
</table>

<sup>a</sup>ALSFRS-R: Amyotrophic Lateral Sclerosis Functional Rating Scale-Revised.

<sup>b</sup>Loss of ALSFRS-R points per month.

<sup>c</sup>MYMOP: Measure Yourself Medical Outcome Profile.

<sup>d</sup>PT: physical therapy.

The Duration and Frequency of Physical Therapy

There was no significant difference between prescribed physical therapy time and session frequency in the different baseline cohorts. Given the fact that a regular physical therapy unit lasts between 45 to 60 minutes and patients receive 3 units per week, the mean duration of therapy sessions amounted to 2 and a half to 3 hours per week. Interestingly, an additional 2 hours per week were granted for special treatments. Only online participants who completed the study prematurely received fewer special treatment time of just 1 hour per week. However, this did not reach statistical significance (P=.19).

Disease Progression and Functional Impairment

The ALSFRS-R at baseline was comparable with other trials, but the ALS progression rate was 0.57 (SD 0.4), which is lower than in an average ALS population where the loss is usually 0.8 to 0.9 of a point [23]. In the online cohort, the constant decline in motor function was represented by an expected significant decline in the total ALSFRS-R from 39.4 to 36.4 (P=.05).

The 18/45 (40%) patients who did not participate in the online assessment showed a significantly more advanced stage of the disease compared to those who attended (ALSFRS-R: 34.4 versus 38.5, P=.05). Seven of 45 (16%) participants withdrew from the online survey after 7.7 weeks (SD 5.8). Among these
participants a higher proportion was female (43% versus 20%) and tended to be more affected (ALSFRS-R: 36.1 versus 39.4, \(P=0.13\)) with a higher rate of progression (delta ALSFRS-R: 0.72 versus 0.53, \(P=0.19\)).

**The Most Bothersome Symptom, Activity, and Well-Being**

Based on the initial MYMOP questionnaire, 62% (28/45) of participants defined symptoms in the legs as most bothersome, while 31% (14/45) cited restrictions in their arms as the most important issue. Three of the 45 participants (7%) named axial symptoms like torso weakness as the dominating symptom (Figure 3).

The total MYMOP of all cohorts at baseline was similar between 2.9 and 3.1. The profile score of MYMOP at baseline of 3.0 (SD 0.9, N=45) did not significantly correlate with the total ALSFRS-R at baseline (\(r=0.27, P=0.17\)). Whereas the correlation of the MYMOP with the according ALSFRS-R subscore related to functional loss of arms and legs was significant (\(r=0.45, P=0.03\)). However, the highest correlation was seen between the ALSFRS-R lower extremities subscore and the MYMOP symptom assessment subscore (\(r=0.62, P<0.001\)). This correlation was reproducible throughout the trial.

In the online cohort (\(n=20\), Table 2) the profile score of MYMOP increased from 2.9 to 3.7 (\(P=0.005\)). The MYMOP subscores for activity increased from 3.1 to 4.0 (\(P=0.02\)). The burden of the target symptom increased from 3.1 to 3.9 (\(P=0.02\)). The well-being subscore displayed a strong trend towards poorer well-being after 20 weeks (from 2.6 to 3.2) but without statistical significance (\(P=0.08\)).

The 7/27 (26%) online participants who withdrew initially showed a poorer well-being subscore in the MYMOP as compared to participants who finished the assessment (3.4 versus 2.6, \(P=0.08\)).

Figure 3. Distribution of the most concerning symptom at baseline (\(N=45\)).
Table 2. Change over 20 weeks in the online cohort (n=20).

<table>
<thead>
<tr>
<th>Outcome parameter</th>
<th>Baseline, mean (SD)</th>
<th>Week 20, mean (SD)</th>
<th>P value(^a)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ALSFRS-R(^b)</td>
<td>39.4 (1.0)</td>
<td>36.4 (1.3)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>MYMOP, profile</td>
<td>2.9 (0.2)</td>
<td>3.7 (0.2)</td>
<td>.005</td>
</tr>
<tr>
<td>MYMOP, well-being</td>
<td>2.6 (0.3)</td>
<td>3.2 (0.3)</td>
<td>.08</td>
</tr>
<tr>
<td>MYMOP, activity</td>
<td>3.1 (0.2)</td>
<td>4.0 (0.3)</td>
<td>.02</td>
</tr>
<tr>
<td>MYMOP, symptom</td>
<td>3.1 (0.2)</td>
<td>3.9 (0.3)</td>
<td>.02</td>
</tr>
<tr>
<td>Recommendation</td>
<td>7.6 (0.4)</td>
<td>8.6 (0.3)</td>
<td>.02</td>
</tr>
<tr>
<td>NPS(^d)</td>
<td>20</td>
<td>50</td>
<td>—</td>
</tr>
</tbody>
</table>

\(^a\)Wilcoxon test for related samples.
\(^b\)ALSFRS-R: Amyotrophic Lateral Sclerosis Functional Rating Scale-Revised.
\(^c\)MYMOP: Measure Yourself Medical Outcome Profile.
\(^d\)NPS: Net Promotor Score.

**Recommendation Levels for Physical Therapy**

The total value of the recommendation of physical therapy went from 7.6 to 8.6 (\(P=.02\), Figure 4). In the 7/45 (16%) withdrawing participants, we could see a not statistically significant decrease of recommendation based on the last assessment before withdrawal: 7.4 (SD 2.2) versus 7.0 (SD 3.5).

The recommendation was not influenced by the factors (1) age, (2) gender, (3) amount of physical therapy, (4) location of the most concerning symptom, (5) degree of functional impairment, and (6) well-being or activity (data not shown). Based on the recommendation we calculated the NPS, which increased from 20 at the beginning to 50 at the end of the observation interval (Figure 5).

Figure 4. Recommendation of physical therapy at week 1 and at week 20 (\(P<.05\)).
**Discussion**

**Principal Findings**

This study aimed to determine patients’ perception of physical therapy during disease progression. To our knowledge, there are few systematic reports about the extent to which physical therapy is applied to ALS patients. Baseline assessment of this study revealed a mean duration of 269.3 minutes of prescribed physical therapy including special treatments and a mean frequency of three units per week. Our data did not show a significant correlation between the recommendation of physical therapy and the extent (duration and frequency) of its application.

The ALS progression, measured by the ALSFRS-R, was complimented by the MYMOP in order to show the effect of motor decline on the perception of physical therapy. The correlation between MYMOP and the motor domain of the ALSFRS-R was strong, although this score is unable to measure new or coexisting problems and concerns. The patient-centered assessment was unable to measure other perceived benefits, like the social and psychological meanings of physical therapy.

However, the studies found no evidence that declines in well-being, motor function, or levels of activity significantly degrade the overall recommendation of physical therapy. Remarkably, throughout the study, the rating of physical therapy improved in the majority of participants despite the functional decline. As shown by the NPS rating of 20 in the first online assessment, we found strong satisfaction with physical therapy. By week 20 the NPS value reached a value of 50, which is considered to be excellent and shows a high acceptance of physical therapy within the studied cohort.

**Limitations**

Our findings must be considered in the context of their limitations. Out of all 45 participants, male patients were overrepresented in comparison to the general ALS population. This inadequacy was exacerbated in the online cohort, which we also have observed in previous online assessment trials. To reduce this bias, we attempted to recruit participants offline. However, women were more likely to terminate the assessment early. The 7 participants who discontinued online-assessment showed a trend towards faster progression, lower well-being and lower recommendation of physical therapy. Presumably, more aggressive disease progression might be a reason for dropping out, as might discontent with physical therapy. Measuring satisfaction using online self-assessment can be challenging. The NPS enables patients to rate physical therapy from the perspective of their own experience. At the same time, it is a 1-dimensional questionnaire and therefore assumed to be less reliable and more volatile than a composite index. In future studies, multidimensional or open designs should be considered to explore patients’ perspectives towards physical therapy in greater depth.

Further limitations in the study were the single center recruitment and the small sample size. Therefore, generalizations must be made with caution. Our cohort was representative of the ALS population regarding mean age and ALSFRS-R, but the participants showed a longer mean disease duration. The progression rate of 0.52 (SD 0.4) is lower than in an average ALS population, which is because a wider range of disease progression was represented as compared to homogenized populations within pharmaceutical trials. We can imagine that long-time survivors and patients whose diseases are progressing
slowly will have a certain and eventually more positive attitude towards physical therapy, even though the effect of therapy on motor function might be considered more relevant in the early stages of the disease. Finally, our population was seen at a specialist center supported by a case management platform. Furthermore, it is located in an advanced country with a universal multi-payer health system where costs for physical therapy are covered mostly by compulsory health insurances. Consequently, our findings may not be broadly applicable to other populations.

Conclusion
The overall positive assessment of physical therapy cannot be fully explained with the established rehabilitative concept of physical therapy. Our data suggest physical therapy plays an important role in a palliative context, where therapy and presumably the therapist hold considerable meaning for the patient. Physical therapists serving as interdisciplinary team members in palliative settings provide care for patients that extend beyond physical and bodily aims. Embracing this concept could entail shifting priorities across a disease continuum, and changing the perception of physical therapists as well as other allied health specialists [24]. Palliative and multidisciplinary approaches should be encouraged during the education, training, and qualification of physical therapists to implement the changing perceptions of physical therapy.

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Conflicts of Interest
TM received consultancy fees from Cytokinetics, GSK, and Desitin Arzneimittel GmbH and served on scientific advisory boards for Cytokinetics, GSK, and TEVA. TM and CM are founders of the internet platform Ambulanzpartner and hold shares of Ambulanzpartner Soziotechnologie APST GmbH.

References


Abbreviations

ALS: amyotrophic lateral sclerosis
ALSFRS-R: Amyotrophic Lateral Sclerosis Functional Rating Scale-Revised
APST: Ambulanzpartner Soziotechnologie APST GmbH
MYMOP: Measure Yourself Medical Outcome Profile
NPS: Net Promoter Score
NRS: numeric rating scale
PT: physical therapy
They Don’t Care About Us! Care Personnel's Perspectives on Ambient Assisted Living Technology Usage: Scenario-Based Survey Study

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Abstract

Background: Demographic change represents enormous burdens for the care sectors, resulting in high proportions of (older) people in need of care and a lack of care staff. Ambient Assisted Living (AAL) technologies have the potential to support the bottlenecks in care supply but are not yet in widespread use in professional care contexts.

Objective: The objective of our study was to investigate professional caregivers’ AAL technology acceptance and their perception regarding specific technologies, data handling, perceived benefits, and barriers. In particular, this study focuses on the perspectives on AAL technologies differing between care professionals working in diverse care contexts to examine the extent to which the care context influences the acceptance of assistive technologies.

Methods: A Web-based survey (N=170) was carried out focusing on professional caregivers including medical, geriatric, and disabled people’s caregivers. Based on a scenario, the participants were asked for their perceptions concerning specific technologies, specific types of gathered data, and potential benefits of and barriers to AAL technology usage.

Results: The care context significantly impacted the evaluations of AAL technologies ($F_{14,220}=2.514; P=.002$). Professional caregivers of disabled people had a significantly more critical attitude toward AAL technologies than medical and geriatric caregivers, indicated (1) by being the only caregiver group that rejected evaluations of AAL technology acceptance ($F_{2,118}=4.570; P=.01$) and specific technologies ($F_{2,118}=11.727; P<.001$) applied for gathering data and (2) by the comparatively lowest agreements referring to the evaluations of data types ($F_{2,118}=4.073, P=.02$) that are allowed to be gathered.

Conclusions: AAL technology acceptance is critical because of technology implementation reasons, especially in the care of people with disabilities. AAL technologies in care contexts have to be tailored to care professional’s needs and concerns (“care about us”). The results contribute to a broader understanding of professional caregivers’ needs referring to specific data and technology configurations and enclose major differences concerning diverse care contexts. Integrating these findings into user group-tailored technology concepts and communication strategies will support a sustainable adoption of AAL systems in professional care contexts.

