JMIR Rehabilitation and Assistive Technologies

Contents

Original Paper

A Personalized Self-Management Rehabilitation System with an Intelligent Shoe for Stroke Survivors: A Realist Evaluation

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Abstract

Background: In the United Kingdom, stroke is the most significant cause of adult disability. Stroke survivors are frequently left with physical and psychological changes that can profoundly affect their functional ability, independence, and social participation. Research suggests that long-term, intense, task- and context-specific rehabilitation that is goal-oriented and environmentally enriched improves function, independence, and quality of life after a stroke. It is recommended that rehabilitation should continue until maximum recovery has been achieved. However, the increasing demand on services and financial constraints means that needs cannot be met through traditional face-to-face delivery of rehabilitation. Using a participatory design methodology, we developed an information communication technology–enhanced Personalized Self-Managed rehabilitation System (PSMrS) for stroke survivors with integrated insole sensor technology within an "intelligent shoe.". The intervention model was based around a rehabilitation paradigm underpinned by theories of motor relearning and neuroplastic adaptation, motivational feedback, self-efficacy, and knowledge transfer.

Objective: To understand the conditions under which this technology-based rehabilitation solution would most likely have an impact on the motor behavior of the user, what would work for whom, in what context, and how. We were interested in what aspects of the system would work best to facilitate the motor behavior change associated with self-managed rehabilitation and which user characteristics and circumstances of use could promote improved functional outcomes.

Methods: We used a Realist Evaluation (RE) framework to evaluate the final prototype PSMrS with the assumption that the intervention consists of a series of configurations that include the Context of use, the underlying Mechanisms of change and the potential Outcomes or impacts (CMOs). We developed the CMOs from literature reviews and engagement with clinicians, users, and caregivers during a series of focus groups and home visits. These CMOs were then tested in five in-depth case studies with stroke survivors and their caregivers.

Results: While two new propositions emerged, the second importantly related to the self-management aspects of the system. The study revealed that the system should also encourage independent use and the setting of personalized goals or activities.

Conclusions: Information communication technology that purports to support the self-management of stroke rehabilitation should give significant consideration to the need for motivational feedback that provides quantitative, reliable, accurate, context-specific, and culturally sensitive information about the achievement of personalized goal-based activities.

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Introduction

In the United Kingdom, stroke is the most significant cause of adult disability. Stroke survivors are frequently left with physical and psychological changes that can profoundly affect their functional ability [1], independence [2], and social participation [3-6]. With the global incidence of stroke set to escalate from 15.3 million to 23 million by 2030 [7] and the decrease in mortality and rise in morbidity, more stroke survivors will be living with long-term disability [8].

Research suggests that long-term, intense, task-specific, context-specific, goal-oriented, variable rehabilitation that is goal-oriented and environmentally enriched improves function, independence, and quality of life after a stroke [9]. Over recent years, there has been a contextual shift in service delivery from hospital-based rehabilitation to the community. It is recommended that rehabilitation should continue until maximum recovery has been achieved [9,10]; however, the increasing demand on services and financial constraints mean that needs cannot be met through traditional face-to-face delivery of rehabilitation. Radical innovation and the adoption of a self-management paradigm need to be considered as a way to deliver home-based rehabilitation, thereby meeting the challenges faced in health care.

In 2007, the SMART consortium began a program of research to develop and evaluate an Information Communication Technology (ICT) enhanced Personalized Self-Managed System for people with complex long-term conditions [11,12]. The program aimed to deepen our understanding of the potential for technology to support self-management of long-term chronic conditions through an iterative, user-centered design methodology focused on health and social care [13]. Three conditions were chosen for the study—chronic pain, chronic heart failure, and stroke—with the intent of exploring how a multimodular system could support the three areas, with a proposition that other long-term conditions could be integrated into the system at a later stage. The intervention model for the stroke system was based around a rehabilitation paradigm underpinned by theories of motor relearning and neuroplastic adaptation, motivational feedback, self-efficacy, and knowledge transfer [14-17].

The SMART interdisciplinary research team applied a mix of health, social sciences, and user-centered design methods to develop the Personalized Self-Management Rehabilitation System (PSMrS) for stroke survivors [18]. The PSMrS is a prototype ICT system integrated with home hub sensor technology—the intelligent shoe—developed to enable stroke survivors to self-manage their rehabilitation to achieve identified life goals specific to them (Figures 1-3). While other wearable devices are available, the sensored insole was deemed to be the most appropriate as walking re-education and foot placement are key components of a stroke rehabilitation program. Data from the sensors give feedback to users through screens (Figure 3) designed with stroke survivors to depict balance and heel strike as a percentage of normal values. The aim of this final aspect of the research program was to understand the conditions under which this technology-based rehabilitation solution would most likely have an impact (outcome) on the motor behavior of the user, what would work for whom, in what context, and in what way.

Figure 1. The PSMrS home hub for stroke survivors with insole and data logger providing walking feedback through the PSMrS.
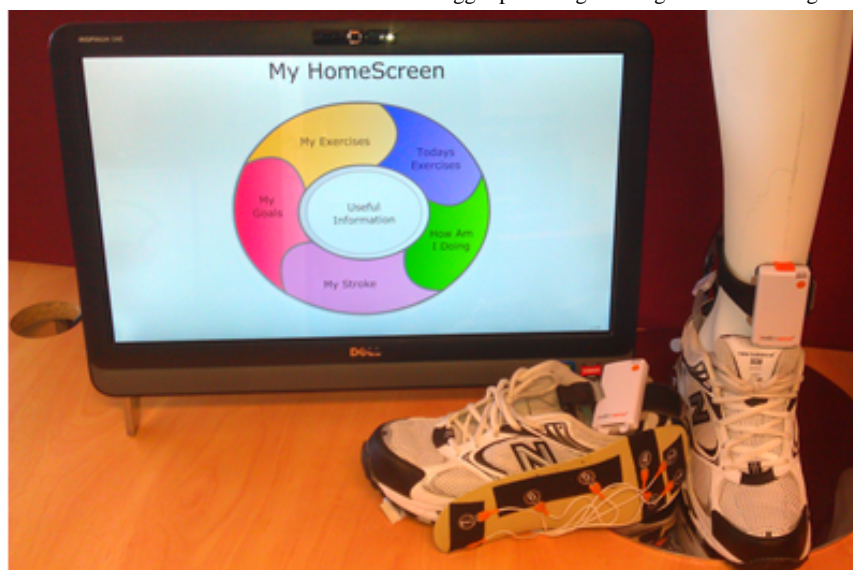
Figure 2. Screenshots of the PSMrS user interface.

Methods

In order to enhance and strengthen our previous research, we used a Realist Evaluation (RE) approach [19] to evaluate the final prototype of PSMrS, prior to a feasibility pilot study, in order to explore in depth the value, usability, and potential impact such technology could have on an individual's ability to self-manage their rehabilitation following a stroke.

Realist evaluation is a well-recognized methodology with its roots in philosophy, social sciences, and evaluation methods. To conduct realist evaluation, it is necessary to assume that the program (or in this case the PSMrS intervention) consists of a series of configurations that include the context, the underlying mechanisms of change, and the potential outcomes or impacts. Realist evaluation is underpinned by theory described as a set of prepositions about the nature of change that is predicted, as well as the hypothesis that change can be maintained by the action of particular mechanisms within particular contexts (eg, the proposition that a simple touch-screen computer interface can motivate people even with low or no computer literacy to use the system for monitoring their health in the context of their home).

This methodology also tries to explain those contexts that are "conducive" or "resistant" to change [20]. Any realist evaluation must fully engage stakeholders, clinicians, stroke survivors, and caregivers in the generation of theories to be tested through the evaluation and the identification of subsequent working hypotheses that then drive the evaluation process. An overview of the realist evaluation plan adopted in this research is summarized in Figure 4.

The overall evaluation questions for this research were what works, for whom, why, in what way, and under what circumstances? In the case of the PSMrS, we were interested in what aspects of the system would work best to facilitate the motor behavior change associated with self-managed rehabilitation and which stroke user characteristics and circumstances of use could promote improved functional outcomes.

Figure 3. User feedback for symmetry and heel strike data from insole.

The theories to be validated through the realist evaluation process were generated through literature reviews together with empirical data collected in the earlier work [18,21,22]. These theories were then validated or refuted through individual and focus group interviews conducted with patients/caregivers and health professionals as described below. There were a number of theories that we wished to explore in this aspect of the evaluation; for example, the theoretical models of self-management rehabilitation that are amenable to technological solutions, the implications of motor behavior change mechanisms such as neuroplasticity and how they can be taken into account in technology development, and the extent to which technology can facilitate a shift in responsibility for the management of care from the professional to the stroke survivor.

The theories generated a number of hypotheses/propositions, to be explored rather than tested:

1. Specific elements of self-management can be successfully promoted through the use of technology designed for this purpose.
2. This technology can help individuals relearn motor behavior by encouraging achievement of personal functional goals and repetition of key motor activities within those goals.

3. The technology facilitates partnership working between the user and others to achieve self-management.

4. The stroke PSMrS gives users the opportunity to perform exercises as much as they can through repetition and provides them with tailored feedback. Both these attributes can promote motor relearning and neuroplastic adaptation.

5. The technology can enable users to interpret physiological data through motivational feedback screens.

6. By mastering (mastery) the tasks involved in self-management programs and being provided evidence

of this through real-time feedback on performance, users develop confidence (self-efficacy) that then leads to a more active role in the management of their condition.

In accordance with the realist evaluation methodology, the process of hypothesis validation and generation were followed by operationalization of the hypotheses into mechanism, context, and outcome configurations (CMOCs). These were explored, refined, developed, and tested through practitioner and participant engagement.

Figure 4. An overview of the realist evaluation plan.
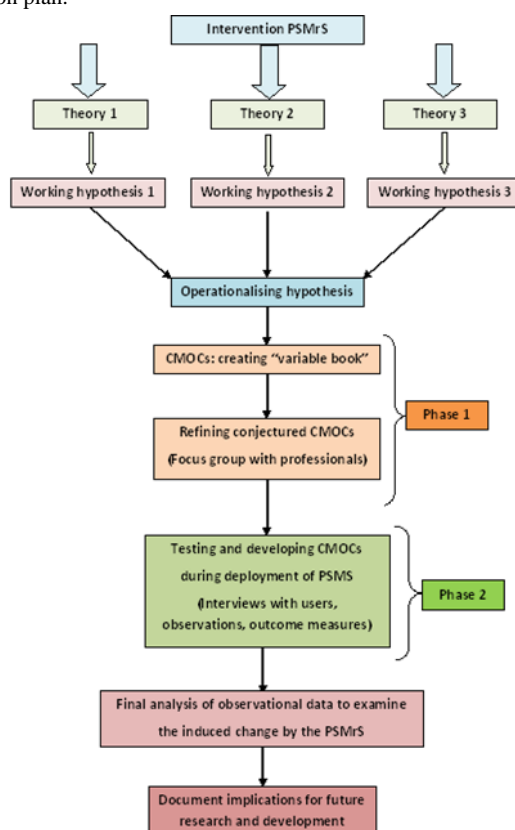
Recruitment and Participant Involvement

All participants were recruited via health services and deemed to be fit to join the study by the referring physiotherapist. Ethics approval was obtained through the Leeds Ethics committee (08/H1306/46), and informed consent was obtained before the system was deployed to participants' homes. All participants had to be able to comprehend written English, not have significant cognitive impairment, and be clinically stable. The stroke survivors needed to be willing and able to use the

equipment and report back on their experiences to the research team. Specific inclusion criteria for participants were that they did not have any communication problems that would significantly impede comprehension or have severe hemiplegia to the extent that they were not able to get up out of the chair independently.

Participants' demographic characteristics and baseline clinical data were recorded at the outset (see Table 1). The stroke survivors were also interviewed qualitatively before and after the period of installation about their views and experiences.

Table 1. Patient demographics.

Participant	Age of patient/ age of caregiver	Side affected	Time since stroke	Computer experience[a]	Able to comprehend written English	Walking aid
17	63/57	R hemi	13 months	++	Yes	None (FES)
23	73/73	L Hemi	18 months	+	Yes	Frame and tripod (FES)
33	45/44	R Hemi	18 months	+++	Yes	None (FES)
34	60/60	L Hemi	15 months	++	Yes	None (FES)
35	42/44	R Hemi	12 months	++	Yes	None (FES)

[a]+ denotes the amount of computer experience.

Information collected from the deployed systems were transferred and stored using a non-identifying format on a server hosted at one of the partner universities. The security and privacy of data between the stroke survivor's devices and the server were protected using two methods. The first was to keep the data private by anonymizing all of the data so that sensitive information was never transmitted across the Internet. The second was to store the information in a secure manner; information was stored on a university server that was held in a secure room under lock and key and behind a firewall. In addition, the server was also active only during the realist evaluation and was disconnected from the Internet once the realist evaluation was completed. Technical support was available over the telephone and by researcher follow-up visits where necessary during office hours.

Five people with stroke were recruited from either Sheffield Community Intermediate Care Services or the Assessment and Rehabilitation Centre while they were still receiving rehabilitation. The engagement of therapists at this service was obtained through an initial focus group where the technology was explained and demonstrated together with the requirements for participant involvement (local agreement for access has already been obtained). Participants were identified during the period of community rehabilitation by the therapists, with the anticipation being that the PSMrS would be integrated into the standard stroke care pathway prior to discharge from the stroke service or where they were still engaged in active rehabilitation.

The treating physiotherapist in partnership with the stroke survivor personalized the system and the stroke survivor (with or without their carer) practised using the system under supervision within the rehabilitation center. The service participants were then encouraged to continue using the system for up to 4 weeks independently at home. The participants were advised to contact a health care professional if any health issues arose during the deployment period. A researcher was available by telephone if technical difficulties arose during the 4-week period.

Conducive Context

In order for the mechanisms underpinning the PSMrS to work, a number of generic contextual conditions had been previously identified [21,23]. The system had to be reliable, accurate, and robust; be adapted and personalized to the individual personal, environmental, and social context of the stroke survivor; be accessible in the home setting; be person-centered (customized for the individual) and used independently of the therapist; and provide the user with adequate resources to enable them to understand and have knowledge about their stroke and rehabilitation processes.

Examples of what some of the contexts, mechanisms, and outcomes (CMO) for the PSMrS are provided in Table 2. This combination of theory, hypothesis generation, and development of CMOC was the foundation work for the evaluation; a realist evaluation demands a synthesis of qualitative and quantitative methodology.

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Table 2. Context mechanisms outcome configurations for the PSMrS.

Some plausible mechanisms (why)	Some potential contexts (who/in what circumstances)	Some possible outcomes
M1: By using the PSMrS, users will gain a sense of task mastery which might increase their confidence.	C1: A system that provides rewarding feedback as a result of improved symmetry and heel strikes.	O1: Increased confidence in the user's ability to carry out everyday tasks. Measure: Qualitative data
M2: By using the PSMrS, users will be facilitated to set specific, measurable, attainable, realistic, and time-specified goals that might promote more responsibility towards their rehabilitation.	C2: A system that is used by a participant where they continue to desire improvement(s) and those improvements are achievable.	O2: Increased self-efficacy and ownership of their rehabilitation. Measure: Qualitative data
M3: By using the PSMrS, users performing selected exercises in the home and repeating these exercises might lead to users' developing knowledge about carrying out stroke rehabilitation in the home environment.	C3, C3a: A system that can be used in the home and has specific goals and exercises that can be carried out within the home/domestic environment.	O3: Context-dependent/ place-based and culturally meaningful rehabilitation. Measure: Qualitative data and quantitative data from the TELER quiz style indicator.
M4: By using the PSMrS, users have problem-solving opportunities that might lead to the successful achievement of goals and attribution of success to users' personal abilities.	C4: A system that enables users to set and achieve personal goals through shared decision-making between patients and professionals.	O4: Increased users' agency and their active roles in self-management. Measure: Online data sources from insole and qualitative data.
M5: The use of the PSMrS will facilitate the translation of physiological data, which might enable the user to interpret their symptoms.	C5: A system that translates physiological data through feedback.	O5: An understanding of symptoms and change in symptoms throughout the usage of the system. Measure: Qualitative data and quantitative online data sources from insole.
M6: The use of the PSMrS might encourage increased intensity of practice with consequential neuroplastic changes.	C6: A system that provides individualized motivational feedback on the achievement of walking skill.	O6: Increased functioning and achievement of improved walking skill. Measure: Online quantitative data sources from insole.

Observation of Context, Mechanism, and Outcome Configuration

Our goal was to gather both qualitative and quantitative data before, during, and after participant interaction with the technology. The quantitative data gathered before, during, and after the technology deployment enabled us to observe changes in physical activity, specifically walking ability, and quality and changes in knowledge levels. To achieve the latter, a measure called TELER Quiz style outcome indicators was used [24-26]. Quantitative walking data on heel strike, gait speed, and symmetry was recorded online from the sensors in the intelligent shoe during the time stroke survivors used the PSMrS. The amount of walking activity was also measured in order to provide data to support the proposition around neuroplastic adaption and intensity of practice. We also applied a measure of technology usability, the System Usability Scale (SUS) [27].

In order to ensure that the quantitative gait data gathered from the insole was valid, providing accurate and reliable results, two approaches were adopted. In the first instance, the hardware and sensor technology consisted entirely of off-the-shelf products that were then integrated into the PSMrS in a novel way. This ensured that the technology complied with European Union safety, health, and environmental requirements. In addition, there were assurances that the manufacture has produced a product that was fit for purpose and had been through rigorous manufacturing processes such as quality assurance and testing. Second, a consistent hardware configuration was adopted in relation to sensor deployment, as any deviation from this template would have serious implications on accuracy and repeatability of results.

Finally, qualitative and quantitative analysis was carried out across all participant cases to establish whether the theories underpinning the personalized self-management system had been supported or refuted [28] and to what extent the intervention had created change in user behavior. Due to the extensive amount of information gathered during the evaluation, this paper reports only the qualitative data with the quantitative data reported elsewhere [29].

Data Analysis

The focus of the qualitative analysis was based on both the exploration of the pre-existing context and the development and refinement of the hypothesized CMOC using thematic analysis [30-32]. This innovative approach to the analysis draws on Yin [30], Miles and Huberman [33], and Patton [34] and is underpinned by the principles of realist evaluation [19].

This approach allowed for themes to emerge from the data and examines interconnections and relationships between the mechanisms and contexts in relation to proposed outcomes [31,32,35].

Results

The next stage of the realist evaluation cycle (see Figure 3) involves the specification phase where findings are synthesized and presented as refined CMO configurations to answer the question, "What works for whom and in what circumstances and ways?" [19,20].

What Work Works for Whom, and in What Circumstances and Ways?

Data analysis reveals that in order to achieve desired outcomes through the use of computer technology, a number of issues—such as the technology itself, the provision of feedback, the motivation of the user and what impacts on this, and the personal and social environment in which the system is used—can affect the mechanisms underpinning the intervention. The following section will discuss each of these issues in detail.

Technology

The limitations of PSMrS and the SMART insole had an impact on the usage of the system. Users relied on their caregiver to don the anklet, three of the five experienced Internet connection difficulties, the system required re-booting due to freezes, and the on/off switch was fragile and subsequently needed replacing: "It's quite fiddly to get the devices around the ankles and the insoles could do with being stiffer" (Participant 17) and "I always set off on my walking with my heart in my mouth thinking 'is it going to work?'!" (Participant 23).