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KEYWORDS
Ambient Assisted Living technologies; assistive technologies; care professionals; diverse care contexts; web-based survey; quantitative scenario-based approach; technology acceptance; user diversity
Introduction

Background

Demographic change involves higher proportions of older people and people in need of care, bringing the care sector to its knees due to personnel, economic, and organizational shortcomings [1,2]. Geriatric care, nursing care, and—as a comparatively new development [3]—care institutions for (older) disabled people suffer badly from a lack of care personnel in combination with raising needs of care for older (geriatric care), chronically ill (curative care), and disabled (care of the disabled) people [4,5].

The development of technical innovations is proceeding constantly to relieve care staff, complement care supply, enhance safety in emergencies, and enable a largely autonomous life for people in need of care [6]. Within these developments, diverse Ambient Assisted Living (AAL) technologies and systems [7,8] enable monitoring of vital parameters, detecting falls and emergencies, and a longer stay at home using smart home technologies [9,10].

Such technologies and systems are rarely used in both real-life and professional working environments [11]. Beyond availability and technical possibilities, users’ acceptance and the broad willingness to use these systems are decisive for a sustainable integration of AAL technologies in everyday life [12]. As recently reported [13], there are considerable differences in AAL acceptance between people in need of care and professional caregivers, indicating a more critical and restraint attitude of care staff compared with people in need of care and their relatives.

The professional caregivers’ perspectives on specific AAL technologies and on the data gathered in line with perceptions regarding benefits of and barriers to such systems are not known. This study, therefore, takes professional caregivers’ perspectives on AAL technologies into account, comparing different care contexts—geriatric care, medical care, and disabled people’s care.

In the following sections, we have presented the theoretical background starting with examples of current AAL technologies and systems, followed by AAL acceptance studies in professional care contexts.

Ambient Assisted Living Technologies and Systems

Assisting technologies or systems contribute to an increased autonomy in everyday life and are applied in care for prevention and rehabilitation, summarized under the term “Ambient Assisted Living” technologies. They cover diverse functions such as monitoring, detection, or reminders [10,14,15] and have the potential to empower collaborations in self-care [16].

Integrating Information and Communication Technologies (ICT; eg, cameras, microphones, motion sensors) into people’s living environments enables monitoring to enhance safety by detecting falls and emergencies in private [17] as well as professional care environments, for example, care institutions, hospitals, or retirement homes [18]. In addition, some approaches aim for monitoring and tracking outdoors using radio frequency identification [19], for example, to locate missing people suffering from dementia or confusion.

In addition to safety-related goals, automated technologies are used to facilitate everyday life (eg, memory aids, home automation) [20,21]. Enabling communication with families, friends, doctors, and caregivers by integrating ICT into home environments is a further aim of AAL [10]. Besides technologies integrated into devices and rooms, wearable technologies (eg, emergency arm strap) worn on the body or integrated into clothes present a further field of AAL enabling communication with smart home environments [7,22]. Although a considerable number of systems are already available on the market, success and sustainable integration of those systems have failed to appear so far [11,23]. Thus, reasons for their failure have to be investigated as caregivers’ acceptance of assistive technologies is of paramount importance for successful integration and usage of AAL technologies; as relevant stakeholders and users of these systems, professional caregivers’ perceptions, needs, and willingness to adopt AAL technologies need to be focused upon.

Acceptance of Ambient Assisted Living Technologies in Professional Care Contexts

Overall, AAL technologies were mostly evaluated positively; key drivers to use AAL technologies are the benefits of independent and autonomous living as well as a longer stay at the own home for older, chronically ill, or disabled people [13,24]. At the same time, feelings of isolation [13,25] and surveillance as well as perceived threat of privacy violations [26,27] were key barriers that impeded the integration of AAL technologies into people’s living environment.

The perspectives and perceptions of care professionals on integrating AAL technologies into their working environments have rarely been considered in acceptance research so far. Frequently, the research investigates care in emergency or ambulance contexts involving perspectives of (elderly) patients and care professionals [28,29]. One study has considered caregivers and their perceptions toward in-home monitoring technologies [30] and one has derived guidelines for design and implementation in the context of professional care environments [31]. Overall, a positive attitude of nursing staff toward health care information technology has been revealed, while poor system design and fear of dehumanizing patient care have been reported to be the main barriers of health care information technology usage [32]. Furthermore, ICT support in dementia care [33] has showed a positive general perception of ICT, but similarly diverse and mixed evaluations during technology implementation. In contrast to those—predominantly—positive generic attitudes toward technology usage in care contexts, a recent, more specific study revealed quite critical and restraint attitudes of professional nursing staff toward AAL technologies compared with more positive perspectives of disabled participants, the relatives of disabled persons, and “not”-experienced participants (persons without experiences with care) [13].

These diverse and partly contradicting results in different care contexts might serve as a starting point for explaining why AAL technologies are not widely used in professional care contexts yet. In addition, the thin body of knowledge in this context
stresses the necessity for more specific research exploring possible reasons for accepting or declining care technology, such as the type of AAL technology, the issue of data collection and privacy handling, as well as the impact of different care contexts on AAL technology acceptance [34].

As a theoretical base, the acceptance of assisting ICT has been grounded by long-time established acceptance models such as the Technology Acceptance Model (TAM) [35] and the Unified Theory of Acceptance and Use of Technology (UTAUT) [36], which had been developed for ICT usage mostly in healthy persons in the working context. For the specific nursing and care requirements, those models of technology acceptance are not sufficient, mostly because the main determinants of acceptance models—ease of using a system and perceived usefulness—might be an oversimplification of the situation in complex care settings, where not only the technology but also the fragile situation of patients, in line with the sensitive relation between caretakers and caregivers, is of importance. Furthermore, previous acceptance models do not consider different caring contexts and the inherent trade-offs between simultaneously existing positive and negative usage motives [37].

Objective and Aim of the Study

Due to abovementioned reasons, it was necessary to use a qualitative approach first; interviews were conducted with professional caregivers working in diverse care areas (n = 6) to identify challenges in care and the perceived benefits of as well as barriers to AAL technology usage from a care staff’s perspective. The differentiated look on professional caregivers allowed us to investigate what assistive technology should and should not do. Based on the qualitative results of this preceding study, the Web-based questionnaire for this study was conceptualized.

Therefore, this study aimed to quantitatively investigate the professional caregivers’ acceptance of assistive technologies in professional care contexts, differentiating between geriatric care, medical care, and disabled people’s care. This investigation was driven by the following research questions:

1. Do professionals of different care contexts differ with respect to their perceptions of AAL technologies?
2. Do professionals of different care contexts differ with respect to their willingness to share care-related data?
3. Do professionals of different care contexts differ with respect to their willingness to be assisted by specific AAL technologies in their daily routines?
4. On a data level, which are the main predictor variables for the AAL acceptance across the different care contexts?

Methods

Methodology

In order to reach a larger sample of care professionals, a Web-based survey was developed and specifically tailored to professional caregivers working in diverse care contexts. A preceding interview study focused on professional caregivers’ daily routines, their perceptions of different assistive technologies, and their wishes and needs. These qualitative results enabled the development of a scenario- and Web-based survey that addresses professional caregivers in a realistic and comprehensible way.

Research Variables

As an independent variable, we explored the care context contrasting 3 areas: (1) geriatric care; (2) nursing care; and (3) disabled people’s care and support. Naturally, these are not distinct categories as sometimes, there are overlaps across these care areas in real-life care settings. However, the responding caregivers had to assess themselves in terms of their main professional area. Thus, we took their self-assessment as an expert classification.

As dependent variables, we analyzed different acceptance ratings. First, participants answered items with respect to AAL technology acceptance, differentiating among data storage, access, and collection, as well as perceived benefits and barriers respecting AAL technologies. The items for these areas were taken from a preceding qualitative interview study with professional caregivers of different care areas. Furthermore, the next dependent variable relates to different types of gathered data and different types of technologies used for AAL assistance. All constructs, the respective items, and their evaluations have been presented in Multimedia Appendix 1.

Empirical Design of Web-Based Survey

Overall, the survey contained 14 questions pictured on 9 pages (including the starting page, final page, and scenario introduction). Measuring was operationalized by 6 forced-choice questions, open comment fields, and 82 items departed in 8 thematic blocks. These items were block wise randomized and had to be evaluated on 6-point Likert scales (1 = min: “I strongly disagree” to 6 = max: “I strongly agree”). Thereby, values < 3.5 indicated rejection, whereas values > 3.5 indicated approval. During the Web-based survey, participants had the opportunity to review and change their answers if desired.

Demographic characteristics (age, gender, education, and duration of professional experience) and the care sector of respondents (ie, geriatric care, nursing care, and disabled people’s care) represented the questionnaire’s first part of the survey. In the second part, participants’ attitudes toward technical self-efficacy (4 items, alpha=.884; based on [38]), their needs for privacy (6 items, alpha=.833; based on [39,40]), and their interpersonal trust (3 items, alpha=.793; based on [41]) were assessed.

To ensure that all participants refer to the same baseline concerning the evaluation of AAL technology, a scenario approach was adopted; the participants should imagine the integration of an AAL system into their professional working environment. Room sensors, microphones, video cameras, and ultrasonic sensors were introduced as part of the AAL system, and their functions within the AAL system were detailed (eg, automatic opening and closing of doors and windows, reminders, and alarms [emergencies, falls]).

Subsequently, participants were asked to evaluate perceived potential benefits (14 items, alpha=.923) and potential barriers (17 items; alpha=.861) referring to the described AAL system.
Both benefits and barriers of the described AAL system were obtained from the interview study. Furthermore, participants indicated whether they would accept gathering different types of data (14 items, alpha=.856; based on the information needed to realize technical functions). Afterward, participants assessed different technologies to gather data (using 12 items, alpha=.892; based on technical configurations of the AAL system). Additionally, participants assessed data access (alpha=.802) and data storage (alpha=.760) issues, each using 3 items referring to diverse types of data (video data, audio data, position data, and room data).

The acceptance of AAL system was evaluated using 6 statements (alpha=.932; eg, “I find the described AAL system useful”). Finally, participants could reason their opinions and their feedback concerning the study on an optional basis.

Before the study was started, the Web-based survey was pretested by communication scientists concerning comprehensibility and technical functionality. Additionally, pretests with “laypeople” were conducted to ensure comprehensibility and to enable the estimation of the length of time participants would need to fulfill the survey.

Recruitment and Sample

As the study aimed at reaching professional caregivers exclusively, it was not a typical convenience sample. The link to the e-survey was purposefully distributed (1) in specific Web-based networks (geriatric care and nursing care); (2) via mail by personal contact to caregivers (mostly geriatric and nursing care); and (3) via mail by project contact to care institutions (care of people with disabilities). Participation in the open survey was completely voluntary, and no monetary incentives were offered.

Of course, the collection of participants is one of the most important issues in empirical studies. In this case, it was especially sensitive as professional caregivers were asked to unveil possibly sensitive data and share personal insights into their working environment. Prior to data collection, we intensively discussed aspects concerning data protection and privacy policy with a German umbrella organization of care personnel and the main organization for people with disabilities. Participation in the open survey was completely voluntary, and no monetary incentives were offered.

For this study, we did not seek ethical approval from the ethics committee as our study falls in the category where no such approval is necessary in Germany. This category spans all noninvasive, nonclinical research on human subjects, where subjects are transparently informed about the purpose, aim, and risks of the studies and when these risks are reasonably low. Prior to starting the procedure, participants were informed that it is of high importance to understand free opinions and attitudes on assistive technologies from the caregivers’ expert perspective and that we would be delighted if they would share their opinions with us. In addition, we informed participants about the duration of the survey, the main purpose, and our department as investigators. Furthermore, we ensured a high standard of privacy protection and let participants know that none of their answers could be traced back to them as persons.

Demographic data were also submitted voluntarily, and all participants were informed that their personal data would be deleted from our encrypted hard drives on request. After these careful explanations, participants reported feeling well informed about the purpose and aim of this study and about their freedom to quit participation at any time. Regarding the privacy policy explanations, participants reported understanding that high standards were applied, and they deliberately accepted participation. From comments in the open question fields at the end of the survey, we learned that participants were interested in the topic and were keen to look at the results, which we assured them to receive.