Due to storage and accessibility issues, 3 users suggested that they would have preferred alternative devices to view their feedback such as a tablet or smartphone: "that [PSMrS] is a little bit cumbersome…if that could have been a laptop or an iPad size where you could put it somewhere. You could hold it on your knee" (Participant 35).

Feedback

Receiving feedback following performance was of particular importance to the users. More specifically, the provision of accurate, reliable quantitative Knowledge of Results (KR) feedback of goal attainment (ie, 100% heel strikes) affected users' motivation to use the system: "Having a numerical result to what you're doing helps because it is very easy to see that you've got an improvement" (Participant 23).

All of the users described how being able to make visible the invisible, observe their improvement, and track progress over time was of great importance. This would not only indicate that they are continuing to make improvements but they are also "returning to normality." They were therefore using improved scores as recovery markers: "It makes me feel like I'm making progress. I'm going down that road to full recovery. I know full recovery is never going to happen but I just keep saying to J I've passed another milestone" (Participant 23).

However, trusting the PSMrS and the scores provided affected their usage. For example, one of the users suggested that the system provided unexpected results: "you might not walk perfectly but the machine says that you're doing quite well!" (Participant 17).

Interestingly, 2 users reported practicing walking around without the SMART insole in their shoes so that when they used the insoles, they might get a better score: "I got it down in the low thirties…so without the sensors on we did an exaggerated heel–toe, the next time the score had improved a lot" (Participant 23).

Motivation

Motivation emerged as being related to feedback in that the scores obtained following performance focused their determination to improve. The users expressed their desire to strive for better scores following feedback: "I shouldn't be satisfied until I'm in the green and that little man pops up" (Participant 23).

Notably, because they had a score for their performance, the users were able to involve significant others, which reinforced behavioral change. This would involve caregivers and family members expressing their admiration for the improvements made, which would instill a level of mastery and confidence.

Researchers were interested in the consequences of negative feedback, that is, how they would respond if they received a poorer score than previously achieved. However, all of the users suggested it increased their determination: "It made me want to do it again, to better it!" (Participant 35).

However, a number of negative factors affected the motivation, such as fear of failure (users would practice without the shoe to ensure they achieved a better score) and self-awareness of their limitations (they were aware of how far they could walk, the risk of falling, environmental obstacles, fatigue, and the concerns of caregivers/family members).

Furthermore, the caregivers also influenced user motivation. Caregivers had safety concerns that the stroke survivor would push themselves too far in an attempt to achieve greater scores: "I'm getting more relaxed with it than I was when I thought b****y hell, what's she doing!!" (Caregiver 35).

Self-Management

A number of self-management principles were observed during testing. These included problem-solving whereby users would make a conscious effort to change their movements to obtain higher scores, promoting self-efficacy through mastery, involving others in the process of rehabilitation to reinforce behavior change, and utilizing resources (using the system and its components to improve): "It makes me feel like I'm making progress. I'm going down that road to full recovery" (Participant 23) and "Oh I'm confident yes, yes! Just little things like in a morning when I'm at the wash basin in the bathroom I do free standing now as a matter of course" (Participant 23).

Two users described how close family members noticed their improvements, which provided encouragement and reinforced their efforts to continue striving for improvements. Participant 35 described how she was able to open the door for her grandchildren when they had come to visit:

> My nanna look at my nanna!" And it's what I used to do whenever they used to come. I used to go to the door and open the door for them. And I'd done it again, hadn't I? And he [son] said it really did them good to see you do that! [Participant 35]

> Occasionally [granddaughter] says to me that I'm getting like the grandma that I used to be…she tells me know that I'm getting back to where I was. [Participant 35]

Context, Mechanism, and Outcome Configuration Refinement

This research aimed to test and refine intervention theories by exploring the complex interactions of contexts, mechanisms, and outcomes. Table 3 sets out the refinement of pre-existing CMOCs and highlights the changes following the observation of these CMOCs.

Table 3. Refinement of CMOC following observations and analysis.

Some plausible mechanisms (why)	Some potential contexts (who/in what circumstances)	Some possible outcomes
M1: By using the PSMrS, users will gain a sense of task mastery which might increase their confidence.	C1: A system that provides rewarding feedback as a result of improved symmetry and heel strikes.	O1: Increased confidence in the user's ability to carry out everyday tasks. Measure: Qualitative data
M2: By using the PSMrS, users will be facilitated to set specific, measurable, attainable, realistic, and time-specified goals that might promote more responsibility towards their rehabilitation.	C2: A system that is used by a participant where they continue to desire improvement(s) and those improvements are achievable and that provides accurate, reliable, quantitative KR feedback of goal attainment.	O2: Increased self-efficacy and ownership of their rehabilitation. Measure: qualitative data
M3: By using the PSMrS, users performing selected exercises in the home and repeating these exercises might lead to users developing knowledge about the importance of carrying out stroke rehabilitation in the home environment for recovery.	C3: A system that can be used in the home and has specific goals and exercises that can be carried out within the context of the home/domestic environment and provides meaningful feedback following goal-based activity; C3a: A system that can be used in the home and has specific goals and exercises that can be carried out within the context of the home/domestic environment.	O3: Context-dependent/place-based and culturally meaningful rehabilitation. Measure: qualitative data; O3a: An awareness of the need to carry out rehabilitation
M4: By using the PSMrS, users have problem-solving opportunities that might lead to the successful achievement of activities/goals and attribution of success to users' personal abilities.	C4: A system that enables users to set and achieve personal goals through shared decision-making between patients and professionals; C4a: A system that encourages independent use in the home and to set personal goals.	O4: Increased users' agency and their active roles in self-management taking action (practicing). Measure: Online data date sourced from insole; Qualitative data
M5: The use of the PSMrS will facilitate the translation of physiological data, which might enable users to interpret their symptoms.	C5: A system that translates physiological data through feedback.	O5: An understanding of symptoms and change in symptoms throughout the usage of the system. Measure: Qualitative data; online data sources from insole.
M6: The use of the PSMrS might encourage increased intensity of practice with consequential neuroplastic changes.	C6: A system that provides individualized accurate, reliable quantitative motivational feedback on the achievement of specific tasks.	O6: Increased functioning and achievement of life goals. Measure: TELER, online data sources from insole.

Discussion

Principal Findings

This realist evaluation set out to explore the conditions under which this technology-based rehabilitation solution would most likely have an impact (outcome) on the motor behavior of people with stroke, what would work for whom, within a home context, and in what ways the system would have an impact. The pre-existing CMOs were based on theories of motor relearning, neuroplastic adaptation, and behavior change, specifically on the theories underpinning self-efficacy and the relationship between changes in self-efficacy and self-managed behaviors. The findings of the study confirmed the original CMOs and further highlighted two emerging propositions related to the context of use together with two new outcomes that were recorded in the qualitative transcripts.

The first proposition, which is perhaps to be expected, relates to the need for the system to be reliable and accurate in terms of providing quantitative feedback to the stroke users. The results suggest that this feedback should be about the attainment of goal-based activities with a specific emphasis on "knowledge of results." The second proposition to emerge was related to the self-management aspects of the system. The study revealed that the system should also encourage independent use and the setting of personalized goals or activities. The stroke survivors identified the importance of goals using the words "activities" and "goals" interchangeably.

The outcomes identified from the data were first related to the users' agency and their active role in self-management, where it emerged that "taking action" independently was an important outcome. The second related to "knowledge gain" where users became aware of the need to carry out rehabilitation in order to achieve their identified goal. This finding links well to the pre-existing CMO where the need for context-dependant and culturally meaningful rehabilitation had been identified as an outcome.

We suggest two implications that this study may have for both clinical practice and research. First the findings suggest any system that purports to support the self-management of stroke rehabilitation should give significant consideration to the need for motivational feedback that provides quantitative, reliable, accurate, context-specific, and culturally sensitive information about the achievement of personalized goal-based activities. A second implication is the role that complex interventions such

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as the PSMrS could have in changing knowledge and attitude to lead to behavior change. The PSMrS is a systems change intervention with complex effects in which contextual factors such as a network of relationships, as illustrated in this study, play a significant role in how the intervention is used and how sets of interdependent factors affect an individual's decision to use the system [36].

Conclusions

The research consortium will take this confirmation of theory and development of new propositions and recommendations into the development of the next iteration of the system prior to the implementation of robust population-based evaluation of a defined technology. This will test the effectiveness of the system in the promotion of self-managed rehabilitation and recovery.

In its current form, the system and in particular all of its software components are available to be deployed on a personal computer and smartphone. Current trends within computing indicate that the adoption of mobile computing continues to grow and dominate the market place. Therefore, plans for future work would focus on porting the current system to mobile-only platforms such as tablets and mobile phones. There are a number of advantages to doing this. Usability can be improved as mobile devices offer more flexibility and can operate in a wide range of environments and scenarios. Furthermore, practical considerations relating to the management and operation of any future randomized controlled trial would be more easily controlled.

Conflicts of Interest

None declared.

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Abbreviations

CMO: contexts, mechanisms, and outcomes
CMOC: mechanism, context, and outcome configurations
FES: functional electrical stimulation
ICT: information communication technology
KR: knowledge of results
PSMrS: Personalized Self-Management Rehabilitation System
RE: realist evaluation

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SUS: System Usability Scale

TELER: system for making and presenting clinical notes on a patient so that they can be used to establish the effectiveness of the treatment or care

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<u>Original Paper</u>

Novel Use of a Smartphone to Measure Standing Balance

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Abstract

Background: Balance assessment and training is utilized by clinicians and their patients to measure and improve balance. There is, however, little consistency in terms of how clinicians, researchers, and patients measure standing balance. Utilizing the inherent sensors in every smartphone, a mobile application was developed to provide a method of objectively measuring standing balance.

Objective: We aimed to determine if a mobile phone application, which utilizes the phone's accelerometer, can quantify standing balance.

Methods: Three smartphones were positioned simultaneously above the participants' malleolus and patella and at the level of the umbilicus. Once secured, the myAnkle application was initiated to measure acceleration. Forty-eight participants completed 8 different balance exercises separately for the right and left legs. Accelerometer readings were obtained from each mobile phone and mean acceleration was calculated for each exercise at each ankle and knee and the torso.

Results: Mean acceleration vector magnitude was reciprocally transformed to address skewness in the data distribution. Repeated measures ANOVAs were completed using the transformed data. A significant 2-way interaction was revealed between exercise condition and the body position of the phone ($P<.001$). Post-hoc tests indicated higher acceleration vector magnitude for exercises of greater difficulty. ANOVAs at each body position were conducted to examine the effect of exercise. The results revealed the knee as the location most sensitive for the detection of differences in acceleration between exercises. The accelerometer ranking of exercise difficulty showed high agreement with expert clinical rater rankings (kappa statistic>0.9).

Conclusions: The myAnkle application revealed significantly greater acceleration magnitude for exercises of greater difficulty. Positioning of the mobile phone at the knee proved to be the most sensitive to changes in accelerometer values due to exercise difficulty. Application validity was shown through comparison with clinical raters. As such, the myAnkle app has utility as a measurement tool for standing balance.

Introduction

Balance is defined as the body's ability to remain steady with minimal sway and with the center of gravity over a base of support [1,2]. Balance is defined as the body's ability not to fall by integrating the activities of the vestibular, somatosensory, visual, and musculoskeletal systems [1,3]. Improving standing balance has become a critical component of rehabilitation and has gained much attention in sports medicine as both preventive of and restorative for lower limb injuries. Balance training is utilized for injury prevention, performance enhancement, and for rehabilitation from sport-related and physical-activity-related

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injuries [1,4,5]. There is, however, little consistency in terms of how clinicians, researchers, and patients measure standing balance [1,6,7].

One commonly used method of assessing standing balance in sports medicine is the Balance Error Scoring System (BESS). The BESS shows inter-rater reliability ranging from poor to good, depending on how the evaluators were trained to score the BESS [8,9], as well as poor validity to detect subtle balance differences [8]. To improve reliability and validity, force plates are used in research to measure standing balance [10,11]. Force plates do not rely on clinical scoring and they have high test-retest reliability [12,13]. However, force plates are generally expensive and inaccessible to most clinicians and patients [6,14].

As a cost-effective and more accessible alternative, accelerometers are used to measure standing balance in athletes and nonathletes [14-16]. An accelerometer can be worn on the body to quantify human movement [14] by measuring movement in the x, y, and z axes. Body-worn accelerometers have demonstrated concurrent validity and high test-retest reliability when compared to force plates [14-16]. Some researchers have suggested that due to their portability, low-cost, and their ability to quantify human movement in natural and clinical environments, accelerometers are superior to force plates for quantifying standing balance [14-17].

Given patients' poor accessibility to and understanding of current measures of balance, it is not entirely surprising that these measures are ignored by individuals undergoing treatment for impaired balance. Additionally, the literature points to poor patient compliance with rehabilitation exercises [18]. Perhaps increasing patients' understanding of what is being measured and their ability to track their own progress would address part of the compliance issue. As technology advances, devices such as accelerometers become more affordable and more widely available. In fact, every smartphone contains an accelerometer.

As such, the authors have designed a mobile phone app, myAnkle, that utilizes the built-in accelerometer to quantify standing balance.

The aims of the current study are to: (1) determine whether the app can distinguish between balance exercises of varying difficulty on a firm or foam surface; (2) compare various bodily locations for the mobile phone and their effects on measuring standing balance; and (3) assess the validity of the myAnkle app, as rated by expert clinical raters.

Methods

The study protocol was approved by the Office of Research Ethics at the University of Toronto. Participants were recruited using posters within an athletic facility and a sports medicine clinic at a university, by verbally soliciting interested participants from varsity teams and, subsequently, by snowball sampling.

Subjects

Fifty participants were recruited for the study. Two participants halted testing of their own accord due to fear of injury; ultimately, 48 participants completed the full testing protocol. Reported results reflect the 48 participants who completed the full protocol. All participants were between 18-30 years old (mean = 22 years; SD = 2.5 years). Twenty-one males and 27 females were tested with the myAnkle app on 8 different balance conditions separately for the right and left lower limbs (Table 1).

All participants were free of ankle, hip, knee, and lower-back injuries at the time of testing and had not sustained any injuries for at least 1 month prior to testing based on self-report. Demographic data for participants included in the analyses are summarized in Table 2. Informed consent was obtained from all participants prior to testing.

Table 1. Balance conditions (in the order they were tested).

Balance Condition	Eyes Open	Surface
Double leg stance, feet apart	Yes	Ground
Double leg stance, feet together	Yes	Ground
Tandem (1 foot in front of the other)	Yes	Ground
Single leg stance	Yes	Ground
Single leg stance	No	Ground
Double leg stance, feet apart	Yes	Foam Board
Single leg stance	Yes	Foam Board
Single leg stance	No	Foam Board

Table 2. Demographics.

Characteristic		
Age, y, mean (SD)		22 (2.5)
Height, cm, mean (SD)		175 (9.7)
Weight, kg, mean (SD)		72.57 (1.29)
Physical activity[a], d, mean (SD)		5.08 (1.2)
Physical activity[a], hr, mean (SD)		11.33 (5.5)
Gender	Male	21
	Female	27
Team	Varsity	33
	Nonvarsity	15
Handedness	Right	43
	Left	4
	Both	1
Kicking foot	Right	45
	Left	3

[a]Self-reported average days or hours of physical activity over the past year over 7 days.

Exercises

Eight balance exercises were selected representing a gradation of exercise difficulty including firm or foam surfaces and with the participants' eyes open or closed (Table 1). Exercise selection was based upon a review of the literature and a pilot study we performed with 8 subjects.

Clinical Assessment of Exercise Difficulty

To obtain clinical rankings of the 8 balance exercises, 8 clinicians (3 physical therapists and 5 athletic therapists) were asked to rank the exercises from easiest to hardest. The clinicians were blinded to the results of the study and had an average of 12 years of clinical experience working in a sports medicine environment. Each clinician was provided with 1 full-page picture of each balance condition as well as the foam surface used in the testing and asked to rank the exercises using their clinical experience.

Testing Protocol

All testing was completed by the primary author. Three identical mobile phones were strapped to the participant's body using a commercially available, Velcro arm band for mobile phones (Figure 1). Additional Velcro was sewn onto the armband to extend the circumference such that it would accommodate the mobile phone being strapped above the knee and around the umbilicus.

No participant had prior knowledge of the testing protocol and each was given verbal instructions prior to each balance exercise. For all of the "eyes open" conditions, the participant was instructed to fixate on a black "X" located on a wall 437 cm from the participant. Participants were counterbalanced for the starting leg of testing. The rest periods between balance exercises and between right and left legs were 30 seconds and 3 minutes, respectively.

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Figure 1. This picture shows the position of the mobile phones, participant testing position (hands on the hips), and the foam board used for balance testing. Three identical mobile phones were utilized. The first phone was positioned so that its lower edge was above the talocrural joint line, the second so its lower edge was above the superior midline of the patella, and the last so its center was at the level of the subjectÃ¢â‚¬â„¢s umbilicus. All subjects wore shorts and a t-shirt with no shoes or socks, as depicted.

Accelerometer

The LG Optimus One (P500h), which utilizes Google's mobile platform Android 2.2 (also known as Froyo), was utilized for all testing. The mobile phone weighed 129 grams and its dimensions were 113.5 mm long, by 59 mm wide, by 13.3 mm deep. The mobile phone accelerometer was triaxial, measuring acceleration in the x, y, and z axes. The accelerometer sampled at a rate of 14-15 Hz, the result of hardware limitations. Consequently, between 420-450 raw measurements were collected for each exercise on each of the 3 axes.

Calibrating the Accelerometer

Each of the 3 mobile phones was calibrated once at the start of the study. The purpose of the calibration was to adjust for any static bias of the accelerometer. Static bias is the inaccuracy in the accelerometer readings when the phone is immobile. The accelerometer measures in both the positive and negative directions for all 3 axes (ie, x+, x−, y+, y−, z+, z−). The static bias affects each of the 6 directions independently to varying degrees. Each phone was calibrated using the following procedure:

1. The mobile phone was placed on a stable, level surface so that 1 of the axes was vertical.
2. Accelerometer measurements were recorded for 30 seconds.
3. Steps 1 and 2 were repeated for all 6 directions (ie, for each side of the mobile phone).

A correction factor (C) for each direction for each phone was obtained by dividing the acceleration due to the force of gravity (9.81 m/s^2) by the mean of all the samples in a given axis plane, both positively and negatively. For example, if the mean of all samples in the x+ direction was 9.95, then Cx+ = 9.81 / 9.95 = 0.986. A total of 6 correction factors were derived for each phone. The specific correction factors for a given phone were applied to each of the 420-450 raw measurements collected by that phone for each exercise performed.

Mean R Calculation

Each accelerometer measurement comprises 3 values, 1 for each axis (ie, x, y, and z). The values were first corrected for static bias using the correction factor as described above. For example, if the raw x-axis value (x_raw) of a measurement was positive, the corrected value (x_corr) would be x_corr = x_raw × Cx+. Likewise, if the value was negative, then x_corr = x_raw × Cx−. Once the corrected value was applied, the magnitude of the resultant vector (R) was calculated for each of the 420-450 measurements as sqrt(x_corr^2+ y_corr^2+ z_corr^2). The metric mean R is the average magnitude of the 420-450 resultant vectors. The mean R variable was then used as an index of balance for all subsequent analyses. A Perl script was used to calibrate, correct, and calculate all mean R values.