For completing the questionnaire, participants took on average 20 minutes, and data were collected in Germany from April to June, 2017. Overall, 287 participants opened the Web-based survey and 4.9% (14/287) participants canceled the survey after viewing the introducing start page. Thus, 95.1% (273/287) of the respondents participated in the survey; 64.8% (186/287) participants filled out the survey completely. From these participants, 16 were excluded from further analyses because they did not match the criterion of being a professional caregiver within the areas of geriatric, nursing, and people with disabilities’ care (eg, employees of administration). Finally, 59.2% (170/287) care professionals were considered for the data analysis.

The mean age of participants was 36.26 (SD 11.23) years, with a higher proportion of female (74.7%, 127/170) care professionals; 42.2% (72/170) participants indicated a completed apprenticeship as the highest educational level, whereas 23.0% (39/170) reported holding a university degree or a university entrance diploma. Furthermore, 7.6% (13/170) indicated holding a secondary school certificate, and 4.2% (7/170) reported holding other certificates.

All participants were experienced care professionals; 25.3% (43/170) participants reported working in geriatric care, 22.9% (39/170) in medical care, and 51.8% (88/170) in disabled people’s care. On average, care professionals had long-term experiences, with 42.8% (73/170) of them having >10-year experience and 42.8% (73/170) having between 3- and 10-year professional experience; 14.4% (25/170) reported having <3-year professional experience.

Regarding attitudinal aspects, participants had a medium technical self-efficacy (mean 3.4 [SD 0.7]; min=1, max=6) and a middle interpersonal trust (mean 3.5 [SD 0.8]; min=1, max=6). Participants’ needs for privacy and data security were on a moderate positive level (mean 4.2 [SD 0.9]; min=1, max=6).

Data Preparation and Analysis

For data analysis, only completely filled datasets and only participants with a professional care background were considered. As additional adjustment criterion, datasets with an atypical timestamp were excluded, indicated by a processing time <50% of the calculated median referred to all completed datasets’ processing time (18 minutes). Regarding Internet Protocol (IP) address check, the link to the survey used for direct invitations via mail and used on social Web-based networks was related with the condition that one IP address was allowed
to access the Web-based survey only once. For the link to the survey distributed via project contact to care institutions for people with disabilities, using this condition was not possible. In these institutions, the caregivers filled the survey at stationary computers, and we had to allow using the same IP address multiple times. As this institution for disabled people’s care is part of the research project, there is a proprietary interest regarding the study’s results.

Before descriptive and inference analyses were performed, item analyses were calculated to ensure measurement quality. A Cronbach alpha >.7 indicated a satisfying internal consistency across the scales. Data were analyzed descriptively, as well as by linear regression analyses and, with respect to effects of the professionals’ care context and user diversity, by multivariate inference analyses (significance level was set at 5%). Furthermore, post hoc tests were analyzed using Tukey honestly significant difference test.

**Results**

**Fundamental Differences in Ambient Assisted Living Technology Perception**

We have reported descriptive findings as well as inference statistics differentiating between care professionals working in different care contexts (group differences are reported based on post hoc tests [Tukey honestly significant difference]). Looking at the results for the constructs of AAL technology perception (Figure 1), significant differences for the 3 care contexts were revealed ($F_{14,220}=2.514$, $P=.002$). Multimedia Appendix 1 presents means and SDs of all items for the whole sample and the 3 care contexts.

Participants working in the area of disabled people’s care indicated a significantly lower acceptance of AAL technologies ($F_{2,118}=4.570$, $P=.01$) than those working in geriatric and medical care. Furthermore, regarding the data that are allowed to be gathered, the perception was significantly different ($F_{2,118}=4.073$, $P=.02$): participants working not only in medical care but also in geriatric care showed more positive evaluations compared with participants working in disabled people’s care. Regarding technologies that can be used to gather data, the same result was found ($F_{2,118}=11.727$, $P<.001$); participants working in medical and geriatric care differed significantly from those working in disabled people’s care, who indicated a more negative attitude toward specific technologies. In contrast, potential benefits of ($F_{2,118}=0.350$, $P=.71$) and barriers to ($F_{2,118}=1.853$, $P=.16$) AAL technology usage were not found to be significantly different across the care contexts (disabled people’s care: mean 4.5 [SD 0.7]; medical care: mean 4.2 [SD 0.7]; and geriatric care: mean 4.3 [SD 0.9]). Issues of data access ($F_{2,118}=0.340$, $P=.71$) and data storage ($F_{2,118}=2.235$, $P=.11$) were not found to be significantly different as well, showing a homogenous evaluation independent of the care context.

**Figure 1.** Results for the constructs of Ambient Assisted Living (AAL) technology perception (*$P<.05$; **$P<.01$).
Specific Differences in Data, Technology, and Acceptance Evaluations

In this section, we present the significant differences within the evaluation of AAL technology acceptance, applied technologies, and data collection in more detail.

Willingness to Share Care-Related Data

Participants evaluated their willingness to share 14 different types of data that could be usefully collected for AAL technology usage. The evaluation of gathered data strongly depended on care context. Figure 2 shows the results for all types of data, and Multimedia Appendix 1 presents all means and SDs. For data collected in the context of emergencies (eg, actuation of emergency buttons [caretakers: $F_{2,151}=1.729; P=.18$], cries for help or shouts [F$_{2,151}=5.36; P=.59$]), the evaluation was positive and approved by all caregivers regardless of the care context. The gathering of data concerning rooms (opening windows and doors [F$_{2,151}=1.709; P=.19$]) and fixations (F$_{2,151}=2.891; P=.06$) did not significantly differ with regard to the care context, even though the highest evaluations were given by the group of medical caregivers. A slight but not significant difference was revealed for data regarding sleeping ($F_{2,151}=2.315; P=.10$), which was slightly rejected by medical care (mean 3.1 [SD 1.1]) and disabled people’s care (mean 3.1 [SD 1.5]) professionals, while slightly accepted by geriatric care professionals (mean 3.7 [SD 1.7]).

The most striking and significant difference was present for data collection about the position of caretakers ($F_{2,151}=8.283; P<.001$), which was moderately accepted to be collected by participants working in medical (mean 4.0 [SD 1.1]) and geriatric (mean 4.0 [SD 1.6]) care, while rather rejected by participants working in disabled people’s care (mean 3.1 [SD 1.4]).

Collecting data about care duration (per person; $F_{2,151}=1.351; P=.26$) was rejected by all participants. The collection of data about whole care situations ($F_{2,151}=4.517; P=.01$) and times (rooms are entered or left; $F_{2,151}=4.049; P=.02$) was generally rejected by all participants, but it differed significantly across care contexts; people working in disabled people’s care showed a stronger rejection than medical care and geriatric care professionals.

Figure 2. Results of different types of potential gathered data (*P<.05; **P<.01).
Descriptively, a similar result was found for data about positions of caregivers, indicating a higher rejection by people working in disabled people’s care, even though the differences missed statistical significance ($F_{2,151}=1.609; \ P=.20$). There was a significantly higher rejection of data concerning a 24-h observation ($F_{2,151}=4.080; \ P=.02$) by disabled people’s care professionals than by medical and geriatric care professionals. Finally, the gathering of data about conversations during care ($F_{2,151}=1.199; \ P=.82$) was rejected most strongly by all participants regardless of the care context.

**Willingness to be Assisted by Specific Ambient Assisted Living Technologies in Daily Routines**

Overall, 12 different types of AAL technologies were evaluated, and the outcomes are depicted in Figure 3. Again, Multimedia Appendix 1 presents all means and SDs for the whole group of participants as well as the 3 care contexts. First, the usage of emergency buttons was found to be most positive (caregivers: $F_{2,151}=2.281; \ P=.11$; caretakers: $F_{2,151}=6.362; \ P=.002$). Medical care and geriatric care professionals showed higher evaluations concerning emergency buttons that are activated by caretakers than the evaluations of disabled people’s care professionals.

The use of fall sensors integrated into the floor ($F_{2,151}=4.962; \ P=.008$) was also rated significantly more positively by medical and geriatric caregivers than by people working in disabled people’s care. Fall sensors in clothes or on the body were evaluated less positively than fall sensors on the floor, but again, ($F_{2,151}=7.908; \ P=.001$) disabled people’s care professionals (mean 3.8 [SD 1.6]) showed less positive assessments compared with geriatric (mean 4.7 [SD=1.3]) and medical (mean 4.7 [SD 1.2]) care professionals. A similar evaluation pattern occurred for room sensors, even though statistical significance was not reached ($F_{2,151}=2.752; \ P=.07$).

Motion detectors in rooms ($F_{2,151}=8.494; \ P<.001$), ultrasonic sensors ($F_{2,151}=7.315; \ P=.001$), and motion detectors in the clothes of caretakers ($F_{2,151}=15.271; \ P<.001$) were all evaluated slightly positively by medical and geriatric care staff. However, they were rejected by disabled people’s care professionals.

Figure 3. Results of different types of potential applied technologies (*$P<.05$; **$P<.01$).
Table 1. Final regression model for care staff in 3 different care contexts.

<table>
<thead>
<tr>
<th>Group of participants and dimension</th>
<th>B^a</th>
<th>Standard error B</th>
<th>beta</th>
<th>t^b</th>
<th>Variance inflation factor</th>
<th>Adjusted r^2c</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Geriatric care</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.839</td>
</tr>
<tr>
<td>Technology</td>
<td>.961</td>
<td>.126</td>
<td>.658</td>
<td>7.605</td>
<td>1.389</td>
<td></td>
</tr>
<tr>
<td>Barriers</td>
<td>-.421</td>
<td>.124</td>
<td>-.253</td>
<td>-3.400</td>
<td>1.439</td>
<td></td>
</tr>
<tr>
<td>Benefits</td>
<td>.424</td>
<td>.125</td>
<td>.295</td>
<td>3.387</td>
<td>1.017</td>
<td></td>
</tr>
<tr>
<td><strong>Medical care</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.604</td>
</tr>
<tr>
<td>Technology</td>
<td>.742</td>
<td>.162</td>
<td>.558</td>
<td>4.573</td>
<td>1.164</td>
<td></td>
</tr>
<tr>
<td>Benefits</td>
<td>.450</td>
<td>.140</td>
<td>.392</td>
<td>3.215</td>
<td>1.164</td>
<td></td>
</tr>
<tr>
<td><strong>Disabled people’s care</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.621</td>
</tr>
<tr>
<td>Technology</td>
<td>.581</td>
<td>.156</td>
<td>.388</td>
<td>3.726</td>
<td>1.664</td>
<td></td>
</tr>
<tr>
<td>Benefits</td>
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<td>.118</td>
<td>.340</td>
<td>3.687</td>
<td>1.347</td>
<td></td>
</tr>
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<td>Data</td>
<td>.477</td>
<td>.151</td>
<td>.291</td>
<td>3.156</td>
<td>1.293</td>
<td></td>
</tr>
</tbody>
</table>

^a^B: regression coefficient B.

^b^t: t-statistic (coefficient divided by its standard error).

^c^r^2^: coefficient of determination.

In contrast, the usage of *infrared cameras* (*F*^2,151^= 8.494; *P* = .048), *motion detectors in the clothes of care staff* (*F*^2,151^= 8.494; *P* = .004), *microphones* (*F*^2,151^= 8.494; *P* = .046), and *video cameras* (*F*^2,151^= 8.494; *P* = .05) was rejected by all participants, even though the most negative evaluation was prevailing in disabled people’s care professionals.

**Predictors for the Acceptance of Ambient Assisted Living Technology**

Finally, to analyze whether different factors were relevant for AAL technology acceptance in different care contexts, regression analyses were performed. Table 1 shows the linear regression models. The sum-score AAL technology acceptance was integrated as a dependent variable, whereas the sum-scores of perceived benefits, perceived barriers, types of gathered data, the specific technology types, data access, and data storage were integrated as independent variables within the linear stepwise regression analysis.

The final regression model for geriatric care professionals explained 83.9% variance in AAL technology acceptance, grounded on the type of technology, in particular, and on perceived barriers and perceived benefits. In comparison, the final regression model for medical care staff explained 60.4% variance in AAL technology acceptance based on two dimensions—the applied technology and perceived benefits. In contrast, the final regression model for disabled people’s care professionals explained 62.1% variance in AAL technology acceptance and was influenced by the applied technology, perceived benefits, and the types of gathered data.