Statistical Analyses

In order to assess the consistency of clinicians' ratings of exercise difficulty, pairwise weighted kappa statistics were calculated for each combination of rater pairs. Further, pairwise kappa statistics were calculated between each clinical rater and the accelerometer device, providing a measure of device validity.

The calculated mean R variable described above was used in all subsequent statistical analyses. The observed values were initially assessed with respect to their distribution. In the event of a non-Gaussian distribution, various data transformations were utilized and characterized. Repeated measures analysis of variance (ANOVA) was then conducted with 3 within-subject variables (eg, exercise condition, leg tested, body position of phone) and 1 co-variate (eg, participant's sex). Post-hoc comparisons with Bonferroni correction for multiple comparisons were then conducted to tease apart any interactions.

Results

Distribution of Mean R Data

Data were collected and classified according to exercise condition, leg tested, and body position of phone. With 8 exercise conditions, 2 legs tested, and 3 body positions for the phones, this resulted in a total of 48 individual cells of data. Examination of the calibrated and corrected mean R data revealed a non-Gaussian distribution for the majority of the 48 cells. A reciprocal transformation (1/mean R) was then implemented for all observations. The reciprocal mean R values represent the time required in seconds to reach a given velocity.

The reciprocal transformation rendered the distribution for most of the cells reasonably bell-shaped but 2 cells continued to exhibit bimodal distributions. The 2 cells with bimodal distributions were examined in further detail. The data were separated into 2 groups via a median split. The data were then examined for group differences with regards to the demographic (eg, sex, handedness, foot dominance), anthropometric (eg, foot length), and clinical measures (eg, number of injuries, physical activity) collected. Chi-square analyses for both cells revealed a significant effect of participant sex ($\lambda^2(1,48) = 6.857$ ($P<.01$); $\lambda^2(1,48) = 30.561$ ($P<.001$)). With participant sex used as a covariate in subsequent ANOVAs, residual distributions appeared bell-shaped.

Independent Clinical Assessment of Exercise Difficulty

Using an 8-point scale where 1 is least difficult and 8 is most difficult, 8 independent therapists individually ranked the 8 balance conditions based upon their clinical experience of each condition's difficulty (Table 3). Pairwise weighted kappa statistics were calculated for all combinations of the therapists for a total of 28 values ranging from 0.88 to 0.98, indicating high accordance between raters.

The myAnkle app rankings of exercise difficulty were identical for each body location (ie, ankle, knee, torso). Pairwise kappa statistics assessing concordance between the device ranking of exercise difficulty and expert rankings revealed values ranging from 0.9 to 1.0. With all kappa values above 0.8, this was interpreted as good agreement between the device and clinical experts [19].

Table 3. Therapist and myAnkle difficulty ranking of the 8 balance conditions.

Assessor	Difficulty Ranking							
	1	2	3	4	5	6	7	8
Therapist A	DL[a]	FT[b]	TAN[c]	SLS[d]	FDL[e]	SLSE[f]	FSLS[g]	FSLSE[h]
Therapist B	DL	FT	SLS	FDL	TAN	FSLS	SLSE	FSLSE
Therapist C	DL	FT	TAN	SLS	FDL	FSLS	SLSE	FSLSE
Therapist D	DL	FT	FDL	TAN	SLS	FSLS	SLSE	FSLSE
Therapist E	DL	FT	TAN	FDL	SLS	FSLS	SLSE	FSLSE
Therapist F	DL	FT	FDL	SLS	TAN	SLSE	FSLS	FSLSE
Therapist G	DL	FT	TAN	FDL	SLS	SLSE	FSLS	FSLSE
Therapist H	DL	FT	FDL	TAN	SLS	SLSE	FSLS	FSLSE
myAnkle (R[i])	DL (8.0)	FT (6.9)	FDL (6.0)	TAN (4.6)	SLS (2.5)	SLSE (1.2)	FSLS (0.9)	FSLSE (0.5)

[a]DL: double leg stance on ground, feet apart

[b]FT: double leg stance on ground, feet together

[c]TAN: tandem (1 foot in front of the other)

[d]SLS: single leg stance on ground

[e]FDL: double leg stance on foam, feet apart

[f]SLSE: single leg stance on ground, eyes closed

[g]FSLS: single leg stance on foam

[h]FSLSE: single leg stance on foam, eyes closed

[i]Mean reciprocal R values for the myAnkle app at the knee location.

Effects of Exercise Condition, Leg Tested, and Body Position of the Mobile Phone

A repeated measures ANOVA was conducted on reciprocal acceleration values with 3 within-subject variables (eg, exercise condition, leg tested, body position of phone) and 1 co-variate (eg, participant's sex). A significant 3-way interaction was revealed between exercise condition, leg tested, and body position of the phone $(F(14,644) = 19.490, P<.001)$.

As noted in the introduction, our primary questions of interest included: (1) whether myAnkle is capable of differentiating balance performance on exercises of varying difficulty and (2) at which body location should the mobile device be positioned for maximal detection. In light of our research foci and the identified 3-way interaction, we first explored the issue of laterality by examining the laterality-exercise interaction at each body location. A significant interaction was found for the ankle $(F(7322) = 13.021, P<.001)$ and knee locations only $(F(7322) = 16.098, P<.001)$. The effect of exercise at each leg-body position combination (ie, right leg-torso, left leg-torso, right leg-knee, left leg-knee, right leg-ankle, left leg-ankle) from separate, univariate ANOVAs with 1 within-subject variable (eg, exercise condition) and participant's sex as a covariate reflects this finding also. Table 4 presents exercise and residual sums of squares for each ANOVA.

The exercise sum of squares values provide an estimate of variation due to different types of exercise while residual sum of squares values provide an estimate of unexplained variation. Residual variability for the ankle location was higher than that of either the knee or torso, indicating the ankle to be a less ideal location for the smartphone.

In the case of the more difficult exercises (ie, single leg stance on ground, eyes closed; single leg stance on foam; single leg stance on foam, eyes closed), higher raw acceleration values were observed. As a consequence of the reciprocal transformation (1/mean R), any potential differences in detection sensitivity between the different body locations for these more difficult exercises would be obscured.

Thus, separate, univariate ANOVA were completed including only these 3 exercises with 1 within-subject variable (eg, exercise condition) and participant's sex as a covariate for each leg-body position combination (ie, right leg-torso, left leg-torso, right leg-knee, left leg-knee, right leg-ankle, left leg-ankle). Reciprocally transformed data were used due to a non-Gaussian distribution of the raw data for these 3 exercises. The general finding was that the exercise sums of squares values for the ankle and knee locations were comparable; however, the residual sums of squares values for the ankle location were slightly lower than those of the knee but at the cost of possibly increased asymmetry between the left and right ankle and the practical cost of necessitating a move of the mobile phone during testing. Refer to Table 5 for detailed results.

The repeated measures ANOVA also revealed a significant 2-way interaction of exercise condition by body position $(F(14,644) = 14.151, P<.001)$. In post-hoc analyses of this interaction, we see a significant effect of exercise at all 3 body position locations $(P<.001)$; the largest effect of exercise was at the knee. Based upon these findings, we contend that the knee appears to be the best location at which to position the mobile phone to detect differences in balance performance across exercises. Refer to Figure 2 for the mean values.

In summary, we find that the mobile app can distinguish between exercises of varying difficulty and that the knee location overall maximally detects balance differences.

Table 4. Sums of squares for univariate ANOVA models—exercise condition and residual—at each body location ($P<.001$ for all locations).

Leg-Body Position	Sum of Squares Exercise	Sum of Squares Residual
Right leg-torso	754.168	237.958
Left leg-torso	785.728	259.915
Right leg-knee	1062.591	159.272
Left leg-knee	1183.151	178.214
Right leg-ankle	767.891	337.189
Left leg-ankle	621.819	265.445

Table 5. Sums of squares for univariate ANOVA models—exercise condition (eg, single leg stance on ground, eyes closed; single leg stance on foam; single leg stance on foam, eyes closed) and residual—at each body location ($P<.001$ for all locations).

Leg-Body Position	Sum of Squares Exercise	Sum of Squares Residual
Right leg-torso	7.527	19.605
Left leg-torso	9.676	18.576
Right leg-knee	3.510	6.572
Left leg-knee	3.122	7.047
Right leg-ankle	5.337	4.795
Left leg-ankle	2.949	3.505

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Figure 2. Mean reciprocal R values. A significant 2-way interaction between exercise condition and body position (P<.001) was identified. Mean reciprocal R values and standard error of the mean values are reported for each exercise condition for each body position.
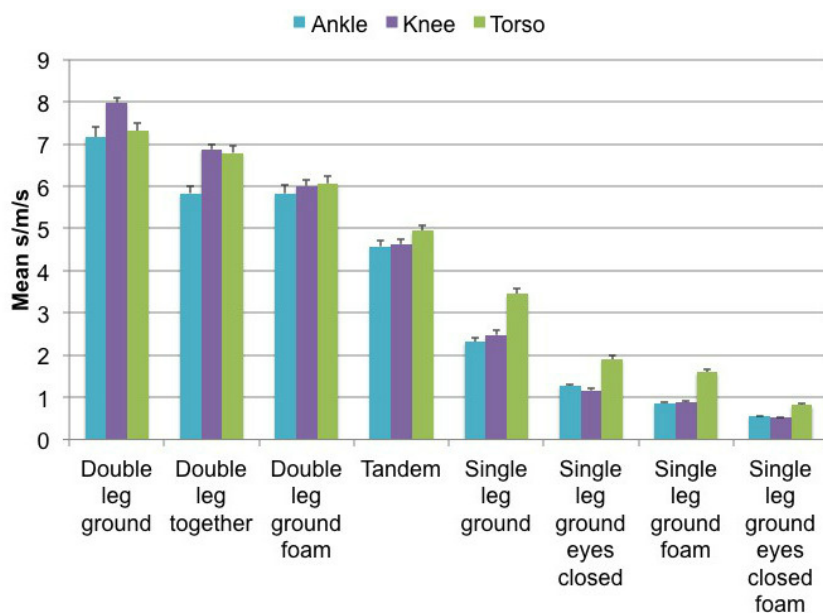
Discussion

Principle Results

There are 2 unique contributions that this study makes in the area of balance research. Firstly, we have demonstrated that a readily available form of software, namely a mobile phone app, can be utilized to quantify standing balance and can differentiate between exercises of varying difficulty. Our study concurs with other balance research that indicates poor balance on a foam surface as compared to a firm surface and with the eyes closed compared to eyes open [6,7,9].

Second, we have shown that the optimal location for measuring standing balance using a low-cost accelerometer is at the knee, as opposed to the trunk, as suggested by previous researchers [14-17]. The majority of researchers who have utilized accelerometers have placed them at the approximate center of mass of the individual over the L3-4 lumbar spinous process [14-17]. This would measure trunk acceleration while performing balance exercises. Unfortunately, unless the individual's balance is challenged significantly or the accelerometer has a high sampling rate, there can be little to no trunk movement detected by an accelerometer. Since our population was relatively young, healthy, and athletic and our accelerometer had a low sampling rate of 14-15Hz, we assumed that measuring at the trunk would not produce robust results for the easier balance conditions. Thus, we decided to measure at the trunk to stay consistent with previous research, at the knee as a midpoint between the ankle and the trunk, and the ankle since we assumed that the accelerometer would obtain the most robust measures due to the degree of perturbations around the ankle. Previous researchers have utilized accelerometers that sample at between 40-2000 times per second (40-2000Hz) [16,20,21]. Due to our low-cost accelerometer and low sampling rate, we wanted to determine the optimal placement of the

mobile phone to obtain meaningful measurements of the subjects' balance. It is interesting to note that most mobile phones released after 2013 have sampling rates of at least 150-200 times per second [22]. This seems to suggest that as mobile phone technology advances and the embedded accelerometers improve, myAnkle may be able to provide more robust measures of standing balance. Of note, for more difficult exercises, the ankle location may provide greater detection sensitivity but this would be at the cost of potentially greater asymmetry between the left and right legs. A recent study evaluating a mobile application for home monitoring of Parkinson's disease also utilized a mobile device strapped to the patient's ankle to conduct a walking and turning test [23]. In terms of ease of application and feasibility for patients, the ankle may be the preferred location for self-monitoring of balance and gait.

The degree of difficulty of all 8 balance conditions, as determined by independent clinician rankings, showed high agreement with the ranking results of myAnkle. This is suggestive of strong validity for the application when compared with clinical judgement.

Comparison with Prior Work

Accelerometers are utilized in research and clinical settings to measure standing balance and gait patterns; compare injured versus uninjured subjects and older fallers versus nonfallers; test balance abilities of patient's with Parkinson's disease; and classify human movement and sport performance [14-17,20,21,23,24]. Previous research has established that balance measurements performed using research-grade accelerometers show concurrent validity when compared to both force plates, clinical balance tests, clinician raters and they also demonstrate test-retest reliability[14-17,20,24]. Based on previous studies, it is clear that the use of an accelerometer to measure balance is not a novel concept. What is novel about

this study is the use of a mobile phone app to quantify standing balance. Five previous studies have utilized a mobile phone to quantify human movement in the context of rehabilitation. The first utilized a mobile phone to classify different sporting activities, the second to assist with Gaze Stabilization Exercises, and the third to test the validity of its measurements to the Timed Up and Go test [25-27]. The 2 most recent publications also utilize a mobile device's inertial sensors to perform home monitoring of frail elderly and to measure aspects of gait and turning in subjects with Parkinson's disease [23,28].

Mobile phones and apps are becoming ubiquitous throughout the world. In fact, it is estimated that in 2012, of those who own a mobile device over 40% of European adults and 50% of US adults owned a smartphone [29]. On a global scale, it is projected that smartphone users will reach 2 billion by 2016 [30,31]. This widespread use of mobile phones and smartphones has led to the emergence of mobile health or mHealth.

The field of mHealth has emerged as a way for patients to monitor their own health and for health care providers to monitor and provide remote assessment and treatment for their patients—especially for those in resource-constrained areas [31]. The potential benefits of mHealth include being remote, patient-centered, and cost effective, as well as the ability to improve research and health outcomes, reduce health care visits, allow patients to self-manage chronic disease, and empower patients with information and to measure body functions that previously required specialized equipment and/or a health care provider [32,33]. The pace of mHealth development and uptake is moving very fast; however, one of the main critiques of mHealth is that growth has far outpaced the outcomes and research that validates its use as a health care tool [31,32]. An mHealth app review in October 2013 stated that there are currently 43,000 health care apps available for download from the US Apple iTunes app store, but the majority only provide information and have very simple and limited functionality [34]. Researchers are recommending increased input from health care providers and patients for mHealth initiatives, as well as more rigorous evidence-based research in the field of mHealth to demonstrate its efficacy as a health care tool [31-33].

With the emergence and popularity of mHealth, the current paper suggests a method of measuring standing balance that takes advantage of the capabilities of a mobile phone while addressing some of the recommendations and limitations of mHealth identified in the literature. The myAnkle app can bridge the gap between how balance is measured by the clinician, the researcher, and the patient. It can empower patients to understand and measure their standing balance and, in the future, improve compliance with their rehabilitation for balance deficits. The myAnkle app can also provide the clinician with a method of assessing and tracking standing balance that is easy to perform in the clinical setting without expensive equipment or additional training.

A key aim of this app is to make balance measurement as widely accessible and usable as possible. The mobile phones utilized were purchased for $160 CAD each, and the armband can be obtained online from $5 to $30 each. One of the initial barriers to the widespread use of this app was the requirement of offline post-processing of the data. However, the latest version of myAnkle, which can be downloaded for free from the Google Play Store, performs all data processing in real-time without the need for post-processing.

Study Limitations

The main limitation of this study is that myAnkle's balance measurement was not compared to a gold standard such as a force plate or a research grade accelerometer that was tested for validity and reliability. The measure was also not compared to a visual scale, which could enhance its clinical applicability. The next phase of research and testing of myAnkle will involve testing the app concurrently with a force plate and a visual scale to determine concurrent validity and reliability. We also plan to test the app on multiple mobile phones to determine if the app is reliable when used concurrently on different devices.

Conclusions

The myAnkle app measured significantly greater mean acceleration values for balance conditions of greater difficulty. The myAnkle app also showed foam surface and eyes closed balance exercises to be more challenging compared to the same exercises on the ground or with eyes open, with the knee location as the optimal site for measuring standing balance. The myAnkle app demonstrated strong validity as compared with expert clinical ratings. These results indicate that myAnkle may have wider utility as a measurement tool for standing balance in clinical, research, and home settings.

Conflicts of Interest

The primary author may have financial gain if myAnkle is commercialized in the future, although there are no immediate plans to do so. MyAnkle is a free mobile app intended for clinicians, researchers, and the general public to measure and track their standing balance. The authors have no other competing interests to declare. The authors received no sources of funding for this study.

Multimedia Appendix 1

Screenshot of the main screen.

[PNG File, 78KB - rehab_v3i1e4_app1.png]

Multimedia Appendix 2

Screenshot of the exercise selection screen.

[PNG File, 395KB - rehab_v3i1e4_app2.png]

Multimedia Appendix 3

Screenshot of the exercise instruction screen.

[PNG File, 471KB - rehab_v3i1e4_app3.png]

Multimedia Appendix 4

Screenshot of the exercise results screen.

[PNG File, 98KB - rehab_v3i1e4_app4.png]

Multimedia Appendix 5

Screenshot of the progress screen.

[PNG File, 107KB - rehab_v3i1e4_app5.png]

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Abbreviations

ANOVA: analysis of variance
BESS: Balance Error Scoring System
C: correction factor

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DL: double leg on ground, feet apart
FDL: double leg on foam, feet apart
FSLS: single leg stance on foam
FSLSE: single leg stance on foam, eyes closed
FT: double leg on ground, feet together
R: resultant vector
SLS: single leg stance on ground
SLSE: single leg stance on ground, eyes closed
TAN: tandem (1 foot in front of the other)

Original Paper

Communications Technology and Motor Neuron Disease: An Australian Survey of People With Motor Neuron Disease

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Abstract

Background: People with Motor Neuron Disease (MND), of which amyotrophic lateral sclerosis (ALS) is the most common form in adults, typically experience difficulties with communication and disabilities associated with movement. Assistive technology is essential to facilitate everyday activities, promote social support and enhance quality of life.

Objective: This study aimed to explore the types of mainstream and commonly available communication technology used by people with MND including software and hardware, to identify the levels of confidence and skill that people with MND reported in using technology, to determine perceived barriers to the use of technology for communication, and to investigate the willingness of people with MND to adopt alternative modes of communication.

Methods: An on-line survey was distributed to members of the New South Wales Motor Neuron Disease Association (MND NSW). Descriptive techniques were used to summarize frequencies of responses and cross tabulate data. Free-text responses to survey items and verbal comments from participants who chose to undertake the survey by telephone were analyzed using thematic analysis.

Results: Responses from 79 MND NSW members indicated that 15-21% had difficulty with speaking, writing and/or using a keyboard. Commonly used devices were desktop computers, laptops, tablets and mobile phones. Most participants (84%) were connected to the Internet and used it for email (91%), to find out more about MND (59%), to follow the news (50%) or for on-line shopping (46%). A third of respondents used Skype or its equivalent, but few used this to interact with health professionals.

Conclusions: People with MND need greater awareness of technology options to access the most appropriate solutions. The timing for people with MND to make decisions about technology is critical. Health professionals need skills and knowledge about the application of technology to be able to work with people with MND to select the best communication technology options as early as possible after diagnosis. If people with MND are willing to trial telehealth technology, there is potential for tele-consultations via Skype or its equivalent, with health professionals. People with MND can benefit from health professional involvement to match technology to their functional limitations and personal preferences. However, health professionals need a comprehensive understanding of the application of available technology to achieve this.

Introduction

The loss of the ability to communicate by speech, facial expression or hand gestures is one of the most devastating aspects of motor neuron disease (MND) [1]. Communication difficulties affect the majority of people with MND at some stage of the disease, and as such, assistive technology is essential for enabling them to continue with their everyday activities [2]. Likewise, telehealth and online communications are often important lifelines when leaving home or travel becomes too risky or difficult.

This article reports on an exploratory survey of people with MND about their use of communication technology, including generic and assistive technology. Assistive technology is defined broadly as any piece of equipment that is used to increase, maintain or improve function for people with disabilities [3], and will include communications technology. In the context of rapidly changing technology, public debate about telehealth, and projects such as the rollout of the National Broadband Network (NBN) in Australia, this project aimed to identify the current use of technology by people with MND, their attitudes towards technology use and how technology supports their communication needs.

Literature Review

Motor Neuron Disease and the Needs of People With Disabilities When Identifying Technology Solutions

Motor neuron diseases (MNDs) are a group of progressive neurological disorders that destroy motor neurons, the cells that control essential voluntary muscle activity such as speaking, walking, breathing, and swallowing. In adults, the most common MND is amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease. It is a degenerative condition characterized by damage to the motor neurons in the brain cortex, brainstem & spinal cord, and can involve both upper & lower motor neurons. Commons symptom include muscle wasting of the hand and feet muscles leading to foot drop, weakness and atrophy of the lower and upper limbs, fasciculation or involuntary muscle twitching, bulbar signs in the muscles of the palate, pharynx, & larynx leading to swallowing and speech problems. Generally, intellect, memory, sight, hearing, touch and taste remain intact, unless an individual is affected by fronto-temporal dementia. ALS affects adults and usually more men than women with an average age of onset of 58 years, usually when people are at highly active stages of their lives. Life expectancy is typically short (around 20-48 months) after diagnosis, combined with rapid loss of function, making the implementation of technology solutions very urgent [4,5].

Being able to create an optimal match of the needs of a person with a disability with technology solutions as early as possible, and involvement of the consumer in decision-making about the selection of the assistive technology solution are both essential for a successful outcome [6]. Such processes may help prevent

the high levels of dissatisfaction with and non-use of technology solutions by people with disabilities [7]. This can be a very complex process, as the availability and development of potential technological solutions are constantly expanding, and reactions to physical and sensory changes associated with a disability have to be accommodated. Individual personalities, attitudes, past experiences, cultural values, environments, perceived capabilities and functional levels all have to be considered [8]. This is particularly true for technology to assist with communication, but people with MND are also likely to be faced with technology use in other areas of their lives, such as mobility, daily living tasks and home modifications. Therefore, the early use of technology has to be balanced by adjustments of people with a disability, as well as issues of grief, loss and identity.

Communication Needs and Solutions for People With MND

Due to the inconsistency of symptoms and the speed of deterioration in function, many people with MND are unprepared for the disabling loss of communication and the need to use assistive technology for communication [9]. The individual level of functional disability affecting communication and individual capabilities to use technology solutions are both likely to change throughout the progression of MND. This complicates potential intervention decisions and increases the learning demands for people with MND [10]. Augmentative and alternative communication (AAC) is defined as any mode of communication other than speech and includes low-tech as well as electronic communication devices [9]. Research on the attitudes and acceptance of the use of AAC and other technology in a range of communication settings is limited. However it is not uncommon for users to utilize more than one access strategy [11].

Literature indicating preferred communication hardware for people with MND is limited. Online forums for people with MND indicate a preference for lightweight, portable options, particularly the iPad or tablet computer. The most common difficulty of these devices is their inability to support adaptive equipment, so their useful life spans are short [12]. Current communication technology options include speech synthesis software for desktop, laptop and tablet computers, portable amplifiers, digital recorders, email and message boards [13]. Although there are several high-tech adaptive devices to use with computers such as SmartNav, eyegaze technology and the brain-computer interface [14], they all require extensive user training. The challenges with eye gaze interfaces are shared with other interfaces. For instance, the eye gaze technique is reported to be inaccurate in the selection of small objects, effortful and difficult to master, as well as being difficult to calibrate and expensive [15].

People with MND have reported that communication technology is essential to develop and maintain social closeness, and this is more important to them than the transfer of information to

express needs and wants [11,16,17]. As a result, low-tech solutions may be adopted over high-tech equipment in many instances.

One common platform that can be used for social contact or to access health interventions is Skype (a voice over Internet protocol, or VoIP platform, with video capability). However, a review of research concluded there was no firm evidence in support of or against the use of Skype for telehealth [18]. Regardless of the platform chosen, the use of telehealth is expected to double in the next decade [19]. The advantages of VoIP include lower costs of providing care within the client's own environment. The disadvantages include privacy, security and confidentiality risks [20,21], technological challenges and barriers to access such as cost, lack of access to Internet, low end-user technological literacy and confidence [22], and the preference of some clients for face to face consultations [23]. Telehealth has been used for assessment and rehabilitation in speech pathology, with clients reporting high satisfaction with the process [24]. Some consumers are also willing to adopt eHealth solutions despite some challenges in service dissemination [25].

Unfortunately, sometimes access to the appropriate information to engage with communication technology is particularly difficult for those who need it most [26]. Certainly the trend towards an "information society" brings the risk of a widening gap between those with access to technology and those without [26]. The Australian government NBN rollout is expected to extend the use of telehealth to aged, palliative and cancer care services as mainstream consultation options [27]. While the health system moves into the information age, it is assumed that consumers are keeping up with the pace.

Literature highlights the importance of early education and decision making about communication technology in recognition of the need and potential of various devices for people with MND [9,11]. Caregivers, family, doctors and allied health professionals are recognized as important contributors to this process, which should begin well before AAC is needed as a substantial communications support. Ultimately, consumer resistance may be the biggest challenge in achieving AAC solutions for people with MND. The use of a device for communication is perceived by some as "giving in" to the disease, and reflects a constant reminder of what the person has lost [9].

Therefore, this exploratory study aimed to investigate the types of technology (hardware and software) used by people with MND to communicate, their confidence and skill levels relating to technology, their perceived barriers to the use of technology for communication and their willingness to modify or update modes of communication, especially when interacting with support organizations and health professionals.

Methods

A cross-sectional self-administered online survey was developed as a time and cost-efficient method of gathering data from people with MND who may have motor and speech difficulties. The survey was distributed to the Motor Neuron Disease Association of New South Wales (MND NSW) members. MND NSW is a non-government organization that supports people with MND throughout NSW, and is the peak body representing the interests of people with MND in New South Wales. Ethical clearance was obtained for the study from the University of Sydney Human Research Ethics Committee.

Survey

The researchers completed a 26-module Web-based MND training course for professionals prior to developing the survey [28] to ensure they fully understood the key issues for people with MND. The 20-item technology survey encompassed three major themes: communication technology devices including AAC (eg, desktop and tablet computers), information sourcing (eg, Internet, social media) and communication methods (eg, email, VoIP). The objective was to collect detailed, specific data across a wide spectrum of topics without tiring the participants, so many questions had multiple tick box options. The draft survey was tested amongst the authors and piloted with informal contacts before being reviewed by MND NSW staff with expertise in the needs of people with MND. The final survey contained 18 closed-ended questions, each with space for free text comments, and 2 open-ended questions for free text responses at the conclusion of the survey. The survey can be seen in Multimedia Appendix 1. SurveyMonkey was chosen as the platform for the Web-based delivery of the survey system.

Study participants were given a choice of response methods depending on their preferences and capacity: (1) completing the survey online, independently, (2) completing and returning a mailed hard copy of the survey or (3) verbally responding to questions with a researcher by telephone. Questions were identical across all response methods.

Procedure

MND NSW members who had responded positively to a "consent to contact" question in the annual MND NSW Member Satisfaction Survey (N=447), were invited to participate in the study by distribution of a participant information statement and consent form by MND NSW staff. Consenting participants indicated if they were willing to be contacted by researchers, and identified their preferred method of contact on a consent form. MND NSW staff distributed hard copies of the survey and reply-paid envelopes to participants requiring them, and sent an email to participants requesting the link to the Web-based survey. MND NSW staff provided researchers with the contact details of participants requesting a telephone interview to complete the survey. The survey remained open for 2 weeks.

All MND NSW members who were living with MND were eligible to participate. Carers were also eligible if they spoke on behalf of the person with MND.

Data analysis

Survey data were downloaded in Excel, coded, and entered into SPSS. Descriptive statistics were used to summarize frequencies and cross tabulations. Free text data or participant responses from telephone interviews to the open ended questions were consensus coded and analyzed using thematic analysis [29].

Results

Of the 93 members of MND NSW who consented to be contacted, 57 requested the online survey link, 27 requested a phone survey/interview and 9 requested a postal survey. A total of 79 completed surveys were returned. Of these, 70% (55/79) responded on line, 27% (21/79) responded by telephone interview and 4% (3/79) by mail. See Table 1 for further details.

Table 1. Responses to the survey.

Survey delivery method	Members agreeing to be contacted	Surveys completed
Mailed	9	3
Accessed online	57	55
Telephone	27	21
Total	93	79

The MND NSW membership was 447 at the time of the survey and 79 responses represented 20% of the total membership. As the survey was anonymous, we were unable to determine the characteristics of those members who did not participate in the study.

Characteristics of Survey Respondents

Respondent age, gender and geographical distribution closely aligned to the overall MND NSW membership (see Table 2). However, there was an under-representation of those diagnosed within the previous 6 months (4.3% of respondents compared with 12.1% of the MND NSW membership) and an over-representation of those diagnosed for 3-5 years (21.7% of respondents compared with 14.5% of MND NSW membership).

Use of Communication Technology

Most respondents (66/79, 84%) indicated that they used some form of aid or equipment for speaking and/or typing and/or handwriting, and Table 2 indicates the range of equipment used across these 3 communication modes. Of those surveyed, 4 respondents were unable to communicate in any mode (speaking, writing or typing), without assistance. Table 3 shows that more respondents aged 50-69 had impairments across the communication modes. Fewer respondents aged 70 and over were using any aids or equipment for communication.

Technology and Devices Used

Most respondents (65/79, 82%) owned either a desktop or laptop computer, and 21% of the total group (16/79) owned both. There were no differences in usage between rural and urban respondents. The remaining 18% of respondents (14/79) did not have access to a computer in their home, and none indicated that they were borrowing either a desktop or laptop computer. Tablet computers were used by 33% (26/79) of respondents. Most tablet owners were female (17/26, 65%), and 5 respondents indicated they had a desktop computer but would prefer a laptop or iPad.

Webcams were the most popular assistive device, used by 10 respondents (see Table 2). Free text and verbal comments were provided by 57 respondents about devices used to augment speech. Of these, 9 respondents indicated they used speech Apps (such as SpeakIt, Verbally, Prolo2go and SayIt) and 2 used computer programs (NaturalSoft and E-triloquist). SpeakIt was the most frequent app identified by name by 5 respondents. These apps and programs were used on a range of devices. Laser head pointers and hands-free computer mice were used by 3 respondents, while 5 indicated they used boards or cards to assist with communication.

Internet use

The majority of respondents (66/79, 84%) had access to the Internet at home, with 94% (74/79) having a broadband connection; 8 respondents did not have Internet access. Of these, 4 were aged over 70, 2 were 60-69 and 2 were 50-59, with half of them reporting they did not have the physical ability to use a desktop computer. One person commented that they used the National Relay Service via the Internet and 1 respondent commented their iPad use had changed since obtaining a PocketWifi, stating, "Fantastic. Can use my iPad when away from home. Previously only used iPad for Speakit application."

Many respondents (n=54) indicated that they had used the Internet for email (49/54, 91%), to find out more about MND (32/54, 59%), news (27/54, 50%) and online shopping (25/54, 46%). Respondents reported an increase in time spent on the Internet since their MND diagnosis (23/54, 43%). Two respondents commented that the Internet was a way to fill in time as their physical ability became restricted by MND, making statements such as "It's a pretty big part of filling my week now. I'd be pulling my hair out with boredom without it" and "Inactivity has meant more time for using the Internet".

Table 2. Characteristics of survey respondents (N=79).

		Survey (N=79)		MND NSW Members (N=447)	
		n	%	n	%
Gender (n=79)					
	Male	41	52	257	57.5
	Female	38	48	190	42.5
Location (n=68) [a]					
	Metropolitan	37	55	256	57.3
	Regional	8	12	70	15.7
	Rural	20	29	93	20.8
	Interstate	3	5	28	6.2
Age (n=70) [a]					
	<40	2	3	17	3.8
	40-49	5	7	39	8.7
	50-59	18	26	77	17.3
	60-69	21	30	137	30.6
	≥70	24	34	177	39.6
Length of MND diagnosis					
	<6 months	3	4	55	12.2
	6-12 months	12	17	52	11.6
	1-3 years	23	33	152	34.2
	3-5 years	15	22	66	14.5
	>5 years	16	24	122	27.5
Needing help or equipment with communication tasks					
	Speaking (n=66)[a]	32	21		
	Handwriting (n=61)[a]	28	17		
	Typing/keyboard (n=58)[a]	27	16		
Technology being used (n=61) [a,b]					
	Desktop or fixed computer	32	52		
	Laptop or notebook computer	33	54		
	Tablet (eg, iPad)	26	43		
	Mobile phone	49	80		
	TTY phone	2	3		
	Light writer	6	10		
	Message mate	1	2		
Assistive technology being used (n=14) [a,b]					
	Webcam	10	71		
	Laser head pointer	3	21		
	Hands free computer mouse	3	21		
	Switch adaptation	2	14		
	Trackball computer mouse	1	7		
	Eye gaze	1	7		

		Survey (N=79)		MND NSW Members (N=447)	
		n	%	n	%
	Specialized mounting	1	7		
Sources of advice about technology (n=64) [a,b]					
	Family	44	69		
	Friends	29	45		
	Internet	27	42		
	MND Association	20	31		
	Speech therapist	18	28		
	Occupational therapist	9	14		
	GP	6	9		

[a]Some respondents did not answer all the survey items

[b]Respondents could select more than one response

Table 3. Age and selected survey responses (N=79).

		Under 40		40-49		50-59		60-69		70+	
		n	%	n	%	n	%	n	%	n	%
Needing help for communication [a]											
	Speaking (n=32)	1	3	3	9	10	31	13	41	5	16
	Handwriting (n=28)	2	7	1	4	10	36	13	46	2	7
	Typing/ keyboard (n=27)	2	8	2	8	8	30	9	33	6	22
Use of devices for communication [a]											
	Desktop computer (n=32)	1	3	3	9	10	31	9	28	9	28
	Laptop/Notebook (n=33)			2	6	14	42	10	30	7	21
	Tablet (eg, iPad) (n=26)			2	8	10	39	7	27	7	27
	Mobile phone (n=49)	1	2	4	8	14	29	15	31	15	31
	TTY phone (n=2)							1	50	1	50
	Light writer (n=6)					4	67	2	33		
	Message mate (n=1)							1	100		
Already using email to contact others [a]											
	Neurologist (n=16)	1	6			6	38	8	50	1	6
	GP (n=8)					3	38	3	38	2	25
	Other medical specialist (n=5)					2	40	2	40	1	20
	Other health professional (eg, OT, ST) (n=12)			1	8	6	50	4	33	1	8
	MND Association (n=20)			2	10	7	35	8	40	3	15
	Other people with MND (n=12)			1	8	6	50	2	17	3	25
	Friends and family (n=39)			4	10	11	28	14	36	10	26

[a]Some respondents did not answer this section of the survey.

Advice Sources and Support Requirements

Family members were the most common source of technology ideas and advice (44/64, 69%) especially children (see Table 2), as illustrated in quotes such as "I ask my kids. Our age group is pretty illiterate about this stuff, they're useless" and "I got the cleaning lady's 14 year old son to help me out with the iPhone".

Friends and the Internet were also popular sources of technology advice. MND NSW was selected by 31% (20/62) of respondents as a source of support.

Of allied health professionals, speech therapists were the most common sources of advice, followed by occupational therapists. One respondent commented that their occupational therapist was "really terrific with equipment but doesn't address technology. I could use more support in this area".

Comments from 5 respondents suggested a need for more general assistance with technology, but they were not clear who should provide this assistance, stating things such as "We are really in need of an in-depth consultation with someone who is really an expert in this area".

Respondents indicated that they did not have sufficient expertise to know good technology choices to improve their function, and expressed frustration that there wasn't a *"one-stop shop"* for ongoing assistance. One person had been unable to use the technology they had acquired; a caregiver stated that they "have been supplied with the Eyegaze but am yet to try it as we are unable to install it – we need someone to give him a demonstration". An avoidance of seeking support or information, largely due to difficulty adapting and accepting a diagnosis of MND was expressed by 4 respondents, through such statements as "I think the thing is it is very early in my diagnosis so I have my head in the sand. I sort of hope they have made a mistake", and "He's aware of them (apps) but doesn't want to adapt his lifestyle in any way, he doesn't want to acknowledge the MND. He's afraid if he does he'll sort of go downhill".

Confidence and Skill Level Relating to Technology

Overall, respondents were considerably more confident than not with all forms of technology identified in the survey (Figure 1).

However, levels of confidence were related to age. Respondents aged 30-49 were confident in all forms of technology, although this age group had a low survey participation rate (n=5). Those aged 50-70 plus (n=63) were reasonably confident using desktop computers (47/63, 75%), laptop computers (52/63, 82%), the Internet (51/63, 80%) and email (49/69, 78%). However, they were less confident in using tablet computers (39/63, 62%) text messages (41/63, 65%) and video phones (32/63, 51%). Overall, 27% of people (8/30) identified a lack of confidence with technical skills as a reason for not using technology, however the response rate was low for this question (30/79, 38%).

When asked about adaptive devices, 2 respondents owned SmartNav or a laser head pointer but were unable to use them. One respondent had an Android tablet and an iPad, and found the Android version more difficult to use.