**Discussion**

**Acceptance of Ambient Assisted Living Systems**

In contrast to previous research results reporting mostly positive evaluations of ICT and assistive technologies in care [24,32,33], professional care staff has reportedly been more critical concerning the integration of AAL technologies into their professional routine [13,34].

The evaluations of which data can be gathered and which specific technologies should be used revealed yet underexplored insights into the perceptions of care professionals; the only accepted data collection was regarding emergencies, whereas the collection of other data types was, at the utmost, tolerated if not rejected. The negative assessment had been confirmed by open comments in the questionnaire and was also voiced in the preceding interviews. Apparently, care staff evaluations contradict the reasons why AAL systems can be useful at all: those systems can only be efficiently used if data about the patient and his or her location, health status, and care situation are recorded and, if necessary, interpreted by remote medical services. The evaluation of specific technologies showed similar findings; participants indicated to only accept quite static technologies (eg, emergency buttons), which record static, binary data (eg, door open or closed). In line with previous research [42], more complex AAL technologies (eg, cameras, microphones, and life-logging) were—owing to their still higher potential of violation of privacy—broadly rejected in the care context. Participants’ feedback suggests that the major concern is regarding the sneaking suspicion that the collected data will not only stored for long term but also accessible to others. Here, a general distrust toward illegal data access and abuse by third parties becomes obvious.

The negative attitude might also be attributed to the applied scenario-based approach. Previous research has shown that the methodology used to capture acceptance reactions modulates outcomes considerably; acceptance after hands-on experience with AAL technologies has been much more positive [26] compared with assessing the acceptance through scenario analyses, in which participants should envision the usage of assistive home technologies. Possibly, professional care staff would have evaluated AAL technologies more positively if they...
Diversity of Care Matters

In addition to personal characteristics, for example, experience with technology, which is known to impact AAL technology acceptance [32,34], the interview findings revealed that the working conditions in care context are decisive for AAL technology acceptance in the sensible field of care. This study confirms the influence of the care context. While medical and geriatric care professionals are generally more positive toward AAL technologies, the professionals working in disabled people’s care are more reluctant toward the usefulness of AAL systems and perceive higher concerns regarding data collection in the care situation.

We assume that the differences especially in evaluations of data and technology configurations are caused by disparate internal perspectives of the care institutions. Geriatric and especially medical care are concentrated on the short-term and temporary care of old and chronically ill patients and, therefore, focus on patients’ safety as well as substantial improvement in health. Additionally, geriatric and medical caregivers are involved in high numbers of emergencies, in which monitoring technologies are widely used. On those grounds, geriatric and medical caregivers might have a more positive attitude toward assistive technologies. In contrast, care institutions for disabled people have a completely different disputation. They represent a long-term stationary home and, besides safety issues, focus especially on the protection of human dignity, rights, and privacy of their residents. Therefore, caregivers of disabled people probably have a more restraint attitude toward assistive technology and are specifically critical toward the collection of personal data.

Overall, care does not equal care; the diversity of care needs to be considered in the development process of assistive technologies and especially in the way those technologies are introduced and implemented in daily care routines of care institutions.

Limitations and Further Research

There are some limitations to be considered in future research. While we revealed a basically negative attitude toward (data collection in) AAL systems, stakeholder-specific reasons underlying participants’ reluctance are not known. Possible reasons against using AAL systems might include concerns that (1) employers could control the quality of care (staff); (2) responsibility claims could be pleaded by family members (staff); (3) a low usability of technology might overcharge the technology competence (staff); (4) personal data could appear in public (patient); (5) emergency help would contradict life-end decisions (patient); and (6) a lower supply quality by insurances (family members) or extra financial burden due to costly technology (family members). Future research should clarify which of these reasons should be addressed by adequate information and communication strategies.

A further limitation is related to the applied method and sample issues. Due to our scenario-based approach, the evaluations based on a fictional, and not real, AAL system could have led to an overestimation of potential barriers especially fears concerning data security [26] as well as a general discomfort of being monitored in intimate (care) situations [42]. We, therefore, aim for hands-on evaluations of AAL technologies in diverse professional care environments (ie, in institutions for geriatric, medical, or disabled people’s care).

Moreover, there are sample-related aspects to be considered. Most of our participants were women. Even though this is consistent with higher proportions of women working in care institutions [43], research should aim at exploring more male caregivers to analyze whether acceptance positions are impacted by gender roles.

Furthermore, as we only included participants from one country, outcomes are limited to the German health care system and perspectives on AAL. Future research should extend the perspectives to enable a direct comparison of AAL acceptance as well as data and technology perceptions in different countries and cultures [37].

Application Potential of the Findings

Findings can be used for the development, design, and configuration of AAL technologies as well as for health care and nursing management issues. As data are not needed to be stored for a long-term (only direct processing) and can be processed by the system for nearly all functions, targeted communication strategies could inform the handling of data (eg, only processing not storage). The transparency and the honesty of communication strategies are essential to inform caregivers about the usefulness of AAL systems for them (support in care routine), for the institution (efficiency), and also for patients and family members (patient safety). In addition, the policy of an institution regarding how data are handled should be explicitly made. Likewise, communication strategies could be tailored to diverse care contexts and their particularities in a more detailed and satisfying way. This is especially important as the feedback from our participants during the preceding interview study and also in comment fields during the Web-based survey (“they don’t care about us”) showed that care personnel often do not feel their needs to be heard and appreciated by the care institution’s management, policy, and society. If care personnel are considered as a valuable part in the process of integration of assistive technologies, all stakeholders—caregivers, caretakers, and patients—will benefit alike.

Acknowledgments

We would like to thank all participants for their patience and openness to share opinions on an innovative technology. Furthermore, we would like to thank Simon Himmel for support, ideas, and encouragement in the collaboration. This work was partly funded by the German Federal Ministry of Education and Research projects Whistle (16SV7530) and PAAL (6SV7955).
Conflicts of Interest
None declared.

Multimedia Appendix 1
Descriptive statistics (means and SDs) for the whole sample and the 3 care contexts.

[PDF File (Adobe PDF File), 61KB - rehab_v5i2e10424_app1.pdf]

References


Abbreviations

AAL: Ambient Assisted Living
ICT: Information and Communication Technologies
IP: Internet Protocol
Original Paper

An mHealth Platform for Supporting Clinical Data Integration into Augmentative and Alternative Communication Service Delivery: User-Centered Design and Usability Evaluation

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Abstract

Background: The recent trend of increasing health care costs in the United States is likely not sustainable. To make health care more economically sustainable, attention must be directed toward improving the quality while simultaneously reducing the cost of health care. One of the recommended approaches to provide better care at a lower cost is to develop high-quality data collection and reporting systems, which support health care professionals in making optimal clinical decisions based on solid, extensive evidence.

Objective: The objective of this project was to develop an integrated mobile health Augmentative and Alternative Communication (AAC) platform consisting of an AAC mobile app and a Web-based clinician portal for supporting evidence-based clinical service delivery.

Methods: A questionnaire and interviews were used to collect clinicians’ ideas regarding what constitutes their desired “clinically relevant” data. In response, a Web-based portal was designed by combining mobile and Web technologies with an AAC intervention to create an integrated platform for supporting data collection, integration, and reporting. Finally, a usability study was conducted with health care professionals.

Results: A Web-based portal was created and integrated with a tablet-based AAC mobile app and data analysis procedures. In the usability study, all participants agreed that the integrated platform provided the ability to collect comprehensive clinical evidence, automatically analyze collected data in real time, and generate clinically relevant performance measures through an easily accessible Web-based portal.

Conclusions: The integrated platform offers a better approach for clinical data reporting and analytics. Additionally, the platform streamlines the workflow of AAC clinical service delivery.

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KEYWORDS
Web-based portal; data integration; Augmentative and Alternative Communication; service delivery
Introduction

Improving health care quality while simultaneously reducing costs is a challenging task. To achieve these goals simultaneously, the Institute of Medicine (IOM) recommends the use of information technologies for capturing clinical data that may be then integrated into the process of clinical decision making during care delivery [1]. According to this recommendation, health care professionals are required to collect, analyze, report, and review their patients’ performance data before adjusting treatments. This might be a rather onerous task, given the already demanding nature of health care professions.

Mobile technologies, however, have offered those in health care professions myriad new and low-effort ways of adhering to IOM’s recommendations, especially with regards to capturing patient data. Growing evidence has demonstrated that mobile health (mHealth) platforms make it possible for health care professionals to monitor patient conditions constantly and remotely. Furthermore, mHealth platforms can empower patients to manage their own diseases [2-12]. The integration of mobile technologies into health care may optimize health care practices by enabling professionals to conveniently collect and utilize large amounts of patient data in their clinical practice [13,14]. In this model, convenient data collection, integration, and reporting is of critical importance.

Communication is essential for maximizing quality of life. It is estimated that approximately 10% of the US adult population reported a communication disability, temporary or permanent, because of various reasons, such as hearing loss, head injury, stroke, autism, dementia, cancer, vocal problems, intellectual disability, and neurological causes [15]. Some of these patients use the service offered by Augmentative and Alternative Communication (AAC) technologies, which can enable them to communicate with others and improve their language abilities.

The information technology–supported data collection and integration is especially important within the field of AAC in terms of optimizing health care practices. In AAC, it is necessary to collect, evaluate, and integrate the best clinical evidence available for decision making such as patient assessment and treatment plan adjustment [16,17]. Currently, there are two data collection and reporting approaches in AAC. The first approach has been specifically designed for dedicated AAC devices [18]. In this approach, language samples are stored in the AAC device as text files. For analysis, speech-language pathologists (SLPs) need to retrieve this text file using a USB flash drive from patients’ AAC device when they visit the clinic and load the text file into a specially designed program, where each text item in the file must be manually converted into individual utterances by SLPs. Eventually, the program processes these utterances and generates a language performance report. Evidently, this is a very labor-intensive procedure, and many SLPs choose to forego this data analysis—and, thus, the performance report—altogether. Without the resultant performance reports available when the patient visits the clinic, the adjustment of the patient’s treatment strategy may be delayed.

The second data collection and reporting approach has been implemented in some mobile AAC apps [19]. These AAC apps may collect data, generate performance reports, and provide SLPs a brief summary of patient performance along with a full word or utterance list. From here, SLPs can either review the results directly in the app or ask their patients (or caregivers of their patients) to email the report through the app. These data items, however, are not collected according to any research studies that might indicate the needs of SLPs, and, therefore, they are of limited clinical value.

The objective of this project was to propose and evaluate a solution to the problems existing in these two currently available data collection and reporting approaches in AAC. More specifically, the collected data should be clinically relevant and the data as well as the reports generated from the data should be readily available to SLPs when needed.

Indeed, the portability of mobile apps is critical in facilitating real-time patient data collection and reporting this data to their users. A Web-based portal can further augment the data reporting process to health care providers. Such portals might serve as widely accessible resources for health care professionals in conveniently accessing their patients’ clinical performances from anywhere and at any time. Taken together, mobile apps and a Web-based portal form an effective platform for providing AAC services and allowing SLPs and persons with communication disabilities (PwCDs) to pursue dynamic treatment options.

This paper presents the development and evaluation of an mHealth platform capable of facilitating treatment in the abovementioned dynamic manner. To this end, we implemented a mixed method for identifying clinicians’ requirements on the mHealth platform as well as clinically relevant data items, which include literature review, interview, and questionnaire studies. Additionally, we conducted a study in tandem with health care professionals to evaluate the usability of this mHealth platform and to differentiate the preferences among three different approaches for patient data collection and reporting. This mHealth platform will make data collection and reporting in AAC service delivery easy and efficient if implemented as expected.

Methods

Requirement Analysis

We aimed to create a platform for clinicians that augments the collection of patient data and the generation of clinically relevant reports. This data collection and reporting process can be optimized in the predesign phase by surveying clinicians to determine what they see as the most relevant and specific platform. For instance, we must answer questions such as the following: What current data collection approaches are being used by SLPs? What types of clinically relevant data should be collected from PwCDs when they are using an AAC device? Which data items should be stored? How is language performance measured and what specific outcomes do SLPs desire to see in result reports? If the patient information will be presented on a Web-based portal, what are the desired features?
To this end, interview questions and a questionnaire were designed and administered to two groups of SLPs. A brief summary of the interview and questionnaire studies is provided below. The details of these two studies have been previously described [20].