Figure 1. Ratings of confidence in using technology devices for communication (N=64).
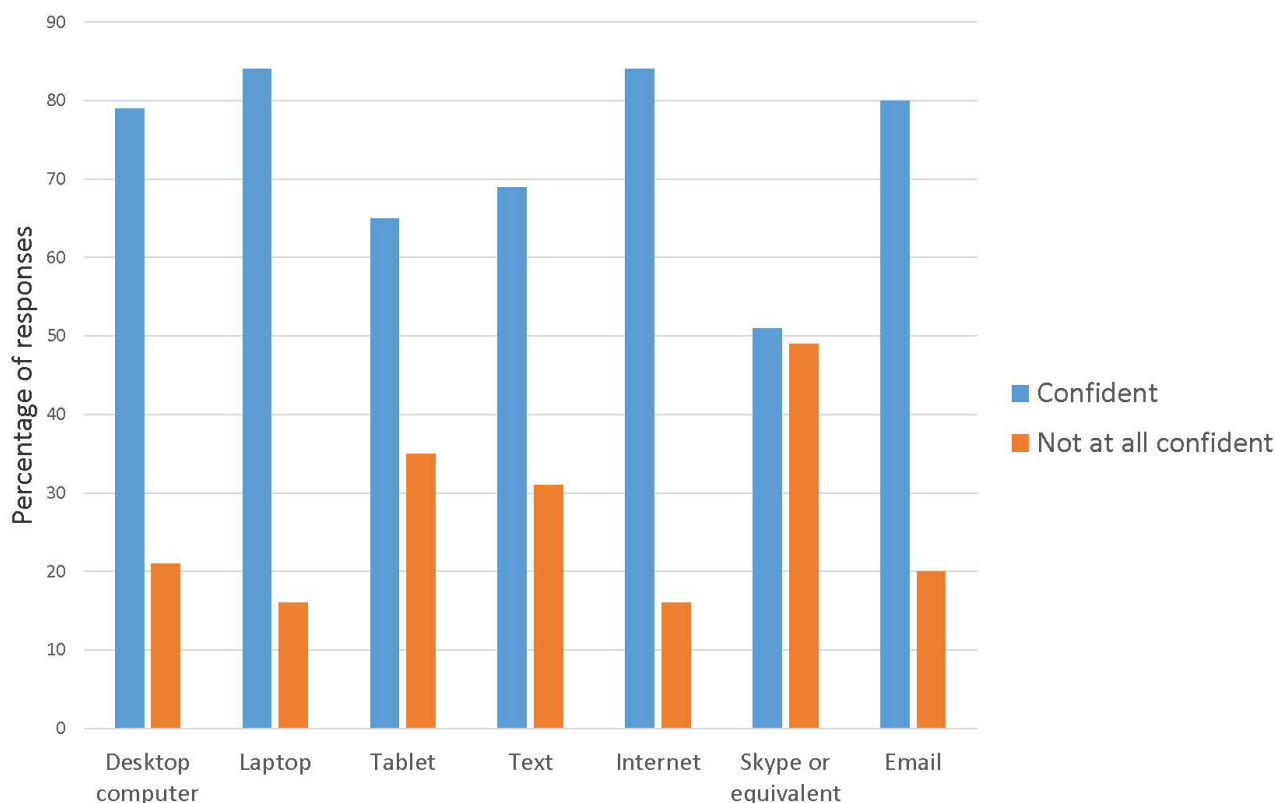
Barriers to Use of Communications Technology

Only 30 respondents (30/79, 38%) answered survey items about barriers to communication technology use. Of those who responded, the most common barrier identified was a lack of physical ability (12/30, 40%), and 4 of these indicated they had limitations of hand or speech function. Others (5 participants) offered comments related to their capacity to use technology, such as "When she was able she used a button to press for attention and a laser head pointer to type - that was fabulous. She was able to do emails and banking when she had head control which she no longer has" and "The email and Internet was a fantastic source and outlet for me when I could operate it independently. Since my hands ceased being able to move I have been isolated from this and have to rely on my family to do any searches, research or emails".

A high proportion of respondents (74/79, 93%) identified the need for support with technology, programs, hardware and/or adaptive equipment as a barrier to their use of technology. Cost was selected as a barrier by 7 respondents, regardless of the type of computer. One respondent identified the cost of apps as a prohibitive factor, stating "I do have them (apps) on my iPad, but rarely use them, the good ones are expensive to purchase, the ones I have are the free apps". Lack of interest was identified as a barrier by 3 respondents, for instance, "He's confident with the programs he knows but not interested in learning how to text or email". A lack of computer literacy was mentioned by 3 respondents.

Willingness to Adopt Use of Technology

Respondents were asked how willing they would be to use email and Internet video phone programs such as Skype to communicate with health professionals and others, if provided with the necessary equipment and skills. Overall, respondents were likely to consider using email (53/64, 83%) and video phone (53/64, 81%) with their friends and/or family, health professionals and MND NSW. Rates were lower for the potential of using these forms of communication with their GP, and 25% (16/64) indicated they would never email their GP, and 33% (21/64) would never use Skype to communicate with their GP.

When related to age, Table 3 indicates that email was already used by many respondents as a communication strategy. The lowest use of email was with GPs and medical specialists, and only 12 (12/64, 19%) of respondents used email to contact health professionals such as occupational therapists and speech therapists. However, most respondents indicated they were willing to consider the use of email to contact allied health professionals in the future.

The use of Skype (or equivalent) had different results (see Figure 2). Only a third of respondents already used Skype with friends and/or family (19/64, 30%) and fewer with their neurologist (3/64, 5%). However no respondents indicated they used this technology to contact other health professionals or MND NSW. This was in contrast to members' willingness to use Skype, which was much more positive overall (see Figure 2).

Comments were offered by 6 respondents who specified that they preferred face-to-face communication, and were reluctant to accept email or Skype as an alternative, making statements such as "I have never done that and don't think my computer is sophisticated enough to do that. I don't think they would want me to do that… If they wanted me to, I guess maybe, but it would have to be them asking me".

Data from the question relating to confidence were compared to that on willingness. While 12 respondents identified that they were not confident in using email, only 3 indicated that they would never email friends and family. This indicates that despite a lack of confidence, 9 people would be willing to email, suggesting a need for training to close this gap. Similar trends emerged for use of Skype or equivalent. While respondents indicated willingness to use this technology to communicate with a range of people (see Figure 2), only 50% (32/64) indicated they had a level of confidence in this technology (Figure 1). Just 10 respondents indicated that they would never be willing to use this to contact friends and/or family.

Tablet users (n=26) had higher email usage rates that users of other computers and while no-one in this group was using Skype or an equivalent technology with allied health professionals, 8% (2/26) were using it with their neurologist and 27% (7/26) were using it with friends and/or family.

Figure 2. Ratings of willingness to use and usage of Skype or equivalent telehealth technology (N=64).
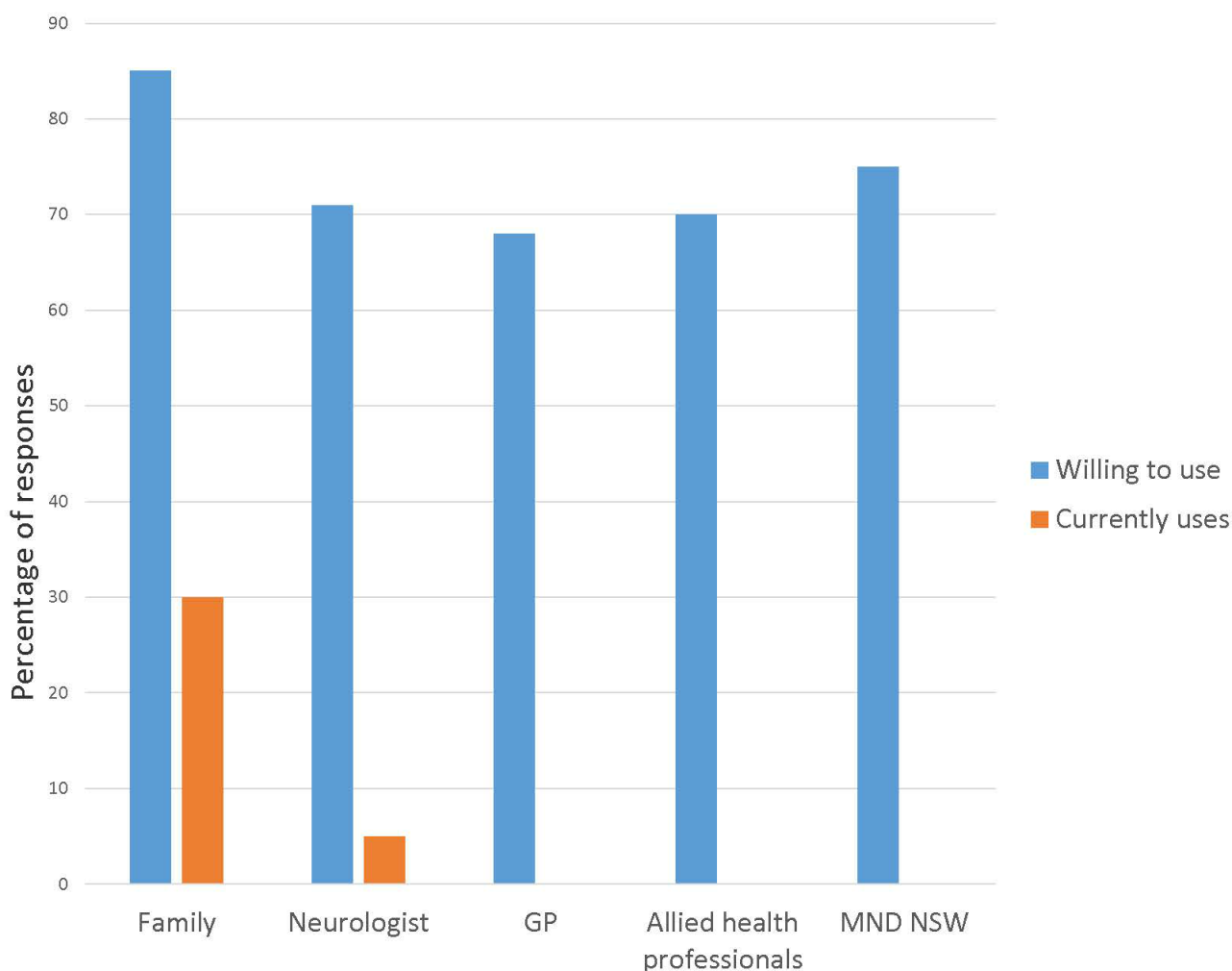
Preferences for Management of Communication Technology

Free text and verbal comments indicated that some respondents were unprepared for their speech loss when it occurred, and this was when the provision of equipment and training became urgent. Therefore, some expressed a preference for early technology interventions. For instance, one carer for a person with MND noted that "I'd be a great advocate for people to start learning technology immediately, because that's the only type of communication you're going to have. Communication is so hard with people with MND".

When asked for additional comments relating to communications technology considerably more respondents discussed their frustrations (n=10) than the benefits (n=5). A need for additional support was expressed by 4 respondents, while 2 felt totally overwhelmed and 2 said they chose not to change their behavior because of their disease. However, 5 respondents expressed their gratitude for technology, and 8 respondents stated how technology was an important tool for facilitating communication and reducing isolation, making such statements as "The biggest thing for me is that MND stops a person being independent, but with a computer (she) was able to communicate, interact and be very much a part of our life – so grateful that she had this

equipment", "Without email, typed notes and text messages I would be unable to communicate my thoughts, wishes, and I would be unable to take care of my own affairs", and "To be disabled without technology is unthinkable".

Discussion

The study met the objectives of exploring the use of communication technology by people with MND, their confidence relating to technology, their perceived barriers to the use of technology for communication and the willingness of people with MND to adopt modes of communication or participate in telehealth. Study results have highlighted a number of opportunities for service providers and support organizations to direct their efforts in promoting communications technology for this client group.

Awareness of Options for Communication Technology

Study participants identified physical limitations as a barrier to technology use, although they tended not to anticipate needing assistance in this area. This suggests a need for greater awareness of the benefits of technology early on following diagnosis, as well as knowledge of the types of adaptive devices available. This will enable people with MND to access appropriate technology in a timely manner. This is consistent

with other studies suggesting that health professionals need to prepare people with MND to recognize the need and potential of communication technology, and these discussions should begin as early as possible after diagnosis [9,10]. However, involving people with MND in the decision-making about technology use early on can be a complex issue for a population of people where skills can rapidly decline. Raising awareness and providing training so that technology can be taken up may be a solution, but the process has to fully account for the psychosocial adjustment of people with MND to inevitable feelings of loss and grief as their personal identity is under threat [6,7]. Carers and health professionals should collaborate in preparing people with MND for this technology [10], and carer involvement is critical, as evidenced by the data from this study.

Any awareness-raising activities should be ongoing as individual needs change, and should take into account unpredictable progression rates and different forms of MND [10], as well as any resistance to acquiring technology. It has been suggested that most people with MND reluctantly accept the need for medical equipment to manage MND, however communications technology is seen as "giving in" [11]. This sentiment was echoed by the survey respondents. Many people with MND and their families may develop their own successful, no-tech solutions for dealing with communication loss [17]. Despite difficulties with distance or mobility and potential solutions using communication technology, many individuals will always prefer face-to-face communication [23].

Use of Skype or Equivalents and Telehealth Technology

The willingness of respondents to use video Internet technology to communicate with family and/or friends suggests that this technology could also be used to ensure levels of social communication and support for people with MND, and to address any isolation associated with MND. Greater social use of this technology may or may not lead to greater acceptance of technology for communicating with professionals. However, such technology will support the primary objective of communication to develop and maintain social relationships [17].

The findings also highlighted the willingness of people with MND to trial telehealth technology options. High rates of broadband Internet connection suggest that Internet connectivity is not a barrier to telehealth. Some health professionals use tele-consultations via Skype with MND clients as a practical form of communication for this client group. Palliative care is another clinical area that is currently a priority for national telehealth trials and growing opportunities for remote consultations [27]. However, study findings support an initial face-to-face visit prior to implementing this technology.

Implementation of telehealth technology would require training for health professionals both around the use of the technology and the ethical issues surrounding remote consultations. A randomized controlled trial demonstrated that remote consultations were less acceptable to patients than face to face visits, and security issues remain a barrier to expansion of telehealth [20,21,23]. Despite access to the Internet and a willingness to try video Internet technologies, findings indicated that people with MND lack the confidence and/or skills to utilize these technologies, so further training and support is needed.

Communication strategies

Study participants already interacted with technology to some extent, as the majority of surveys were completed online, and participants indicated the use of many communication technologies. This suggests that the use of Web-based communication for people with MND should be developed further, and the Internet provides opportunities to deliver education and support. Streaming sessions such as webinars with MND experts could offset any inaccurate online information related to MND [30]. Online support groups could be a worthwhile strategy for people with MND and their carers who, due to personal preference and/or the effects of MND, are unable to attend a face-to-face support group. While such technology cannot fully replicate the support of face-to-face meetings, it may be a valuable tool to supplement meetings and ensure inclusion of remote or isolated people with MND.

Findings also demonstrated that people with MND need more information about communication technology provided by reputable sources, rather than searching online. As respondents indicated that they did a lot of online searching for information around the time of their diagnosis, access to accurate and helpful information at this stage is important.

The Role of Health Professionals

Study participants were less likely to access professional support for technology than asking their family and friends. However, the variety of devices and apps available suggests a need for some professional support in selecting the most suitable technology solution to fit individual circumstances. The challenge for health professionals is ensuring that awareness, referral and interventions are appropriately timed so that technology adoption is more likely [11]. Findings suggest that people with MND are using a range of communication options from very basic to high-tech solutions. Health professionals need to recommend communication strategies that require a minimal challenge in terms of new learning as the disease progresses [11]. Regular review and monitoring should be prioritized to ensure technology that is no longer useful is replaced with appropriate alternatives.

Occupational therapists and speech therapists are considered to be central to the process of assessing for and recommending technology solutions for people with MND (and others), in particular examining access to technology and capacity to operate it (movement, reach, endurance, hand function etc), seating, and visual and cognitive issues [5]. In order to fulfill such roles, therapists need to be knowledgeable about the variety of technology solutions available, both in mainstream technology as well as more specialized applications, and how they can be adapted for use by people with a variety of functional and progressive limitations [30]. However, there is evidence that knowledge and skills in technology applications are not well developed [31]. The World Health Organization reported that health professionals were not sufficiently skilled to manage the needs of people with chronic conditions such as MND, with one defined skills being the ability to implement

information and communication technology [32].While general skills in use of technology may have developed over the last 10 years, and new health professional graduates have skills in social networking and mobile phone use, this may not transfer to competence in implementing technological solutions for people with MND [33].

Provision of electronic assistive technology is regarded as a specialist area due to the sophistication of some technological solutions. Successful provision also requires the capacity to navigate complex local systems of funding [31]. Surveys of occupational therapists in Ireland and the UK indicate that while technology is viewed as an important component of their role, many are not confident about their competence to implement solutions, and identified training needs both at a preparation course level and at a continuing professional education level [31,34]. Little information is available on the competence and practice of Australian health professionals in providing technological interventions.

Limitations of the Study

This study used cross-sectional survey methods and therefore could only provide information on responses to structured questions at one point in time. Not all survey items were mandatory, which allowed a low response rate for some questions. Although free-text comments were encouraged throughout the survey, use of individual interviews may have provided more in-depth information. The response rate to the survey was low, and it is unclear if the 80% (358/447) of the potential respondent pool from the MND NSW membership who did not participate were systematically different to the study sample in their use of technology. It is also possible that as MND NSW membership is voluntary, this organization may not include all people with MND in NSW. Furthermore, as 70% (55/79) of respondents selected the Web-based survey, this may bias results to those who are already using technology. Therefore, the results are not generalizable to the whole population of people with MND.

Bearing in mind the nature of the sample group, a low participation rate could be expected, as some potential participants may not have been able to tolerate the effort required to respond to the survey. This also raises the possibility of some systematic differences in the depth of data drawn from telephone interviews or non-representative views from carers responding on behalf of people with MND. However, taking into the account the limitations of surveying this population and giving all consenting participants the opportunity to have their views included by whatever ethical means were appropriate for them, we can be confident that the findings do represent the views of the sample.

Conclusion and Recommendations

The survey findings indicated there were groups of respondents with different needs and preferences for communication technology. Some were early adopters of technology, with the skills, equipment and confidence to engage with technology. Others were willing but lacked either the confidence or skills to use technology, while some had access to equipment but were not willing to engage with the technology. For this sample, there appears to be a need for ongoing training and support in the use of technology to overcome a lack of confidence or skills in using the devices and software, and to maintain individuals as their disease progresses. To achieve this would require resourcing of technical support and expert advice. Ultimately, some people with MND will choose not to utilize communication technology, but there is an opportunity to target those who are willing to use technology but currently lack the necessary access to devices or skills to use them. All study participants would appear to benefit from the involvement of knowledgeable health professionals to create the right ongoing match between technology solutions, functional limitations and personal preferences.

The study results have identified recommendations for service providers to consider when addressing the needs of people with MND:

- Development of awareness-raising activities to allow opportunities for people with MND to adopt technology at an early stage.
- Training in technology devices for people with MND, particularly in the early stages of the disease, and targeted to those who are willing to use technology but currently lack skills or confidence.
- Provision of information on high-quality technology options to counter less helpful information derived from a free Internet search.
- A formal assessment by a qualified health professional is an important step in accessing effective solutions.
- Opportunities for health professionals to maintain and enhance their technology knowledge, so they can offer the best technology solutions matched to the needs of people with MND.

Future developments in technology are inevitable and will continue to challenge health professionals in working with people with MND with communication needs.

Conflicts of Interest

None declared.

Multimedia Appendix 1

MND Technology Survey.

[PDF File (Adobe PDF File), 179KB - rehab_v3i1e2_app1.pdf]

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Abbreviations

AAC: augmentative and alternative communication
ALS: Amyotrophic Lateral Sclerosis
MND: motor neuron disease
MND NSW: Motor Neuron Disease Association of New South Wales
NBN: National Broadband Network
VoIP: voice over Internet protocol

Review

Information and Communication Technologies in the Care of the Elderly: Systematic Review of Applications Aimed at Patients With Dementia and Caregivers

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Abstract

Background: The interest in applying information and communications technology (ICT) in older adult health care is frequently promoted by the increasing and unsustainable costs of health care services. In turn, the unprecedented growth of the elderly population around the globe has urged institutions, companies, industries, and governments to respond to older adults' medical needs.