**Interview With Clinicians**

To better understand the needs of SLPs with regards to a Web-based clinician portal as well as their perspective on AAC patient-generated data, interviews were performed. Five SLPs were recruited from the greater Pittsburgh area through professional referrals. Each of these SLPs had 5-12 years of work experience in the field of AAC. All participants were asked a series of open-ended questions during the course of a 1-hour interview. Notably, none of the participants expressed satisfaction with current data collection approaches; furthermore, they expected a new approach capable of automatically transmitting real-time patient data to SLPs that also conveniently provides clinically relevant information.

All 5 participants expressed the belief that a Web-based clinician portal could support personalized AAC service delivery, enhance the current data collection and reporting process, and ultimately improve both the quality and efficiency of AAC-based language rehabilitation. Furthermore, these participants indicated several desired features on the Web-based clinician portal such as real-time remote monitoring, a dashboard overview, and detailed language performance information. They expected being able to select data items, collected within a certain time frame, and then flexibly export data in a variety of ways. Markedly, 80% (4/5) participants noted that tracking AAC usage time could generate a critical dataset. Moreover, 60% (3/5) participants expressed a need to distinguish between user logs generated by the patients and their family members. Further outcome measurements included communication rate, mean length of utterance, and error rate.

**Questionnaire Study With Clinicians**

A questionnaire study aimed at identifying specific information for clinical intervention and language rehabilitation outcome measurements was administered to SLPs. The questionnaire was a revised form of the AAC Sampling Procedures and Performance Monitoring Questionnaire [18], although some questions were updated because of advancements in AAC and information technologies. A total of 26 SLPs, each with 1-34 years of AAC field experience, responded. Table 1 presents the measurements believed to be important by ≥70% (14/20) of the respondents. The results of this questionnaire study were used to guide the design and development of the Web-based clinician portal, which is discussed further in the Web-based portal and data analysis section.

**Key Characteristics of the Desired mHealth Platform**

Based on the requirements collected from SLPs in the interview and questionnaire studies, we identified five essential characteristics that the new system must meet. The system must be comprehensive, automatic, in real time, clinically relevant, and easily accessible. These characteristics can be integrated in the process of data collection and reporting in AAC clinical service delivery using the mHealth platform.

Figure 1 illustrates the current model for the AAC mHealth platform’s data collection, integration, and reporting. Every time a user (PwCD) logs on, the mobile AAC app collects comprehensive language and behavioral data. This data is then transmitted, in real time, to a secure server, where it is automatically integrated and analyzed. From this patient-generated dataset, clinically relevant performance measurements will be obtained and then forwarded to a Web-based clinician portal, rendered in an easily accessible visual format, from which the clinicians (SLPs) may design and deliver personalized AAC intervention to their patients.

To create this mHealth platform, the mobile AAC app, data integration and analysis procedures, and the Web-based portal need to be built and integrated together. The mobile AAC app has already been created, and its details have been described in a previous study [21]. In this study, this app will be briefly described in the following section.

![Figure 1: Current Model for the AAC mHealth Platform](http://rehab.jmir.org/2018/2/e14/)

**Table 1.** Important language performance measurements indicated by the majority of respondents.

<table>
<thead>
<tr>
<th>Selected summary measures</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency of using the app (n=22)</td>
<td>20 (91)</td>
</tr>
<tr>
<td>Patient’s language performance at home (n=22)</td>
<td>20 (91)</td>
</tr>
<tr>
<td>Percentage of vocabulary used in the app (n=20)</td>
<td>18 (90)</td>
</tr>
<tr>
<td>Total number of words (n=20)</td>
<td>17 (85)</td>
</tr>
<tr>
<td>Utterance structures (n=22)</td>
<td>18 (82)</td>
</tr>
<tr>
<td>Total number of utterances (n=22)</td>
<td>17 (77)</td>
</tr>
<tr>
<td>Average communication rate in words (n=22)</td>
<td>17 (77)</td>
</tr>
<tr>
<td>Mean length of utterances in words (n=22)</td>
<td>16 (73)</td>
</tr>
<tr>
<td>Frequency of performing other activities in the app (AAC(^a), training, etc; n=22)</td>
<td>16 (73)</td>
</tr>
<tr>
<td>Total number of different words (n=20)</td>
<td>14 (70)</td>
</tr>
</tbody>
</table>

\(^a\)AAC: Augmentative and Alternative Communication.
EuTalk: A New Mobile Augmentative and Alternative Communication App

A mobile AAC app, EuTalk, was created to collect activity and language data from users [21]. This tablet-based AAC app was designed to incorporate the communication interface, training, and reporting capabilities. The communication interface provides both the communication program and clinical treatment exercises for PwCDs. PwCDs can use the mobile app to communicate with other people and attend trainings under the guidance of SLPs.

With EuTalk, each individual activity a user performs in the app—along with all clinically relevant language data items identified in the questionnaire and interview studies—is logged in a local SQLite database, with a corresponding timestamp, and then forwarded to a MySQL database on a secure server. Notably, the local SQLite database does not have any patient identifiers. The data stored on the local database is used to provide progress reports to the app user. Between the mobile app and the secure server, there is one randomly generated but unique number for each app user, which can be used to match the patient records on the secure server.

Web-Based Portal and Data Analysis Procedure

A Web-based clinician portal (Figure 1) aimed at providing SLPs with detailed patient language performance information was developed and deployed on the secure server. This Web-based portal includes three major components: dashboard overview, performance reports, and administration. Since the mobile AAC app forwards all collected data to the server database in real time, this Web-based clinical portal can easily provide the raw data and processed information to SLPs, making it possible for SLPs to have easily accessed, real-time, remote monitoring of their patients’ language performance.

The dashboard presented in Figure 2 provides a sample of what SLPs might see on a graphical interface. This particular interface allows SLPs to examine patients’ comprehensive language performance over a period of time. The specific language performance measures included in such graphics are dependent on the information identified in the questionnaire and interview studies. For instance, the dashboard in Figure 2 shows the results for the app’s frequency of use, the users’ total word count, top five utterance structures, total number of utterances, average communication rate in words, and the mean length of utterances—all presented in line charts as dependent variables with respect to time. While the default interval is 1 week, SLPs can choose to review these results in different timeframes: 30, 45, and 60 days. Additionally, the app’s frequency of use, split between the various intra-app activities, is given in a pie chart. Furthermore, the top five utterance structures are listed in a table with both the sentence structure and the number of times each structure is used. Finally, the percentage of complete utterances in all generated utterances as well as the percentage of target vocabulary used in the mobile app is shown on the dashboard.

The performance report includes outcome measurements, summary measurements, and the language sample data. SLPs can make data selections from programmed options (demonstrated in Figure 3), and the requested data items or language performance measurements from the selected time period will be shown in the performance report. According to the results of the questionnaire study, 91% (20/22) of the study participants believed that it would be important to know patients’ language performance while they are at home. Therefore, a checkbox is provided under each group of datasets so that SLPs can choose to review patients’ performance at home conveniently. From the selected data items or performance reports generated by the Web-based portal, clinicians can obtain a clear picture of their patients’ communication routines and progress over time and, therefore, design the corresponding AAC interventions for individual patients accordingly. For instance, SLPs can adjust their treatment materials and the mobile AAC app settings for each patient. If needed, SLPs can also obtain performance reports for a group of patients in different age groups with different types of communication disorders and determine whether these factors are associated with the patients’ activities using the mobile AAC app and their
Figure 2. Web-based portal—dashboard overview. MLU: mean length of utterance.

Figure 3. Web-based portal—performance report.

Figure 4 shows three examples of performance reports, each with a different set of information. First, the outcomes measurement shows daily average or total for each measure over the selected time period in a diagram and table (top portion of Figure 4). The summary measures provide an overall average or total of each measure over the selected time period (not shown). The language sample list (bottom portion of Figure 4) provides SLPs with detailed information on patients’ language performance. SLPs can choose to add notes to these performance reports after they review the data or results.

Besides the dashboard and performance reports, several other features have been implemented to support the automatic data analysis and AAC service delivery. These features include the following:
Appointments: SLPs can use the appointment feature to track patients’ appointment dates.

Report Storage: SLPs can easily save the generated performance reports for every therapy session with a few button clicks.

Raw Data Management: SLPs can manually remove certain utterances from the analysis. This feature is especially useful if SLPs identify abnormal usage in the app. For instance, utterances generated in one particular time period may be far better than the ones typically generated by the patient. These utterances are most likely generated by caregivers for various purposes, and they should be removed when only patients’ language performance is desired.

Target Vocabulary Setting: SLPs can set a list of target vocabulary for their patients, asking them to use those words frequently. After a certain period of time, SLPs can determine what percentage of this target vocabulary the patients have used. This target vocabulary can be easily updated on the Web-based portal.

Figure 4. Web-based portal—performance report examples.
Evaluation on the mHealth Platform

A usability study was conducted with 20 AAC app users to evaluate the usability of the mobile app, and the study results were reported [21]. Another usability study was conducted with health care professionals to evaluate the usability of this Web-based portal while the data was generated in the mobile app. The health care professionals were also asked to compare the mHealth platform to the other two extant, abovementioned, data collection and reporting approaches. More specifically, professionals from the field of speech-language pathology were recruited for this study, including certified SLPs and graduate students in the Communication Science and Disorders program at the University of Pittsburgh. All participants were aged between 18 and 65 years. Ten individuals who met the inclusion criteria were selected from a pool of volunteers. They were recruited through a recruitment email script sent to the speech-language pathology communities or through word of mouth.

The study session commenced with a brief introduction to the study’s purpose and procedures. The participants were then asked to sign the informed consent form and fill out a questionnaire about background information such as age, years of clinical experience, years of computer experience, and other demographic information. Next, each participant was introduced to three different data collection and reporting approaches on AAC technologies, including our new platform. The participants were then asked to finish multiple tasks in data collection, analysis, and language performance report generation, and answer two “after-scenario” questions, adopted from the IBM “After Scenario Questionnaire” (ASQ) [22], wherein they utilized each of these three approaches. Upon completion of all assigned tasks, the participants were asked to complete a poststudy usability questionnaire and express their overall perception and level of satisfaction with the new mHealth platform. All activities during the hands-on session were logged and then analyzed afterward in order to evaluate the proposed approach. The participants were asked to review the three approaches and complete a poststudy questionnaire to indicate their respective preference for the three data collection and reporting approaches. Further feedback was collected from the participants in an informal interview session.

Results

Results of Usability Study

A total of 10 participants were recruited to participate in this usability study, including 5 SLPs and 5 graduate students from the Department of Communication Science and Disorders at the University of Pittsburgh. All participants were able to complete the assigned tasks and provide feedback through the questionnaires. Participants were aged between 22 and 61 years, mean age: 29.0 (SD 13.20) years. Of all, 80% participants were females and 20% were males. The participants’ work experience in AAC clinical services ranged from 0.5 to 30 years, mean experience: 4.8 (SD 8.64) years.

Two statements were chosen and modified from ASQ:

- Statement 1 (S1, easiness): “Overall, I am satisfied with the ease of completing this task.”
- Statement 2 (S2, efficiency): “Overall, I am satisfied with the amount of time it took to complete this task.”

All 10 participants responded to these statements on a 5-point Likert scale, where 1 corresponded to “strongly disagree” and 5 to “strongly agree.” In other words, a higher number indicated a greater satisfaction with the Web-based portal. Table 2 shows a breakdown of the ratings after each task. From these numbers, one can notice that it was easy and efficient for health care professionals to manage patients on this Web-based portal, with an average Likert rating of 4.7 on both statements after this task. They also indicated that reviewing the dashboard was easy and efficient, reporting a 4.4 on both statements. Apparently, it was slightly difficult to generate and review performance reports, however, with scores of 4.4 for easiness and 4.2 for efficiency. Some participants provided relatively low ratings regarding management of their patients’ profiles, especially for managing their language data, because that still needs to be handled manually. Overall, the app was rated as easy to use and efficient, evidenced by an overall score of 4.28.

The IBM Post Study System Usability Questionnaire (PSSUQ) was adopted to measure the Web-based clinician portal’s overall usability [22]. Fourteen statements were chosen from the PSSUQ and were slightly modified to include the phrase “the Web-based portal” instead of “the system.” All 10 participants completed this modified PSSUQ questionnaire. Participants responded to all 14 statements on a 5-point Likert scale, where 1 corresponded to “strongly disagree” and 5 to “strongly agree.” The overall average on all the usability factors was 4.18, which indicated satisfaction with this Web-based clinician portal. Table 3 presents a breakdown of the numerical ratings for each question. According to the conversations with participants at the end of the usability study, some of the lower ratings were assigned because the study session was their first time using the Web-based portal, and, thus, there was a learning curve associated with locating relevant information on the Web-based portal.

User’s Preferred Approach

In the evaluation study, the participants were asked to compare our integrated mHealth platform with two extant data collection and reporting approaches. They were also asked to indicate their preference when choosing a data collection and reporting approach for use in their own clinical practice. Three more questions were created to collect the study participants’ opinions on the five key characteristics for a desired data collection and reporting system identified in the interview and questionnaire studies in AAC (comprehensive, automatic, real time, clinically relevant, and easily accessible). In sum, the results show that the participants agreed that our integrated mHealth platform could better support data collection and reporting in AAC service delivery. Table 4 shows the responses from the participants.
Table 2. Results from after-scenario tasks on the Web-based portal for statements 1 and 2 (S1 and S2; overall average=4.28).

<table>
<thead>
<tr>
<th>Tasks and After Scenario Questionnaire</th>
<th>S1, mean (SD)</th>
<th>S2, mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Task 1: Manage patient list</td>
<td>4.7 (.48)</td>
<td>4.7 (.48)</td>
</tr>
<tr>
<td>Task 2: Review dashboard</td>
<td>4.4 (.70)</td>
<td>4.4 (.70)</td>
</tr>
<tr>
<td>Task 3: Generate and review performance report</td>
<td>4.4 (.52)</td>
<td>4.2 (.42)</td>
</tr>
<tr>
<td>Task 4: Manage patient profile—language data</td>
<td>3.9 (1.20)</td>
<td>4.0 (.94)</td>
</tr>
<tr>
<td>Task 5: Manage patient profile—patient records</td>
<td>4.0 (.94)</td>
<td>4.1 (.74)</td>
</tr>
</tbody>
</table>

Table 3. The results of posttask usability study.

<table>
<thead>
<tr>
<th>Item</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall, I am satisfied with how easy it is to use this Web-based portal.</td>
<td>4.4 (.52)</td>
</tr>
<tr>
<td>It was simple to use this Web-based portal.</td>
<td>4.3 (.48)</td>
</tr>
<tr>
<td>I could effectively complete the tasks using this Web-based portal.</td>
<td>4.4 (.52)</td>
</tr>
<tr>
<td>I was able to complete the tasks quickly using this Web-based portal.</td>
<td>4.0 (.47)</td>
</tr>
<tr>
<td>I was able to efficiently complete the tasks using this Web-based portal.</td>
<td>4.5 (.53)</td>
</tr>
<tr>
<td>I felt comfortable using this Web-based portal.</td>
<td>3.8 (.63)</td>
</tr>
<tr>
<td>I believe I could become productive quickly using this Web-based portal.</td>
<td>4.5 (.53)</td>
</tr>
<tr>
<td>Whenever I made a mistake, I could recover easily and quickly.</td>
<td>4.0 (.67)</td>
</tr>
<tr>
<td>It was easy to find the information I needed.</td>
<td>3.8 (.79)</td>
</tr>
<tr>
<td>The organization of information on this Web-based portal was clear.</td>
<td>3.9 (.88)</td>
</tr>
<tr>
<td>The interface of this Web-based portal was pleasant.</td>
<td>4.1 (.32)</td>
</tr>
<tr>
<td>I liked using the interface of this system.</td>
<td>4.2 (.42)</td>
</tr>
<tr>
<td>This Web-based portal has all the functions and capabilities I expect it to have.</td>
<td>4.3 (.67)</td>
</tr>
<tr>
<td>Overall, I am satisfied with this system.</td>
<td>4.3 (.48)</td>
</tr>
</tbody>
</table>

Table 4. Comparison of three data collection and reporting approaches (N=10).

<table>
<thead>
<tr>
<th>Questions</th>
<th>Mobile AAC(^{a}) app alone, n (%)</th>
<th>Integrated mHealth platform, n (%)</th>
<th>Dedicated AAC device, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Which approach collects the most comprehensive data?</td>
<td>0 (0)</td>
<td>9 (90)</td>
<td>1 (10)</td>
</tr>
<tr>
<td>Which approach provides the most automatic data collection and reporting?</td>
<td>0 (0)</td>
<td>10 (100)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Which approach provides the easiest access to the clinically relevant information you need?</td>
<td>2 (20)</td>
<td>7 (70)</td>
<td>1 (10)</td>
</tr>
<tr>
<td>Which of the approaches would you prefer to use?</td>
<td>0 (0)</td>
<td>9 (90)</td>
<td>1 (10)</td>
</tr>
</tbody>
</table>

\(^{a}\)AAC: Augmentative and Alternative Communication.

Overall, 90% of the participants selected the new integrated mHealth platform as the approach they would prefer to use in their clinical services, while the other 10% chose the dedicated AAC device as the preferred approach. One possible reason for this 10% response is that dedicated AAC devices are currently the most widely used and many SLPs are familiar with the procedure, even though it is hard to obtain the desired data. Furthermore, 90% of the participants indicated that the integrated mHealth platform collects the most comprehensive data; 70% of participants believed that the integrated mHealth platform provides the easiest access to clinically relevant information. Notably, the participants did not believe that mobile AAC apps or dedicated AAC devices alone could provide automatic data collection and reporting. Markedly, 100% of participants believed that this integrated mHealth platform could provide the most automatic data collection and reporting.

**Results From Semistructured Interviews**

Overall, the participants thought that the Web-based portal provided the most comprehensive information in the most efficient manner and that the user interface was both simple and intuitive. The data from dedicated AAC devices also appeared to be comprehensive, but the interface was too busy and the segmentation of utterances was labor-intensive. For the mobile AAC apps, the detailed utterance data was lost when the performance report was emailed since only the summary was included in the email. The following is some feedback from the participants:
Quickest, easiest, and nicest to look at, user friendly, easy to teach, nice graphic. [Participant 1]

Data is always available on the clinician portal. The data was clearly divided into categories and was very comprehensive. The ability to search for specific time periods was very helpful. [Participant 5]

I think that the Web-based portal provided the most comprehensive information in the most efficient manner. I also thought that the user interface was simple and intuitive. The program for analyzing the text file from the dedicated device also appeared to be comprehensive, but the interface was too busy and the selection of utterances seems labor-intensive. For the existing mobile AAC app, I didn't like that the detailed utterance data was lost when the performance report was emailed. [Participant 7]

Web-based clinical portal is easy to use, data is collected in real time, and clinicians have access to information at any time. [Participant 10]

Provides all date needed for intervention purposes. [Participant 4]

Ability to gather data before the patient’s therapy session. [Participant 9]

Discussion

Principal Results

In this project, we first conducted a mixed-method study, including a literature review, clinician interviews, and clinician surveys, to design the system architecture and identify design specifications, more specifically, the clinician-desired features and clinically relevant data items. Based on these findings, we accordingly created a mobile AAC app and a Web-based portal for SLPs. The Web-based portal makes it convenient for SLPs to track their patients’ situation in real time, which may be helpful for incorporating clinically relevant information into their clinical decision making and for designing personalized interventions. This may eventually lead to higher health care quality and lower costs.

After the Web-based portal was created, it was evaluated through a usability study with health care professionals. Participants were satisfied with the ease of completing all the tasks, such as viewing reports and managing patient data, as well as with the amount of time taken to complete each task. The overall results confirmed that our integrated mHealth platform provides the ability to collect comprehensive clinical evidence, automatically analyze collected data in real time, and generate clinically relevant performance measures. Our evaluation showed that the integrated platform offers a better clinical data analytics approach for AAC clinical service.

The research-based design of the integrated mHealth platform strongly supports its capabilities and application as an AAC tool. The features in the app provide PwCDs with an opportunity to efficiently and conveniently use the app as an AAC intervention tool; the features in the Web-based portal provide SLPs with an effective supporting tool for data collection and reporting. Since the rehabilitation process is usually long and sometimes frustrating, the performance reports can not only help SLPs to design appropriate treatment plans but also help PwCDs to gain confidence, which fulfills the desired outcomes of an evidence-based practice. Moreover, the clinically relevant data can benefit researchers in the field of communication science. Our mHealth platform can improve user engagement, as well as help SLPs adjust the treatment plans, support their clinical evaluation, and, ultimately, streamline the workflow and improve service delivery.

Limitations

The study has some known limitations. First, for the evaluation of the Web-based portal, the study participants included were health care professionals. Patients were not included in the study, and were not using the mobile AAC app to provide real-time data. The study was conducted with a set of simulated data. In other words, the study participants did not see the dynamic changes in the datasets during the study and did not experience the power of real-time data collection and reporting, which could make the mHealth platform even more impressive. On the other hand, this limitation does not impact the results of this study. Since the goal of this study was to determine the usability of the mHealth platform, especially the Web-based portal, it does not matter whether the data was entered by patients at the time of the study. Second, when the study participants were asked to compare the three data collection and reporting approaches, they were only asked to indicate the preferred one in various circumstances. Therefore, preferences were only shown as percentages. Asking the participants to provide a rating on the characteristics of the three approaches would have been better. If that were the case, we would be able to have a better idea about participant preferences and about how much better this mHealth platform is compared with the other two approaches.

Future Work

The work presented in this article is the foundation of our future work. This work demonstrated that the mHealth platform was well designed and implemented according to the needs of clinicians. It can be used to streamline the clinical data collection, analysis, and reporting. The availability of this mHealth platform significantly reduces the burden of clinicians regarding tedious and labor-intensive tasks. In the next step, to evaluate whether this mHealth platform can produce positive impact on the outcome of language rehabilitation, future research is being planned to conduct a larger-scale study, which will seek to evaluate all capabilities of the integrated mHealth platform. The proposed clinical trial will include both PwCDs and SLPs. A full AAC treatment will be provided from SLPs to PwCDs over a longer time period. During the study period, PwCDs will use the new mobile AAC app (EuTalk), while SLPs will periodically review their performance through the Web-based portal. SLPs will be asked to determine whether or not they need to adjust their treatment plans based on the performance reports provided in the Web-based portal. In this study, PwCDs’ clinical performance will be evaluated and SLPs will also be asked to evaluate the performance measures provided on the Web-based portal. Furthermore, the platform will be extended for all clinicians to easily access a summary.
of patient health data that is collected from multiple mHealth apps. The platform will be improved using sophisticated data analysis and data integration algorithms. The proposed enhanced mHealth data integration platform will enable customized, precise health care.

Acknowledgments

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Conflicts of Interest

None declared.

References


Abbreviations

AAC: Augmentative and Alternative Communication
ASQ: After Scenario Questionnaire
IOM: Institute of Medicine
mHealth: mobile health
PSSUQ: Post Study System Usability Questionnaire
PwCD: person with communication disabilities
SLP: speech-language pathologist

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The Use of Telerehabilitation Technologies for Cardiac Patients to Improve Rehabilitation Activities and Unify Organizations: Qualitative Study

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Abstract

Background: Cardiovascular disease is a leading cause of death globally causing 31% of all deaths worldwide. The Danish health care system is characterized by fragmented delivery of services and rehabilitation activities. The Teledialog Telerehabilitation Program for cardiac patients was developed and tested to rectify fragmentation and improve the quality of care. The Teledialog program was based on the assumption that a common communication platform shared by health care professionals, patients, and relatives could reduce or eliminate the fragmentation in the rehabilitation process and improve cooperation between the health professionals.