Objective: The aim of this review is to systematically identify the opportunities that ICT offers to health services, specifically for patients with dementia and their families.

Methods: A systematic review of the literature about ICT applications that have been developed to assist patients with Alzheimer's disease (AD) and their primary caregivers was conducted. The bibliographic search included works published between January 2005 and July 2015 in the databases Springer Link, Scopus, and Google Scholar. Of the published papers, 902 were obtained in the initial search, of which 214 were potentially relevant. Included studies fulfilled the following inclusion criteria: (1) studies carried out between the years of 2005 and 2015, (2) studies were published in English or Spanish, (3) studies with titles containing the keywords, (4) studies with abstracts containing information on ICT applications and AD, and (5) studies published in indexed journals, proceedings, and book chapters.

Results: A total of 26 studies satisfied the inclusion criteria for the current review. Among them, 16 were aimed at the patient with AD and 10 at the primary caregivers and/or family members. The studies targeted applications that included assistive technology (44%, 7/16), telecare (37%, 6/16), and telemedicine (31%, 5/16). The information systems (56%, 9/16) and Internet (44%, 7/16) were the most commonly used enabling technologies for the studies. Finally, areas of attention more covered by the studies were care (56%, 9/16), treatment (56%, 9/16), and management (50%, 8/16). Furthermore, it was found that 20 studies (77%, 8/26) evaluated their ICT applications through carrying out tests with patients with dementia and caregivers.

Conclusions: The key finding of this systematic review revealed that the use of ICT tools can be strongly recommended to be used as a lifestyle in the elderly in order to improve the quality of life for the elderly and their primary caregivers. Since patients with AD are completely dependent in most activities, it is necessary to give attention to their primary caregivers to avoid stress

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and depression. In addition, the use of ICT in the daily life of caregivers can help them understand the disease process and manage situations in a way that is beneficial for both parties. It is expected that future developments concerning technological projects can support this group of people.

Introduction

New information and communication technologies (ICT), including Internet and mobile technology, have become essential tools in most sectors of modern societies, including the health care sector. While et al have defined ICT as instruments and procedures that allow the acquisition, production, treatment, communication, registry, and presentation of information in the form of voice, images, and data contained in acoustic, optical or electromagnetic signals [1]. In an increasingly aging society, it is necessary to establish new alternatives that attempt to satisfy the needs of the elderly and that, at the same time, improve their quality of life. In this context, the term electronic health (eHealth) is widely used by many people, institutions, professional organizations, and financial entities to refer to the adoption of ICT in the field of health care. Meier et al mention that eHealth is an emerging field that bridges health informatics, public health, and the private sector, and it refers to health services and the information that is delivered or improved through Internet and related technologies [2]. For their part, the World Health Organization (WHO) and the Pan American Health Organization (PAHO) define eHealth with regard to the support provided by the cost-effective and safe use of ICT in health and related areas, including health care services, vigilance, and documentation, as well as education, knowledge, and research on health issues [3,4]. It is also important to point out that eHealth offers a set of advantages, for instance (1) supports information exchange; (2) improves access to health care; (3) reduces costs; and (4) improves public and individual health through personalized medicine [3,5,6].

The attention provided by ICT applications in the field of medical care offers plenty of benefits for the elderly. Several studies indicate that the most widely used technologies in medical services are telemedicine and teleassistance [7,8], and recently, mobile assistance is gaining more popularity [9]. For example, the work of Cash et al discussed the use and application of assistive technology for people with dementia, taking into account ethical considerations. In this study, "assistive technologies for smart homes, telecare, and low-level technology" are recognized as accessible tools in the public market [10]. On the other hand, Lauriks et al proposed the use of ICT and Global Positioning System (GPS) technology to assist informal caregivers of people with dementia in their care giving role [11]. Likewise, Evans et al performed a systematic review to investigate how assistive technologies are being designed to help patients with dementia and their caregivers. They found that the use of assistive technologies focuses on the support of daily activities, safety monitoring, memory aids, and preventing social isolation, improving the ease of living, and

also that many elderly individuals prefer to stay at home when aging. Thus, there is an urge to remain an independent and functional person during the old age and assistive technologies could help to achieve this [12].

However, ICT applications used in health services present some limitations. One of them is that older adults are frequently resistant to the use of new technologies, in particular to the acquisition of new knowledge and skills necessary for the use of electronic devices and information systems. On the other hand, Alzheimer's disease (AD) is the main cause of dementia among older adults. Dubois et al indicate that AD is clinically expressed as a slowly progressive dementia that tends to have insidious onset and that generally starts with recent memory failure and ends with a completely dependent, bedridden patient [13]. Providing care to a patient with AD can bring high physical, emotional, and financial costs to the patient's family, the health care institution, and the government. Likewise, overload of the caregiver due to the demands of the patients with AD, even more if the caregiver is an older adult herself, can have negative repercussions on the caregiver's quality of life, mainly due to psychiatric problems like anxiety and depression [14].

From a technological perspective, both the patient and the caregiver are more willing to assume a proactive role in the use of ICT with the purpose of carrying out in-home diagnoses and treatment to improve quality of life. In this context, the caregivers require technological tools that enable them to provide better care as well as timely and efficient attention to the partially or totally dependent patient. These trends have contributed to the strong conviction that ICT can offer useful and efficient tools that improve elderly patients with AD quality of life and, at the same time, provide a support for their family and/or caregivers. Applications and services that are currently being developed seek to facilitate quality enhancement, equality, and access to social and medical care [11].

The purpose of this article is to integrate the knowledge we have about older adults with AD and the opportunities that ICT offers to health services, specifically for this group of patients and their families. For that purpose, this article is divided in six sections. The first section introduces the problem and provides some basic definitions that will be used throughout the study. In the second section, AD as well as its relationship with aging is defined. The third section focuses on caregivers, since these persons have a very close relationship with patients with AD. In the fourth section, the most relevant ICT applications for AD patients and their caregivers are analyzed and classified according to the typology of application, technology, and their domain of application. The innovation opportunities provided by ICT in the field of health care are presented in the fifth

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section. Finally, conclusions and further work are discussed in the last section.

Alzheimer's Disease and its Relationship With Aging

Due to the increasingly aging population, AD has become a problem of great medical and social repercussions. Dementia is a chronic and progressive syndrome characterized by the deterioration of cognitive and behavioral functions causing disability, dependency, and low self-esteem. AD is the most common type of dementia, representing between 60-80% of dementia cases [15]. AD is defined as a progressive neurodegenerative disease characterized by a series of clinical and pathological features of relative variability [16].

Considering the foreseen tendencies of global demographic aging, it is estimated that by 2050 there will be around 2 billion older adults (Figure 1). In 2010, there was an estimated 35.6 million people with dementia around the world and it is expected that this figure will duplicate every 20 years, reaching 65.7 million and 115.4 million in 2030 and 2050, respectively [17]. The increase of dementia will be more dramatic in low and middle income countries where more than two thirds of the number of cases will be diagnosed in 2050 [18]. In the following twenty years, it is expected that the number of people diagnosed with dementia will increase 40% in Europe, 63% in North

America, 77% in the Latin America (eg, Mexico and Argentina), and 89% in developed countries of Asia-Pacific [18].

This situation is an important public health challenge, since it represents one of the major health care and social problems faced by public health at a global scale. For this reason, health professionals and researchers have set out to look for alternative solutions to provide support to this vulnerable group [18]. Similarly, associations related to AD are willing to support their governments with timely data and information to design action plans that ensure high-quality assistance and support for people with dementia and their caregivers.

In order to measure cognitive decline in older adults several trial tests have been designed. One of them is the Mini-Mental State Examination (MMSE) [19]. This test consists of five different sections that include a series of questions and problems related to space-time orientation, information registration, attention, algebraic operations, recall and repetition of short phrases, delayed memory recall, identification of everyday objects, verbal comprehension, writing abilities and medium-complexity drawing abilities [19,20]. MMSE , also called Folstein's Test, was modified for its application in different countries (eg, English and Spanish versions). Older adults living in rural areas are more likely to develop cognitive decline, which is presumed to be caused by the low educational level [21].

Figure 1. Percentage of the population aged 60 years and older in the years 2000, 2003, and 2050. Sources include the World Population Prospects, the 2002 revision and CONAPO, Proyecciones de la Población 2010-2050.
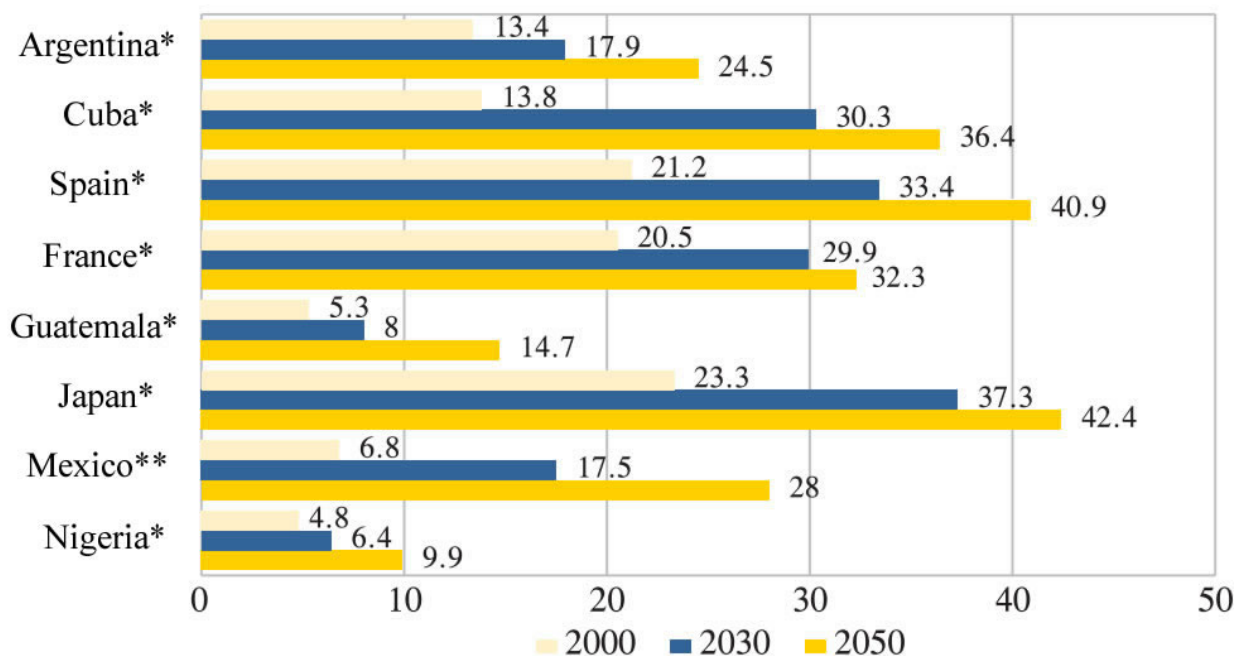
The Primary Caregiver and her Relationship With Alzheimer's Disease

Patients with AD, especially those with mild and moderate levels of dementia, receive most care in their homes from a family member. This event is more common in developing countries, like Mexico, due to poor coverage of health and social care systems.

The primary caregiver is the person who attends to the physical and emotional needs of a person who is ill or disabled. This role is generally assumed by the husband and/or wife, son and/or daughter, a relative or a person who is close to the patient. The work of a primary caregiver gains more relevance for the group that surrounds the patient as the illness progresses, not only because of the direct attention the patient requires, but also for their role in the reorganization, maintenance, and cohesion of

the family. Likewise, the primary caregiver assumes total responsibility for the patients, assisting them in the execution of all the activities that they are unable to perform. Usually the caregiver does not receive economic support or patient care training [22].

Family members and caregivers are the main support for any patient. According to the literature, it has been observed that a median average of 1.6 hours a day are invested in providing care to patients with AD and with other types of dementia, and assisting them in activities of daily living such as bathing, dressing, grooming and eating. Similarly, 3.7 hours a day are spent in assisting them with instrumental activities of daily living such as cooking, shopping, and domestic economies, and 7.4 hours a day are invested in general supervision [23]. All this can significantly affect the primary caregiver by causing stress, work overload, depression, as well as physical and medical problems. Behavioral alterations common among people with dementia tend to be misunderstood causing stigma, guilt, and discomfort in caregivers.

The work overload endured by primary caregivers, once the available resources are exhausted, can have a negative effect on their health. Numerous works on these negative repercussions have been published, where references to psychiatric malaise are abundant (mainly anxiety and depression) [24]. As well, other important repercussions have been described such as negative effects on the caregiver's physical health [25], social isolation [26], lack of free-time [27], poor quality of life or deterioration of economic situation [28]. All of these factors might contribute to what some authors call the caregiver syndrome [14,29].

Nowadays, family members, caregivers, and health professionals show a constant demand of technologically supported tools. Some of the most demanded technologies are systems that improve diagnosis and/or treatment of certain illnesses, and systems that improve communication with the patient or that facilitate assistance and remote monitoring of the patient with the use of different health and social care resources. In this context, it is important that family members and caregivers receive social support (ie, personal interaction, feedback, information, and training), that allows them to understand their role as caregivers [30]. This can be achieved by the adoption of easy-access ICT tools. ICT can provide support to family members and the caregiver and can even allow access to social environments (eg, social networks), all of which brings more autonomy, quality of life, and social inclusion to both the patient and the caregiver [31].

Methods

Procedure

In order to gather more knowledge on ICT applications that have been developed to assist patients with AD and their primary caregivers, a literature review was carried out by two of the main authors of this paper (CIMA and PPP). While the review was performed independently, the authors, maintained constant communication to ensure common agreement. The literature review was performed using a systematic review protocol. Systematic review is a method to evaluate and interpret relevant research works available for analysis dealing with a topic or phenomenon of interest [32]. At the first stage of the literature review process, the following research questions were formulated: (1) What modalities are currently being used for the development of ICT applications? (2) What technologies are most widely used at the moment of developing an ICT application? and (3) What domains of application are mainly covered by ICT applications? These questions allowed for the identification of the modalities used and the technologies applied for the development of such applications. In addition, they allowed us to classify the areas of attention that are contemplated in the development of such applications. In order to respond to each of the research questions, the key words ICT applications, AD, dementias, older adult, elderly, aging, and caregiver were identified. The search strings generated in order to obtain published works were ICT applications and AD, ICT applications and older adult, and ICT applications and caregiver and AD.

Inclusion and Exclusion Criteria

The inclusion criteria for the examined studies were (1) carried out between the years of 2005 and 2015; (2) in English or Spanish; (3) titles containing the keywords; (4) abstracts containing information on ICT applications and AD; and (5) published in indexed journals, proceedings, and book chapters. Studies that were not published during the indicated period and that did not include relevant information on ICTs applications were excluded.

Results

Each study was analyzed taking into account the modalities, technologies, and areas of attention that were considered in each ICT application developed. This was done with the purpose of identifying which area is given more coverage and which needs to be given more attention. The following sections detail the modalities, technologies, and areas of attention identified in the systematic review.

Modalities Employed for the Development of ICT Applications

The description of the modalities considered in the development of an ICT application focused on health care are outlined in Textbox 1.

Textbox 1. Modalities considered in the development of an ICT application.

Modality

- Telemedicine: Use of ICT to provide remote medical service (eg, teleconsultation, telehealth, telegerontology, telemonitoring, telerehabilitation, teletherapy, and tele-education)

- Teleassistance: Use of ICT to offer remote social and health care assistance to patients in their homes (ie, basic teleassistance, video-assistance, and telealarm

- Assistive technologies: Use of technologies to provide support to individuals with a disability or with special needs (ie, ambient assisted living (AAL), assistive technologies, virtual assistance, and domotics)

- Communication: Use of means of communication to assist and/or support individuals with a disability or with limitations, and their relatives (ie, telephony, radio, email, television, satellites)

- Location: Use of means of location for the transmission of real-time location (ie, GPS and global navigation satellite system (GNSS)

- Electronic services (e-services): Use of ICT to access information and digital content (e-services, digital contents, electronic assistance (e-assistance))

- Mobile health (mHealth): Use of mobile technology for medicine and public health practices. These applications allow data collection, medical information delivery, real-time monitoring of patients' vital signs, and direct health care provision.

Technologies for Electronic Health

In this section, enabling technologies that are most frequently applied for the design of eHealth applications were identified (Textbox 2).

Textbox 2. Technologies enabled for the design of eHealth applications.

Technology type and subtype

- Internet

    - e-services, blogs, digital contents, Web 2.0, social networks, collaborative platforms

- Information systems

    - User interface, touch screens, virtual agents

- Telecommunications

    - Mobile phones, video conference, digital terrestrial television (DTT), television, satellites

- Ambient intelligence

    - Ambient intelligence systems, sensors, sensor networks, wireless sensor networks, domotics

- Signal processing

    - Image processing, video processing, signal analysis, pattern recognition, 3D images

- Robotics

    - Robotic assistants

- Virtual reality

    - Simulations and stimulation through consoles

- Geolocation

    - GPS

Areas of Attention

In order to provide a wider classification of ICT applications developed for patients with AD and their caregivers, the areas of attention identified are shown in Textbox 3.

Textbox 3. Areas of attention identified in the systematic review.

Area of attention

1. Research (discover causes): the need to increase knowledge in order to understand the cause(s) of the disease and to provide products that meet the needs of the patient.

2. Treatment (therapy): support for individuals with AD and maximization of their capabilities through safe and effective interventions so that they can act more independently.

3. Diagnosis: timely diagnosis of AD through cognitive and brain activation exercises.

4. Care: provision of medical and social care through the interchange of improved practices in care for patients with AD and their self-care induction.

5. Prevention: action plans for AD through early intervention and epidemiologic studies.

6. Quality of life: psychological support to the patient, family members, and caregivers and advice and promotion of elderly well-being.

7. Awareness raising and social mobilization: promotion of solidarity, mobilization and social engagement, and sensitization of public opinion.

8. Management (monitoring): promotion of assisting services for patients and primary caregivers.


Included Studies

The bibliographic search carried out for this study included works published between January 2005 and July 2015. The searched databases were Springer Link, Scopus, and Google Scholar. A total of 902 results were obtained from the three selected information sources. The Springer Link search was limited to journal articles and it returned 371 references whereas the Scopus database included conferences and journal articles and yielded 19 results. Finally, Google Scholar included congress and journal articles, and book chapters, and returned 522 references. The databases selected in this review were set to maximize the search results of studies in Spanish.

Abstracts and titles were sufficient to rule out papers that did not meet inclusion criteria (points 3 and 4). When it was not clear from the abstracts and titles whether they included ICT (inclusion criteria 4), the full paper was reviewed. References in the selected articles and previous published reviews were also analyzed with the aim of identifying additional studies that had not been identified through the searched databases. Using this method, 4 Springer Link papers, 14 Scopus papers, and 8 Google Scholar papers were detected. In total, 26 studies were obtained where 16 studies described ICT applications aimed at patients with AD and other dementias, and the other 10 described ICT applications aimed at caregivers and/or family members. It is noteworthy that 4 of the 26 studies were directed to both cases (Figure 2).