Objective: This study aimed to assess the interorganizational cooperation between health care professionals across sectors (hospitals, municipal health care centers) in a cardiac telerehabilitation program.

Methods: Theories of networks between organizations, the sociology of professions, and the “community of practice” approach were used in a case study of a cardiac telerehabilitation program. A triangulation of data collection techniques were used including documents, participant observation (n=76 hours), and qualitative interviews with healthcare professionals (n=37). Data were analyzed using NVivo 11.0.

Results: The case study of cooperation in an interorganizational context of cardiac telerehabilitation program is characterized by the following key themes and patterns: (1) integrated workflows via a shared digital rehabilitation plan that help integrate workflow between health care professions and organizations, (2) joint clinical practice showed as a community of practice in telerehabilitation developed across professions and organizations, and (3) unifying the organizations as cooperation has advanced via a joint telerehabilitation program across municipalities and hospitals.

Conclusions: The Teledialog Telerehabilitation Program was a new innovative cardiac program tested on a large scale across hospitals, health care centers, and municipalities. Assessments showed that the Teledialog program and its associated technologies helped improve interorganizational cooperation and reduce fragmentation. The program helped integrate the organizations and led to the creation of a community of practice. Further research is needed to explore long-term effects of implementation of telerehabilitation technologies and programs.

Trial Registration: ClinicalTrials.gov NCT01752192; http://clinicaltrials.gov/ct2/show/NCT01752192 (Archived by WebCite at http://www.webcitation.org/6yR3tdEpb)

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Introduction

Cardiovascular disease (CVD) is a leading cause of death on the global scale [1]. It is estimated that 17.5 million people died from CVD in 2012, equivalent to 31% of all global deaths [1]. Fortunately, CVD can be reduced by addressing behavioral risk factors such as unhealthy diet, obesity, physical inactivity, tobacco use, and excessive alcohol consumption. Cardiac rehabilitation (CR) programs include interventions such as exercise and patient education on risk factors, encouraging the patient to pursue and maintain a healthy lifestyle. Nevertheless, effective implementation of CR following CVD has been inadequate, with participation rates below 50% over recent decades, despite international recommendations [2-5]. A review of the literature highlights several factors that impede patients’ participation in CR programs including (1) inadequate access to health care services, (2) fragmentation of the organization of rehabilitation efforts between hospitals and local health centers, (3) the patient’s lack of motivation and inability to manage their disease, (4) lack of individualized rehabilitation programs, and (5) transport difficulties to the clinic [4,6,7].

The rehabilitation of cardiac patients has evolved from a formerly hospital-based system to a cooperative arrangement that brings together hospitals, health centers, and municipalities [8,9]. The CR of patients is now divided into more specialized rehabilitation activities carried out at hospitals and general rehabilitation activities carried out under the guidance of health care centers linked to municipalities [8,9]. From a comparative international perspective, health care systems are characterized by fragmentation of health care services and rehabilitation activities [10-15]. This fragmentation generates and reproduces knowledge gaps between health care professionals in hospitals and municipalities, loss of information regarding the patient’s status after they are discharged from hospital and referred to a health care center, and a lack of cross-sector coordination in specific rehabilitation activities [14]. This fragmentation process has been ongoing for years, and in a recent survey by the Danish Heart Association, cardiac patients stated that fragmentation remains an organizational barrier for their successful CR [16]. A promising new solution to meet the challenges of this fragmentation is the use of telerehabilitation (TH) for cardiac patients. The term TH is defined as the delivery of rehabilitation services via information and communication technologies [17]. A review of alternative models of CR points out that there is no need to rely only on hospital-based strategies. Community and home-based programs can be used to design a more individualized rehabilitation that can be tailored to the patient’s specific needs and abilities [18-20]. Evaluations of cardiac telerehabilitation (CTH) programs conclude that studies tend to be heterogeneous regarding patients, intervention, use of technologies and outcome measures. Moreover, CTH programs often lack nutritional counseling or psychosocial management [21,22]. Studies focusing solely on exercised-based CTH have been shown to be at least as effective as center-based rehabilitation for improving functional capacity and reducing CVD risk factors [23]. At present, we have found no studies that have focused on the impact of TH technologies on coherence within the cardiac rehabilitation process or cooperation across sectors (ie, between health care professionals in hospitals and health centers in municipalities).

We define “cooperation” as an arrangement in which two or more parties who might otherwise compete with each other engage in a voluntary and mutually beneficial exchange [24]. Cooperation across sectors is desirable because (1) it helps avoid fragmentation, (2) it ensures continuity in information and communication flow in the patient care processes, (3) it brings together complementary competencies between health care professionals, (4) it reduces the potential for adverse events, and (5) it generally secures the quality of care [14,15,25].

This study aims to explore interorganizational cooperation between health care professionals across hospitals and municipalities as it occurs within a single program, the Teledialog Telerehabilitation Program (TTP), and its associated technologies.

Methods

Design

This study is a substudy carried out within the main TTP. The descriptive case study, provided by Robert Yin [26] is the overall method chosen for this study. A case study is defined as “an empirical inquiry that investigates a contemporary phenomenon (the ‘case’) in depth and within its real-world context, especially when the boundaries between phenomenon and context may not be clearly evident” [26].

Description of Sampling

In phase I, from November to December 2012, health care professionals (nurses, a physician, and physiotherapist) were selected based on 2 criteria: (1) they were working within the team of CR staff at a hospital or health care center for more than a year and (2) they were involved in practical CR. In phase II, from December 2013 to January 2014, health care professionals were selected for interviews based on having been directly involved with cardiac patients participating in the TTP at a hospital, health care center or call center.

Presentation of Context in a Case Study

The TTP was developed from May 2011 to March 2012. The program was based on user-driven innovation [27] in workshops involving a range of participants including (1) health care professionals from hospitals and health care centers, (2) cardiac patients, (3) relatives, (4) representatives from companies, and (5) researchers from disciplines such as nursing, medical engineering, psychology and organizational sociology. Participants in the CTH program were a cardiology ward at a regional hospital, a thoracic ward at a university hospital, 4 health care centers located in 2 municipalities and a call center.

KEYWORDS
telerehabilitation; heart diseases; workflow; cooperation; professional practice; community of practice
The Teledialog Network is centered around a Web portal called “ActiveHeart” (see Figure 1).

The target group in this study consisted of patients diagnosed with heart failure, myocardial infarction, angina pectoris, and who had undergone coronary artery bypass surgery. The overall aim of the TTP was to develop a more individualized rehabilitation process, avoid organizational fragmentation and facilitate coherence in the rehabilitation process. Within the TTP, the rehabilitation program was carried out in close collaboration between the cardiac patients, hospitals, health care centers and a call center between 2012 to 2014. The cardiac patients tested the TH program for 12 weeks (see Table 1 for project overview). A video of the Teledialog project is provided in Multimedia Appendix 1.

Each patient was interviewed individually before discharge in order to determine their specific rehabilitation needs and type of rehabilitation program (hospital, health care center, or call center). An individualized rehabilitation plan was then designed with the patient, following current guidelines for cardiac recommendations as developed by European Association of Cardiovascular Prevention and Rehabilitation [28] and the Danish Health Agency [8,9].

Figure 1. The Teledialog Telerehabilitation Network. The small grey square in each “house” represents a mobile device (eg, tablet) that patients have close by and use to transmit information or communicate with health care personnel from home, work or during leisure activities. ECG: electrocardiography.
Table 1. Overview of the technologies used in the Teledialog project.

<table>
<thead>
<tr>
<th>Technology/device</th>
<th>Function</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tablet</td>
<td>Patients used an Android tablet to access data</td>
</tr>
<tr>
<td>ActiveHeart.dk</td>
<td>An interactive portal that functions as a toolbox for cardiac patients</td>
</tr>
<tr>
<td></td>
<td>Site contains information on a range of relevant rehabilitation issues (medicine, smoking, mental well-being, diet, and physical exercises)</td>
</tr>
<tr>
<td></td>
<td>Patients could access the information on a 24/7 basis</td>
</tr>
<tr>
<td></td>
<td>Information was communicated in text, video, and audio and designed to suit patients’ preferred style of information-seeking</td>
</tr>
<tr>
<td>Shared Care Platform (e-rehabilitation plan)</td>
<td>Platform for everyday use between health care professionals, patients, and relatives</td>
</tr>
<tr>
<td></td>
<td>Provides an overview of patient data including medications, goal, and plan for rehabilitation, diary, hospital or health care center appointments and monitored values (blood pressure, pulse, weight, and steps)</td>
</tr>
<tr>
<td>CareConnect</td>
<td>A data platform for integrating and connecting the different project systems</td>
</tr>
<tr>
<td></td>
<td>CareConnect received data from Danish national standards, MyMedic, Fitbit, and the e-rehabilitation plan</td>
</tr>
<tr>
<td>Triage Manager</td>
<td>Health care professionals used this module at hospitals, health care centers, and a call center</td>
</tr>
<tr>
<td></td>
<td>Administered data on the patients being monitored</td>
</tr>
<tr>
<td>Telehealth monitor</td>
<td>Data was transmitted using MyMedic to transfer data via a mobile internet connection to a central server</td>
</tr>
<tr>
<td></td>
<td>Used to transmit data from devices (eg, the sphygmomanometer, digital weight scale, and electrocardiography)</td>
</tr>
<tr>
<td>Sphygmomanometer</td>
<td>Meter was paired with the telehealth monitor in advance</td>
</tr>
<tr>
<td>Digital weight scale</td>
<td>Weight scale was paired with the telehealth monitor in advance</td>
</tr>
<tr>
<td>Fitbit Ultra</td>
<td>Digital pedometer that enabled patients to view steps taken in their e-rehabilitation plan</td>
</tr>
</tbody>
</table>

All patients received training in the use of the various rehabilitation devices, navigation of the ActiveHeart Web portal, and in interpreting and using the e-rehabilitation plan (see Table 1). A physician prescribed the frequency with which the patient needed to measure their blood pressure, pulse, and weight (usually twice a week). Steps were measured every day. All data were transmitted to the e-rehabilitation plan database via a secure transmission line. Nurses at a call center recalibrated the measured values so that the health care professionals in the municipalities could then assess the monitored values each week. During the implementation of the TTP, the health care professionals held 5 meetings of 2 hours each in which they discussed TH issues for the cardiac patients and how to best cooperate and coordinate their activities.

**Theory**

Theories of networks between organizations [24], the sociology of professions [29], and learning theory [30] constitute the tripartite theoretical framework for this case study.

A network is defined as “the basic social form that permits interorganizational interactions of exchange, concerted action, and joint production. Networks are unbounded or bounded clusters of organizations that, by definition, are non-hierarchical collectives of legally separate units” [24]. Described by Abbott [29], the sociology of professions has been applied in order to help focus on the dynamics and interplay between health care professionals from hospitals, call center, and health care centers.

The perspective focuses on professional work, social relations, and internal struggles between occupational groups in an interprofessional context. Finally, learning theory, described in the work of Wenger [30], has been applied in order to highlight the emergence of “communities of practice.” Wenger defined “communities of practice” as groups of people who share a concern or passion for something they do and who interact on a regular basis. The strategy here was to investigate how the technologies used in the Teledialog network affected the learning process among the participants. Central themes from the theoretical framework have been applied in the observation and interview guides used in the data collection process (see Multimedia Appendix 1 and Multimedia Appendix 2).

**Data Collection Techniques in the Case Study**

In this study, a triangulation of data collection techniques was used in order to validate the data.

**Document Analysis**

As background for the descriptive case study, documents and reports on the organization of rehabilitation activities, strategies, and policies within rehabilitation and hompages from hospitals and health care centers were studied. The aim of this background documentation was to (1) obtain intensive knowledge of the context for the case study, such as how conventional rehabilitation had been carried out, (2) division of tasks between health care professionals across sectors, and (3) how
communication and information flow between the health care professionals in the interorganizational context.

Table 2. Overview of interviewees.