The results obtained from the systematic review are categorized into the following two groups: (1) ICT applications aimed at patients with AD and other dementias (Multimedia Appendix 1) [33-48], and (2) ICT applications aimed at the primary caregiver (Multimedia Appendix 2) [49-58]. It is important to point out that in each study several areas of attention and enabling technologies were included.

Figure 2. The systematic review carried out in this study.
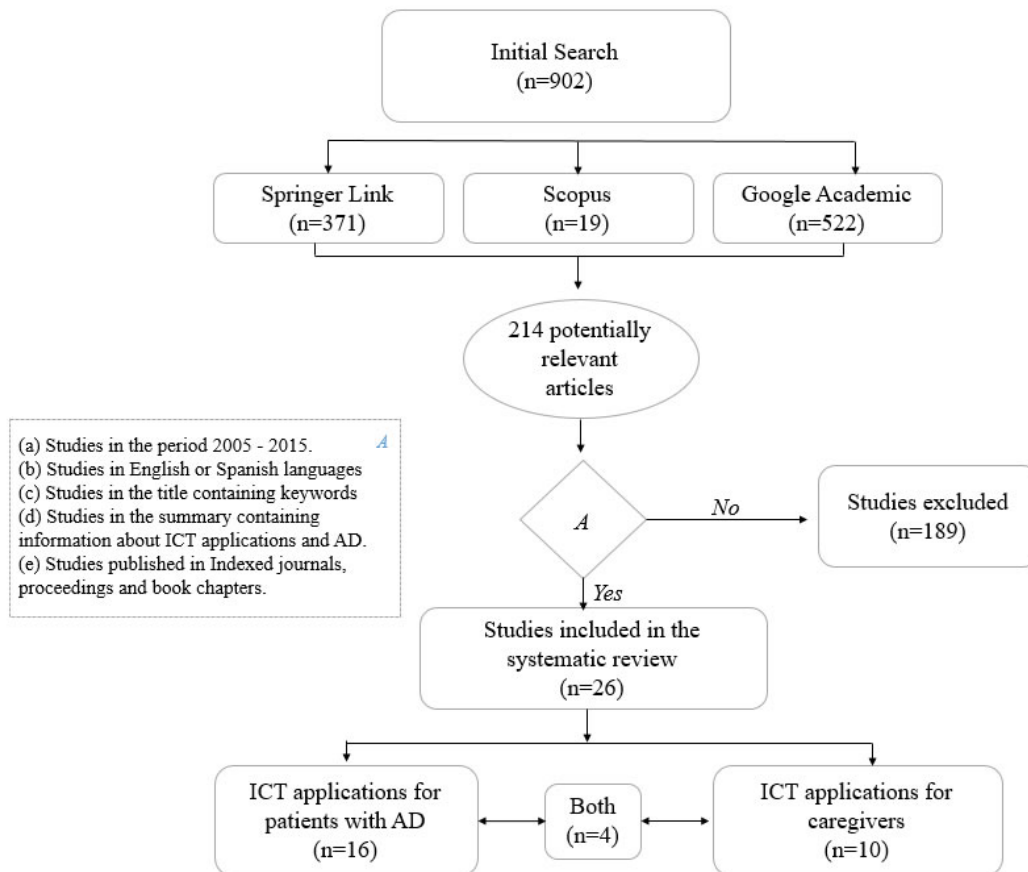

Research Outcomes

ICT applications used for patients with AD and other dementias were analyzed and the results are shown in Figure 3 and Multimedia Appendix 1. The most commonly used application types are assistive technology (44%, 7/16) and teleassistance (37%, 6/16). The most commonly used enabling technologies are information systems (56%, 9/16) and Internet (44%, 7/16). Signal processing (6%, 1/16), robotics (6%, 1/16), virtual reality (6%, 1/16), and geolocation (6%, 1/16) are less frequently used. The areas of attention most frequently covered are care (56%, 9/16), treatment (56%, 9/16), and management (50%, 8/16). The areas of attention less frequently addressed are research (6%, 1/16) and diagnosis (6%, 1/16). It is important to point out that the studies indicated in references [38,39] are projects previously developed in Mexico. These studies are important because there is little evidence of these types of projects in Mexico, to our knowledge.

ICT applications used by primary caregivers of patients with dementia were also analyzed (Figure 4,Multimedia Appendices 1 and 2). The most commonly used applications by primary caregivers are teleassistance applications (86%, 12/14). Less frequently used applications are mobile health (21%, 3/14), assistive technology (21%, 3/14), and telemedicine (21%, 3/14). The most commonly used enabling technologies are telecommunications (71%, 10/14), Internet (64%, 9/14), and information systems (50%, 7/14), whereas ambient intelligence (21%, 3/14), signal processing (7%, 1/14), robotics (7%, 1/14), and geolocation (7%, 1/14) are less frequently used. Finally, the most covered areas of attention are care (79%, 11/14) and quality of life (64%, 9/14), whereas management (43%, 6/14) is less frequently used. It should be mentioned that the studies [37-39,42] were taken into consideration in the analysis of ICT applications used by the caregiver.

Figure 3. Analysis of ICT applications used by patients with Alzheimer's disease and other dementias.
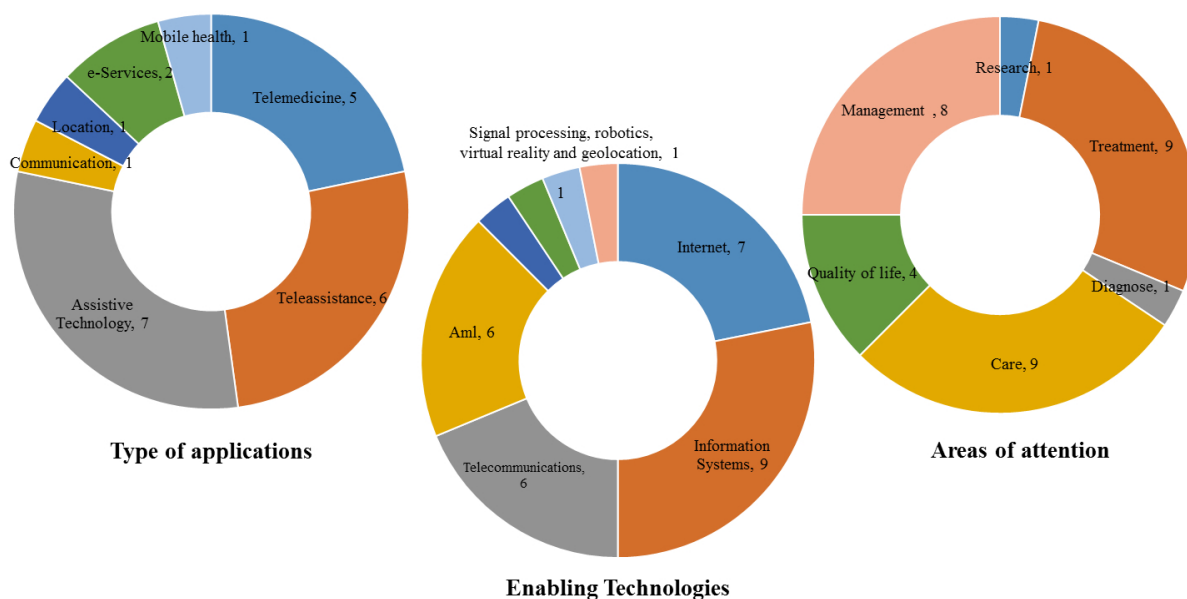
Figure 4. Analysis of ICT applications used by the primary caregiver.
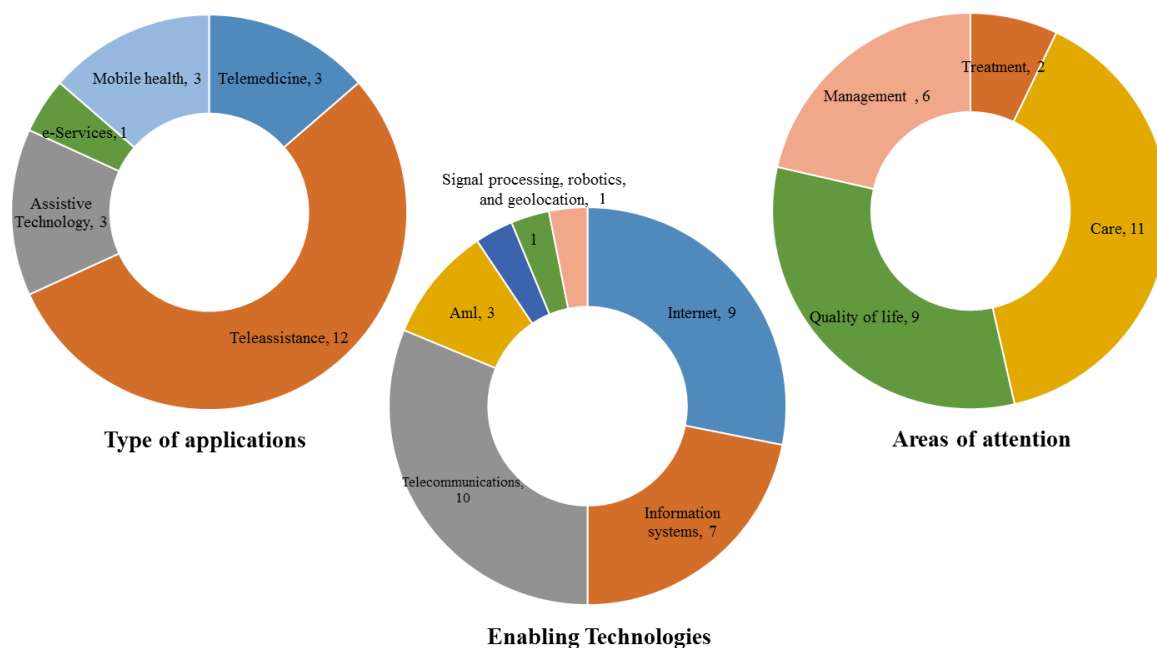
Discussion

Principal Findings

The aim of this review is to systematically identify the opportunities that ICT offers to health services, specifically for patients with dementia and their families.

Here, we identified 26 studies, among which 16 presented projects aimed at patients with AD and 10 at the primary caregiver. From these 16 studies, 9 focused on patients with AD (56%, 9/16), 5 (31%, 5/16) on patients diagnosed with mild

cognitive impairment according to the (MMSE), and only one study was focused on patients with mild dementia. Furthermore, it was found that 13 studies (81%, 13/16) evaluated their ICT applications through carrying out tests with patients.

Among the studies that used assistive technologies, study [33] was found to have carried out 46 tests with patients with mild cognitive impairment, who were suspected to have AD and who were under treatment (cholinesterase inhibitors). Results indicated that after 12 weeks of using interactive multimedia Internet-based system (IMIS System), along with the Integrated Psycho-Stimulation Program (IPP), patients had improved their

initial scores in the Alzheimer's Disease Assessment Scale-Cognitive subscale (*ADAS - Cog*) and MMSE tests, maintaining their scores during 24 follow-up weeks. Similarly, in study [35], 8 patients with mild dementia remained stable after using a televideo monitoring system , while the control group, who did not use the system, showed less stability, indicating a significant difference between the two groups.

Robert et al presented the Sweet Home ANR project, which aims to help patients with mild cognitive impairment perform daily living activities [41]. The tests carried out with patients took place in rooms equipped with audio and video sensors. For the language activities, the system was tested with 21 healthy patients and 24 patients with AD, while the walking test was performed with 17 healthy patients and 16 patients with AD. In the study, they showed that Sweet Home ANR was capable of detecting the full set of activities carried out by the patients. Likewise, the system enabled the differentiation of patients with AD from healthy patients using the video monitoring system (VMS) functional score. Casacci et al [47] presented the ALTRUISM project , in which tests were carried out with 20 patients with AD with the aim of performing remote supervision, through a virtual personal trainer, of rehabilitation exercises and routines executed by these patients. The results showed important and promising data concerning the use of ICT systems of remote rehabilitation.

Among the studies that used teleassistance applications, we found one written by Garcia et al [36] that presented a multi-agent ambient intelligence system aimed at improving attention to and health care of patients with AD living in geriatric residential settings. Although this study did not present an evaluation of the application through tests with patients, it made a comparison with a former version of the system and confirmed that ALZ-MAS 2.0 is much more robust and has better performance than the older version.

Of the 14 studies presenting projects aimed at the primary caregiver, including those shown in Multimedia Appendix 2 , it was found that 11 studies focused on informal caregivers (family members), and 7 focused on formal ones (health professionals). Likewise, it was found that 10 of the 14 studies evaluated their ICT applications through tests with caregivers.

As previously shown, teleassistance is the most commonly used application for caregiver support. In this context, study [50] evaluated the effectiveness of the eCare system with family members older than 21 years old who lived or were in the same geographic area as the patient with dementia. The intervention was carried out over a span of approximately 6 months and the results showed a significant decrease in the family member's workload after using the eCare system. Similarly, it was found that caregivers who presented depression signs at the onset of the intervention significantly improved their state after the intervention. Another study that showed a decrease in stress signs in formal caregivers of patients with dementia is the one carried out by Sugihara et al [53], where 16 formal caregivers were interviewed in order to know the benefits of using the Support Environment system.

Skorupska et al presented the design and implementation of a multimedia platform called Understaid, which provides support

to the family of patients with dementia [57]. This platform was evaluated by 40 caregivers attending patients with different levels of dementia. Caregivers provided information of daily care activities, as well as the patient's behavior through the platform. Although results obtained from the evaluations are not mentioned in this study, the system promises to be a useful tool for caregivers. Another study that was validated by caregivers is the one carried out by Bourennane et al [42], where they describe the experiments performed with patients with AD in a hospital in France. The homecare monitoring system was tested with an 84 year resident and the follow-up was performed by hospital personnel. Results showed that this system is functional and that it can be used for other cases. However, two validations are needed: (1) patients and their family members' consent, and (2) doctors' interest and the necessary arrangements for the system connection.

Among the studies using mobile technology for the assistance of primary caregivers, study [56] carried out semi-structured interviews with 9 informal and 2 formal caregivers in its Phase 1. In Phase 2, 2 patients and 4 caregivers were interviewed in order to evaluate low-fidelity prototypes of the mobileWAY application, and in Phase 3, 5 patients and 10 caregivers were interviewed to evaluate interaction and usability of the application. Finally, caregivers were invited to answer usability evaluations one more time. These evaluations showed promising results, not only in terms of general comprehension of the mobileWAY system, but also in terms of ease of use and potential interest in using the application in the future.

The present review demonstrates that ICT has great potential for supporting the health care field. As we were particularly interested in the study of AD and other dementias that are affecting the aging population, we identified different innovation opportunities that can be designed in order to enhance the quality of life of older adults with dementia and their family members. These innovation opportunities are (1) information services for health professionals which facilitate information exchange and enable access to knowledge on a variety of treatments and practices; (2) more complete information services for counseling and education of patients and informal caregivers; (3) information services for diagnosis, treatment and/or rehabilitation of patients; (4) virtual communities providing psychological support that also allow contact with health professionals; and (5) regarding technology acceptance, the design of strategies for the older adult to integrate the use of ICT tools in his/her daily life should be considered.

Limitations

One limitation of the review is that studies were searched in three databases (Springer Link, Scopus, and Google Scholar) using specific search strings, so it is possible that this searching strategy did not identify some eligible studies. In order to tackle this, manual searches were performed in previous reviews and key journals. Despite the exhaustive search, additional eligible studies were not identified using this method. Another possible limitation of this systematic review is that only documents written in English and Spanish were considered.

Conclusions and Further Work

According to the results obtained from the systematic review, most ICT applications developed for both patients with any type of dementia and primary caregivers are focused on in-home care (teleassistance). The use of ICT in older adults with dementia can be implemented as a lifestyle in order to improve the quality of life of the elderly and their primary caregivers. Given that AD is a degenerative disease which causes progressive deterioration of memory, their primary caregiver's quality of life can be undermined as the disease becomes increasingly severe, which can cause depression in the primary caregiver. In addition, the use of ICT in the daily life of caregivers can help them understand the disease process and manage situations in a way that is beneficial for both parties. As a consequence, this can enhance interpersonal relationships and promote social harmony for both the elderly and their caregiver. Furthermore, the systematic review of ICT applications for patients with AD and other dementias reflected low presence of innovative projects in less developed countries, such as Mexico. Future work is being developed on the design of strategies for older adults to integrate the use of ICT tools in their daily life. With this, progress can be made in the development of technological projects that support this group of people.

Conflicts of Interest

None declared.

Multimedia Appendix 1

ICT applications aimed at patients with AD and other dementias.

[PDF File (Adobe PDF File), 61KB - rehab_v3i1e6_app1.pdf]

Multimedia Appendix 2

ICT applications aimed at the primary caregiver.

[PDF File (Adobe PDF File), 51KB - rehab_v3i1e6_app2.pdf]

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Abbreviations

AD: Alzheimer´s disease
eHealth: electronic health
e-service: electronic service
GPS: Global Positioning System
ICT: information and communication technologies
MMSE: Mini-Mental State Examination

Original Paper

Community-Based Hip Fracture Rehabilitation Interventions for Older Adults With Cognitive Impairment: A Systematic Review

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Abstract

Background: A hip fracture in older adulthood can result in function and mobility decline. The consequences are debilitating and place a great burden on patients, caregivers, and the health care system. Although inpatient rehabilitation programs have proven effective, the best practices for community-based rehabilitation required to maintain the gains in function and mobility post hospital discharge are currently unknown.

Objective: The aim of this systematic review is to identify and evaluate the evidence on the effectiveness of community-based rehabilitation post hospital discharge interventions for older adults with cognitive impairment (CI) following a hip fracture, and to identify the physical recovery outcomes and measures used in previous studies.

Methods: The methods outlined in the Cochrane Handbook for Systematic Reviews of Intervention were followed and findings were reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines. The search strategy included a combination of text words and subject headings relating to the concepts of CI, dementia, delirium, cognitive reserve, and hip fractures. For a study to be included in the review, it had to involve participants with CI who underwent hip fracture surgery, and consisted of an outpatient intervention that occurred in the participant's home or community. Peer-reviewed journal articles were identified by searching various databases. Two independent reviewers screened the titles and abstracts to determine which articles comprising of a rehabilitation intervention within a community setting prior to being included for a full article review. A data extraction form and an evidence and quality checklist were used during the full article data analysis and synthesis. A meta-analysis was not conducted due to heterogeneity of measures and outcomes.

Results: The original search resulted in over 3000 articles. Of those, three studies satisfied the necessary criteria to be included in the systematic review. All studies included inpatient and outpatient physiotherapy, with some including a cognitive component, family education, and a discharge assessment.

Conclusions: The findings from this review suggest that community-based rehabilitation post hospital discharge interventions show promising results towards improving various physical function outcomes, mobility, and activities of daily living for older adults with CI following a hip fracture. This review also demonstrates and discusses the current lack of outpatient rehabilitation interventions targeted towards older adults with CI post-hip fracture. Additionally, several substantive gaps that require attention to move this field forward are highlighted.