<table>
<thead>
<tr>
<th>Respondents</th>
<th>Phase I (Nov-Dec 2012), n</th>
<th>Phase II (Dec 2013-Jan 2014), n</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hospital staff</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurses</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Physicians</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Health care center staff</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurses</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Physiotherapists</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Call center staff (nurses)</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>17</td>
<td>20</td>
</tr>
</tbody>
</table>

Participant Observation

Participant observation [31] was carried out to observe (1) cooperation between health care professionals in hospitals and municipality health centers and (2) their relations with the patients participating in the TH program. Observations were carried out during meetings, at patient discharge, and during the daily routine work of health professionals across sectors and in interactions with patients and relatives based on an observational guide (Multimedia Appendix 2).

As part of the participant observation, we studied communication between health professionals and patients enrolled in the e-rehabilitation plan. The 3 main themes were (1) planning and coordination of the rehabilitation program, (2) communication among groups of health professionals, and (3) communication between health care staff and patients and relatives.

The 2 authors performed participant observation for a total of 76 hours. Through observations in various settings, data was collected on communication patterns at meetings, problem-solving and interaction between health care professionals carrying out clinical tasks across sectors, and interaction between health professionals and patients. Field notes were taken immediately after the observation had taken place, entered as Microsoft Word files, and then analyzed using the NVivo 11.0 qualitative data analysis program.

Qualitative Interviews

The two authors of this study conducted semistructured qualitative interviews described by Kvale and Brinkmann [32] with representatives from all health care organizations involved in the TH of the cardiac patients (Multimedia Appendix 3).

The interviews were conducted in 2 phases. During phase I, the health care professionals were asked to describe how they experienced the cross-sectoral co-operation within cardiac rehabilitation. The aim was to obtain a basic understanding of the context of the case study. In phase II, interviewees were asked to explore the interorganizational cooperation within the TTP and specifically, how they experienced cooperation across sectors using the digital platform. The interviews in both phases lasted from 55-90 minutes (see Table 2).

Data Analysis

A research assistant transcribed all interviews. The transcribed interviews, documents, notes from participant observation were coded using NVivo 11.0 software and analyzed in steps described by Kvale and Brinkman [32]. The data were analyzed using a combination of deductive and inductive strategies. A code tree was designed based on key definitions and concept from the theoretical framework and the interviews. As a first step in formulating the concepts from the respondents, the qualitative interviews were studied and coded by initial impression. This was followed by a rough coding and refined coding based on the reviews of coded data and adjustments. This second step sought to identify key themes and patterns relevant to identifying the participants’ views about cooperation and TH. The final step in the data analysis was an in-depth interpretation that was put in contrast with the participants’ own common sense understandings and motivations. The coding and analysis were carried out by the authors, both of whom have backgrounds in nursing, organizational development, and psychology. To ensure intercoder reliability, the same 2 researchers initially had dialogue and compared codes in order to agree on definitions for subsequent coding, since using a software program to analyze data may decontextualize the analysis of data.

Ethical Considerations

The Teledialog project was approved by the Danish Ethical Committee (N-20120051), and the project was registered at ClinicalTrials.gov (ClinicalTrials.gov identifier NCT01752192). The study was performed according to the Declaration of Helsinki.

Results

Key Themes and Findings

In this section the key themes and findings on interorganizational cooperation in the TTP are presented (see Table 3).
In the following sections, the key themes and findings are elaborated. Illustrative quotations from interviews with health care professionals are presented in the following. The criteria for selecting the quotations was that they should represent the overall theme or subthemes of the data.

**Integrated Workflows**

Health care professionals expressed the view that the e-rehabilitation plan across hospitals and municipalities enabled them to share data on each patient’s rehabilitation program and to communicate with each other and with patients and relatives on a continuing basis. The plan made it possible to establish a high level of coherence and continuity during the entire patient rehabilitation process.

*The digital platform makes it possible for us to share data on the patients between hospital and municipalities. Sharing data prevents adverse events and increases the quality of planning for rehabilitation after patients are discharged from hospital. I think we have reduced fragmentation.*

[Nurse #20, female]

By having online access to the same data for a single cardiac patient, the health professionals concluded that the use of the technological platform facilitated interdisciplinary decision-making for the benefit of the patients. In the beginning, the professionals felt that the task was challenging. However, our observational notes showed that after 4 months, the technological platform became an integrated part of the workflow across sectors.

*Having access to the same data about a patient makes it possible for us across sectors and professional organizations to carry out interdisciplinary decision-making within rehabilitation...in the beginning it was difficult, but after some time we realized the benefit of doing it [this way].*[Nurse #25, female]

**Joint Clinical Practice**

Health care professionals expressed that their relations were strengthened during their work within the TTP. They met with each other regularly in order to discuss issues within TH.

*The meetings we’ve had during the project and the [use of the] digital platform have strengthened relations between our teams.* [Physiotherapist #33, female]

In the interviews, the health professionals expressed the view that the meetings were effective channels for knowledge-sharing and creating a joint vision for TH of cardiac patients. Observations identified engagement and knowledge-sharing between the health professionals from the cardiology ward and those working in the health centers.

*We’ve had the possibilities to exchange knowledge about the challenges of rehabilitation of cardiac patients and to make a joint vision together...I feel like we are working in the same organization.* [Nurse #18, female]

*Not all patients can participate in the telerehabilitation program, so we need to discuss with each other which patients are capable of taking part in the telerehabilitation program.* [Nurse #28, female]

The professionals stated that most of the patients monitored their data very carefully and engaged actively in their rehabilitation process in order to return to everyday life more quickly. Professionals in the municipalities described the patients as collaborators rather than passive clients.

*We feel the patients are becoming more engaged in their own health and rehabilitation because they can see their own data and are part of the telerehabilitation program.* [Nurse #30, female]

**Unifying Organizations**

In geographic terms, the Danish TH program covered 2 hospitals and 4 health care centers in 2 municipalities and a call center. The TH program and its associated technologies made it possible to offer a new joint rehabilitation service on a large scale. The benefits were from pooling resources and know-how, and to offer patients in remote areas the possibility to carry out their rehabilitation in their local community health care centers and in their own homes, thus reducing disruption so as not to disrupt their everyday routines.

*The technological platform facilitates interdisciplinary decision-making on rehabilitation issues*
By having the digital platform, we can substitute for each other during vacation periods and give patients the same level of service. [Nurse #27, female]

Telerehabilitation is a new way of working as a team and of bringing synergy between our disciplines, know-how and manpower and municipalities. [Physiotherapist #35, female]

Observational notes showed that at the beginning of the implementation of the program, there was some frustration among the health professionals in figuring out how to cooperate across sectors and implement the new workflows. By the final evaluation, however, the data from interviews and observations showed that these frustrations were no longer present.

The health care professionals expressed that the interorganizational cooperation and use of the joint e-plan enabled them to bridge across professions and organizations, giving them a feeling of being a single, unified organization.

It’s easier for us to communicate via the digital platform. It makes us feel like a single organization, but it’s important to have the meetings face-to-face. [Nurse #31, female]

Discussion

Principal Findings

The case study of cooperation in an interorganizational context of a cardiac TH program showed (1) the shared digital rehabilitation plan helped increase the level of workflow integration between health care professions and the participating organizations, (2) the joint clinical practice developed into a TH community of practice across professions and organizations, and (3) municipal and hospital organizations became more unified due to their cooperation in the joint TH program.

Interpreting Findings in the Context of the Wider Literature

The TTP was the joint vision for the systematic network of the participating organizations. Planning and coordinating the individualized rehabilitation processes for the cardiac patients was the prime focus for the health care professionals in the Teledialog Network. Regular meetings between health professionals and the elaboration of individualized e-rehabilitation plans for patients constituted the platform for cooperation, knowledge-sharing, coordination, and joint problem-solving between members of the participating organizations.

The e-rehabilitation plan can be compared to a personal health record (PHR), which is an electronic app where individual patients can access, manage, and share health information with anyone whom they allow [33]. The adoption, acceptance, and use of PHR requires a culture of adaptation, user-friendly technology, and a governance structure [34,35]. The governance structure in the TTP, including content, vision, and distribution of tasks and responsibility among health care professionals across sectors, was negotiated and developed in workshops with health care professionals before implementation of the program. A review of the dynamics of interorganizational collaboration [25] states that if participants are involved issues for discussion are agreed on in the process of planning so that it does not become a barrier. Also, it may explain the positive result of this study. The work by Barlow et al [36] supports these findings by emphasizing that implementing complex innovations in an interorganizational context with many stakeholders requires that all parties have had sufficient opportunity to share views and to have an open dialogue on values. We have not identified any cardiac TH studies that have described such a shared care platform in an interorganizational context.

A community of practice was established across professions and organizations in the Teledialog project. These findings are in alignment with Wenger’s community of practice theory [30]. The development of a community of practice based on a digital platform across sectors has previously been identified among patients with chronic pulmonary diseases and health professionals. The result was that the parties could exchange experiences, stories, and strategies for how to manage rehabilitation in the patient’s homes [37]. The theoretical framework has helped to identify the dynamics of cooperation and learning processes between the health care professionals working across hospitals, sectors, and municipalities within the TTP.

A review by Rolls et al [38] concluded that health care professionals who used social media to develop virtual communities to share domain knowledge often exhibit tribal behaviors between each other with the result being a limitation on knowledge sharing. We did not identify this kind of issue in our study, even though we have utilized the sociology of professions approach as part of our theoretical framework. The same authors highlight the need for further research in order to evaluate the effects of social media on knowledge distribution in clinical practice and, equally important, to assess whether patient outcomes are significantly improved. Busetto et al [39] and Otte-Trojel [40] report findings that support our results concluding that IT can serve as a facilitator for complex interventions within integrated care.

The interorganizational cooperation in the Teledialog project was advanced. Mandell et al [41] highlight the fact that for interorganizational innovations to be successfully implemented in a complex context, management/project management must be made aware of the impact of contextual factors. The important factors are the history of relationships, the relative power of the actors in the network, imposition of rules, impact of political/cultural context and culture of the actors. By using the case study with a triangulation of data collection techniques, our interdisciplinary team was able to bring the contextual factors into the analysis as part of the preparation for the trial. By identifying the factors before implementation of the cardiac TH program, implementation became possible within the time frame and the budget of the project. Moreover, we were able to overcome the factors that typically impede or derail the implementation of eHealth systems, such as insecurity, uncertainty, and a sense of not being part of the implementation process. [14,42,43].

The innovation elements of the cardiac TH program, when implemented on a large scale and across hospitals, municipal...
health centers, and a call center, have not been previously published. We did identify a study by Frederix et al [21] on the TH for cardiac patients in Belgium. However, this study was not conducted on a significant scale, nor were the organizational issues explored or evaluated.

Strengths and Limitations
A case study is circumscribed by the possibilities for generalization [44]. A triangulation of data collection techniques has been used in order to collect sufficient and varied data and to ensure validation of different perspectives. A longitudinal study of the cooperation among health professionals across sectors would have strengthened the results, as would a larger randomized control trial study with more patients enrolled so that health care professionals would gain more experience working with TH. We are aware that a potential limitation of this study is that it reflects specific elements of the Danish context, where all health care services are public and free of charge.

Conclusions
The TTP was a new, innovative cardiac TH program that was tested on a large scale across hospitals, health care centers, and municipalities. Assessments of the cooperation between the health care professionals showed that the Teledialog program and its associated technologies helped to integrate workflows, created a joint clinical practice, and fostered a common sense of purpose among the organizations. Interorganizational cooperation was improved, and fragmentation of tasks reduced, resulting in a significant benefit for the patients and satisfaction for the health professionals. Future research should focus on longitudinal case studies for assessing interorganizational cooperation between health care professionals.

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Conflicts of Interest
None declared.

Multimedia Appendix 1
Video of the Teledialog Project.
[AVI File, 63MB - rehab_v5i2e10758_app1.avi ]

Multimedia Appendix 2
Observation guide.
[PDF File (Adobe PDF File), 81KB - rehab_v5i2e10758_app2.pdf ]

Multimedia Appendix 3
Interview guides.
[PDF File (Adobe PDF File), 106KB - rehab_v5i2e10758_app3.pdf ]

References


Abbreviations

- **CR**: cardiac rehabilitation
- **CTH**: cardiac telerehabilitation
- **CVD**: cardiovascular disease
- **PHR**: personal health record
- **TH**: telerehabilitation
- **TTP**: Teledialog Telerehabilitation Program

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