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Introduction

After experiencing a hip fracture, older adults are typically admitted into sub-acute or hospital care units to receive rehabilitation [1-3]. However, the presence of cognitive impairment (CI) has been an exclusion criterion for patients to access rehabilitation services [4-6]. This misalignment of care is particularly problematic as one study estimated that dementia and CI have 19% and 42% prevalence among older adults with a hip fracture, respectively [7]. Evidence indicates that approximately two thirds of older adults have severe difficulties walking independently outdoors 6 weeks after discharge from inpatient rehabilitation suggesting severe difficulties in returning to community activities after hip fracture [8]. Consequently, older adults with CI and a hip fracture from the community who are unable to maintain or regain their mobility and functional abilities after discharge from inpatient rehabilitation are frequently admitted into a long-term care home in order to meet their daily care needs [9].

Permanent placement into long-term care accrues a high burden of cost which is expected to reach approximately $2.4 billion in Canada by 2041 [4]. Comparatively, the economic burden resulting from a hip fracture was significantly less for a person who returns to the community and receives nursing, physiotherapy, and occupational therapy in their home [4]. With a greater proportion of older adults with increasing medical complexity [10] and health care systems attempting to contain costs, there is an urgent need for rehabilitation programs in the community to deliver care so that the progress gained from inpatient rehabilitation after discharge is maintained for older adults with CI following hip fracture.

Evidence is beginning to accumulate that rehabilitation offered in post-acute or community settings are beneficial to older adults with CI post hip fracture [11,12]. However, to date, the effectiveness of community-based rehabilitation programs for older adults with CI is poorly understood. It is imperative for decision makers, clinicians, and researchers to know the evidence supporting the effectiveness of outpatient community-based rehabilitation programs following a hip fracture on critical patient outcomes, such as mobility, physical function, activities of daily living (ADLs), and living situation after the program. Identifying the aspects of community-based rehabilitation programs that are specific to older adults with CI is essential to inform future initiatives aimed to prevent decline and institutionalization, as well as restore mobility and function among older adults with CI. The primary aim of this systematic review is to evaluate the evidence on the effectiveness of community-based rehabilitation post hospital discharge interventions for older adults with CI following a hip fracture, and to identify the physical recovery outcomes and measures used in previous studies.

Methods

Search Strategy and Selection Criteria

The study protocol has been previously published [13]. This review was based on a systematic, comprehensive search of 12 databases (Medline, Medline In-Process, PubMed, PsychINFO, Embase, CINAHL, AMED, Ageline, The Cochrane Database of Systematic Reviews, Central Register of Controlled Trials, Database of Abstracts of Reviews of Effect, and the Allied Health Evidence databases), from their inception to April 2015. The search strategy included a combination of text words and subject headings relating to the concepts of CI, dementia, delirium, cognitive reserve, and hip fractures. The search was limited to English and French articles due to limited resources to review articles in other languages. The literature search was performed by an experienced information specialist (JB). A study was eligible if it included (1) an intervention with a community-based component aimed at maintaining or improving patient physical recovery outcomes, like function, mobility, and dwelling location; (2) a mean age of 65 years or older for participants; (3) analysis of participants with CI; and (4) participants who suffered a hip fracture. Community-based rehabilitation post-discharge was previously defined to include interventions that were initiated once an individual was discharged home from inpatient rehabilitation for a hip fracture [13]. Our definition needed to be revised to include interventions that began during inpatient care and transitioned into the community. However, this review was designed to focus on the outcomes resulting from community-based components. Study designs could be randomized controlled trials (RCTs), prospective (longitudinal), retrospective (longitudinal), cross-sectional, cohort, and quasi-experimental studies. Multiple research designs were included in order to collect a comprehensive overview of the evidence. Publications were excluded if the rehabilitation program or intervention presented did not include or describe a community or home-based component, did not report results of primary data collection (eg, editorials, commentaries), or if the study was targeted for participants with stroke, Parkinson's disease, or frontal-temporal dementia, as these diseases have different physiological and behavioral markers.

Study Selection

The titles and abstracts were first screened by two independent reviewers (CC, PMvW). If one reviewer was uncertain about whether the article fulfilled the inclusion criteria, it was included for full-text review. Two reviewers (CC, KP) independently reviewed full-text studies. All disagreements were resolved by consensus with the research team. Regular team meetings were held to discuss articles, any complications or disagreements that arose, and findings from the studies. If multiple articles were written about the same study, only the article with the most information pertaining to the participants with CI was retained.

For any articles that were missing information, corresponding authors were contacted for clarification.

Data Abstraction and Quality Assessment

Two reviewers (CC, KP) independently extracted data from each of the included studies using a standardized excel sheet developed by the research team. This included information about the: study design, aim, location, sampling method, recruitment period, duration, sources of data collection, sample descriptors (eg, size, age, sex, type of hip fracture, type of CI, pre-fracture living location, and discharge location), interventions (eg, components, setting, duration, assessments and scales used), outcomes, details of statistical analyses, and source of funding. If the study was an RCT, attributes of this design were extracted including randomization, allocation, and blinding methods. To objectively measure the quality of the included studies, two reviewers (CC, KP) independently used the Downs and Black checklist [14]. Any disagreements between the scores were discussed and resolved by the consensus of the research team.

Results

The initial search in September 2013 yielded 3700 articles. From these results, 1493 duplicates were removed and the remaining 2207 titles and abstracts were screened (Figure 1). A total of 52 full-text articles were deemed eligible. After reviewing the full-text studies, 3 articles were included into the review [15-17]. Although the interventions in these three studies were not specifically designed for only individuals with CI, they did include a sub-analysis for the patient population and thus met our inclusion criteria. The findings from one study was reported in three articles [17-19], but only Shyu et al [17] reported on a subgroup analysis of those with CI with physical recovery outcomes. A meta-analysis was not conducted due to heterogeneity of measures and outcomes. To ensure the review included the most current evidence the search was updated using the same strategy in December 2013, February 2014, and April 2015; no relevant studies were retrieved.

Figure 1. PRISMA diagram of search results.
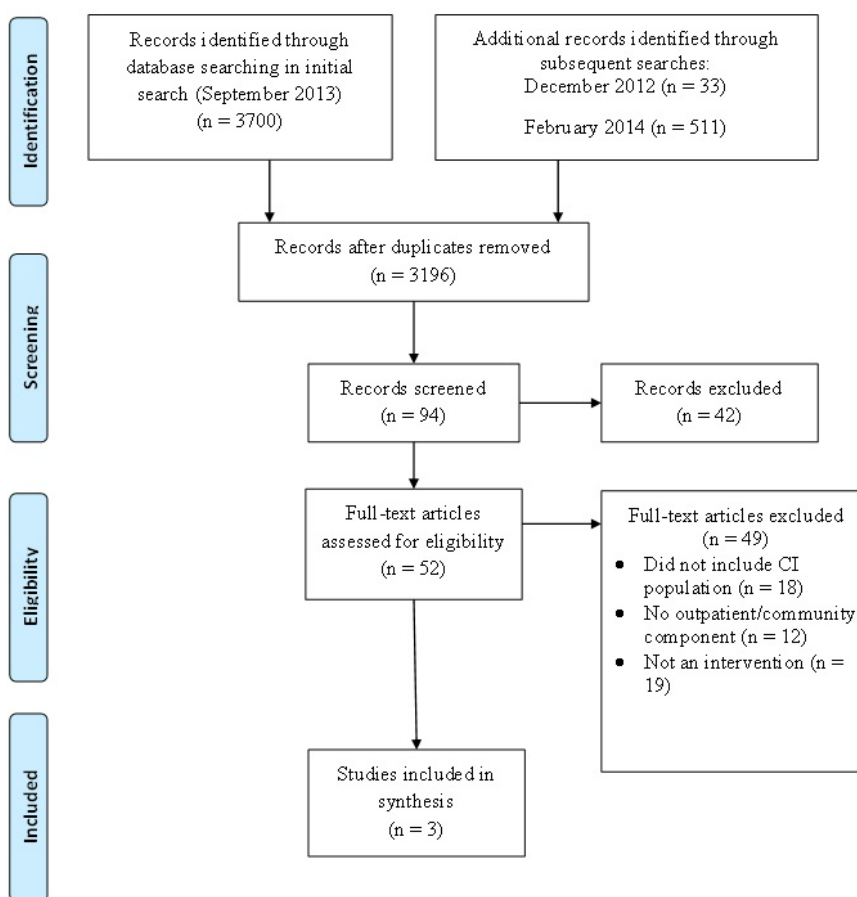
Reference: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

Characteristics of the Included Studies

Characteristics of the included studies are described (Table 1). All three studies were two-group RCTs with different follow-up periods ranging from 16 weeks post-discharge [16] to 2 years post-discharge [17]. Primary data collection was used in all of the studies; in addition, one study [16] used an administrative database.

Table 1. Description of the studies.

Components	Study		
	Huusko et al [15]	Moseley et al [16]	Shyu et al [17]
Study design	RCT	RCT	RCT
Method of random-ization	Computer generated	Computer generated	Coin flip
Location	Finland	Australia	Northern Taiwan
Setting	Geriatric ward home	Rehabilitation unit home	General/acute hospital rehabilitation unit home
Recruitment time	October 1994 to December 1998	March 2002 to May 2005	September 2001 to November 2004
Aims	Determining the effect of intensive geri-atric rehabilitation after surgery for hip fracture on patients with cognitive impair-ment	Determining the impact of a higher dose exercise program on mobility after hip fracture compared to usual care	Two-year evaluation of an interdisci-plinary intervention program on recov-ery following hip fracture for older adults with cognitive impairment
Usual care sample size, n	120	80	81
Intervention group sample size, n	123	80	79
Cognitive screening tool	MMSE[a]	SPMSQ[b]	Chinese MMSE
Inclusion criteria	Community dwelling patients with acute hip fractures; ≥65 years; living independ-ently, had been able to walk unaided be-fore the fracture	Surgical fixation for hip fracture admitted to the inpatient rehabilitation; approval to weight bear or partial weight bear; able to tolerate the exercise programs; able to take four plus steps with a forearm support frame and the assistance of one person; no medical contraindications that would limit ability to exercise; living at home or low care residential facility prior to the hip fracture	Age ≥60 years; admitted to hospital for an accidental single‐side hip fracture; receiving hip arthroplasty or internal fixation; able to perform full range of motion (ROM) prior to hip fracture, moderately dependent or better in ADLs before hip fracture[c]; living in northern Taiwan[c]
Exclusion criteria	Pathological fractures, multiple fractures; serious early complications; those receiv-ing calcitonin treatment; terminally ill pa-tients, severe dementia, or other serious problems with communication	High functioning patients who were dis-charged directly to home; low functioning patients who were discharged to a residen-tial care facility	Severe cognitive impairment (score <10 on the Chinese MMSE); terminally ill
Discharged home	54% community; 46% not reported	Not reported	Not reported
Duration of outpa-tient component	Unclear	Unclear	3 months

[a]Mini-Mental State Examination

[b]Physical Performance and Mobility Exam

[c]Established to include subjects with the most potential to recover after rehabilitation.

The participant inclusion and exclusion criteria used in each study are outlined in Table 1. In order to be eligible for the trials, inclusion criteria included being 60 years of age of older [15,17], admitted to hospital with a hip fracture [16,17], receiving hip arthroplasty or internal fixation [17], and surgical fixation for hip fracture [16]. The participants' pre-fracture physical condition was an inclusion criterion in each of the studies.

Sampling methods included convenience [15,17] and stratified [16] sampling. All three studies recruited their participants from hospitals, and the number of participants ranged from 160 [16,17] to the largest sample size which was 243 [15]. The mean age of the study participants ranged from 79-84 years old. The control and the intervention groups were well balanced. The

percentages of female participants were 90% [15], 81% [16], and 69.1% [17].

A single measure of CI was used to assess participants in all three studies. In Huusko et al [15] participants were considered to have dementia if they scored less than 23 on the Mini-Mental State Examination (MMSE) which was used to assess patients 10 days after surgery and the randomization process when the patient was "in a clinically stable situation" [15]. In another study, participants were considered "cognitively impaired" [17] using the Chinese MMSE. The third study, Moseley et al [16] used a cut-off score of 3 or more adjusted errors on the Short Portable Mental Status Questionnaire (SPMSQ) which identifies those with no CI and mild CI, but did not further describe the inclusion criteria for CI. Those with SPMSQ scores of 4 or less

were excluded. No study used a physician diagnosis of dementia or CI, further no assessment of delirium was considered in the studies.

With respect to describing the participants, only Huusko et al [15] reported the mean level of cognitive function for the control and the intervention groups (MMSE scores were 23 and 20, respectively, *P*<.001), the sample size, and labeled participants with CI as having "dementia." The two other studies [16,17] did not provide the mean age, percent women, type of hip fracture and treatment, or MMSE score of the participants with CI.

The types of hip fractures and their surgical treatments varied among the studies. Shyu et al [17] enrolled participants with accidental hip fractures who underwent hemiarthroplasty or open internal fixation, the study by Huusko et al [15] comprised of patients who had trochanteric fractures managed with osteosynthesis, and Moseley et al [16] included participants with trochanteric and intracapsular fractures who received either bone screws, compression screws, plates, and hemiarthroplasty as treatment. Two studies had participants who lived in the community [15,16] whereas Shyu et al [17] did not report the pre-fracture living location. The comorbidities of the samples with CI were not described in any of the three studies.

Quality Assessment

The quality of each study was determined to be 23 [15], 25 [16], and 19 [17], indicating that they are all of "good quality" according to the Downs and Black checklist [14] (Multimedia Appendix 1). Despite the articles being good quality, the Downs and Black checklist identified noteworthy methodological deficits in the three studies: none of the studies attempted to blind study subjects to the intervention, outcome assessors were not blinded, compliance with the intervention was not measured, and randomized intervention assignment was not concealed from both patients and healthcare staff. Furthermore, the studies lacked component analyses of the interventions, descriptive data regarding the participants with CI, reporting on methodological issues (eg, no protocol for missing data), information regarding comorbidities experienced by the participants, and information regarding the intervention acceptability, feasibility, or treatment receipts.

Interventions

All three of the interventions [15-17] were initiated while the participants were on the inpatient unit. The participants in all three studies received assessments, rehabilitation, home assessments, counseling during inpatient stay and/or discharge planning. The intervention components are listed in Table 2.

Huusko et al [15] referred the intervention group to a geriatric inpatient unit where they would be managed by an interdisciplinary team immediately after randomization whereas the control group was discharged to other hospitals. Their rehabilitation program involved seven intervention components, the highest number of components of all three studies. The seven components included inpatient physical rehabilitation twice a day, cognitive rehabilitation with a psychiatrist four times a week, discharge assessments that involved home assessments and the need for appliances and daily living aids, family education about hip fracture, and registered nurse (RN) and physiotherapists (PTs) weekly meetings to discuss methods of improving rehabilitation. After discharge, participants were provided 10 in-home physiotherapy visits. Information about how long it took to complete the visits or the duration of follow-up was not provided.

The intervention by Shyu et al [17] had six components and began prior to surgery with a geriatric consultation provided by a geriatrician and geriatric nurses. After surgery, the geriatrician provided suggestions to the care team in order to modify or develop a care plan for rehabilitation. The rehabilitation contained six components, including inpatient assessment by a rehabilitation physician, RN and PT, inpatient physical rehabilitation with 2 visits from a PT, daily geriatric nurse visits; comprehensive discharge assessment by a geriatric nurse, and a home assessment prior to discharge. Additionally, Shyu et al [17] included 8 in-home visits from a RN as well as 3 in-home physiotherapy visits in the 3 months following discharge. The control group received routine care which does not include continuity of care, geriatric assessment, an interdisciplinary approach, or in-home visits.

Lastly, Moseley et al [16] provided rehabilitation during inpatient care and continued their exercise regime post-discharge. Their intervention only had two components: high doses of weight-bearing physical rehabilitation that consisted of 1-hour sessions twice a day for 16 weeks, and physiotherapy in the home over 8 visits by a PT after being discharged from the inpatient rehabilitation unit. This was compared to the control group that received usual care with limited weight-bearing exercises. Information about the duration of PTs follow-up was not provided so it was unclear how long patients continued to be seen after discharge.

A geriatric consultation by an interdisciplinary team that typically consisted of a geriatrician, RN, and PT was completed on the inpatient unit in all three studies. In addition to these professionals, a neuropsychologist, social worker, consultant specialist in physical medicine, neurologist, and psychiatrist were involved immediately after admission into the hospital in one study [15]. Geriatric consultants who made suggestions to the surgeon about post-surgery physician orders were also utilized [17].

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Table 2. Summary of intervention components and outcome measures.

Components		Study		
		Huusko et al [15]	Moseley et al [16]	Shyu et al [17]
Intervention components				
	Physical	Physiotherapist visit twice daily; occupational therapy; practice with nurse during day	Weight-bearing exercises twice daily for 60 minutes and walking on the treadmill for 16 weeks	During inpatient stay and 3 months after. inpatient (physiotherapist visits three times daily)
	Cognitive	Psychiatrist up to four times per week	N/A	N/A
At-home physiotherapist		10 visits by a physiotherapist	8 visits by a physiotherapist	3 visits by a physiotherapist
At-home registered nurse		N/A	N/A	4 visits in 1st month, then biweekly until 3rd month
Family education		Family counseling	N/A	N/A
Inpatient assessment		N/A	N/A	Geriatric consultation before and after surgery; nurse and physician visit once a day
Discharge assessment		Discharge plan checked in weekly meetings with the patient and family	N/A	Assessment done by nurse; evaluated (caregiver competence, family resources, family function, patient self-care abilities, and need for community or long-term care services)
At-home assessment		Physiotherapist made home visit before discharge if necessary	N/A	Part of discharge assessment by nurse
Nurse and physiotherapist meetings		Nurse and physiotherapists met weekly to improve rehab	N/A	N/A
Duration of outpatient component		Unclear	Unclear	3 months after discharge
Outcome measures		Length of hospital stay; mortality; place of residence 3 months and 1 year after discharge	Knee extensor strength, and walking speed (primary); PPME, sit to stand, gait aid use, Barthel Index, falls, hospital readmission, pain, EQ5D[a], balance[b] (secondary)	Hip flexion ration; two items on CBI (walking ability, ADL recovery); falls; mortality; emergency room visits; hospital readmission; institutionalization
Function outcome measures		N/A	Knee extensor strength (primary); PPME, sit to stand, patients rank of strength (secondary); at admission, 4 and 16 weeks; by blinded research assistants	Hip flexion ratio; at 1, 3, 6, 12, 18, 24 months post-discharge; by geriatric nurse
ADL outcome measures		N/A	Barthel ADL scale; PPME; at admission, 4, and 16 weeks; by blinded research assistants	Barthel ADL scale; at 1, 3, 6, 12, 18, 24 months post-discharge; by geriatric nurse
Mobility outcome measures		—	6-minute walking speed test and a self-report measure; at admission, 4, and 16 weeks; by blinded research assistants	One item from Barthel; at 1, 3, 6, 12, 18, 24 months post-discharge; by geriatric nurse

[a]Quality of Life patients rank of strength

[b]Balance: max balance range test, step test, body sway, lateral stability, co-ordinated stability, choice stepping reaction time.

Outcomes

The outcome measures are outlined in Table 2 and a summary of the results are described in Table 3. Moseley et al [16] used a primary outcome measure of knee extensor strength for which there was no statistically significant between group differences following intervention, or among those with CI. The intervention group had significantly faster sit-to-stand times at both 4 and 16 weeks and performed more steps in the step test at 4 weeks compared to the control group. A post-hoc analysis revealed that those with CI who were allocated to the intervention group had better outcomes than those without both of these factors in physical function outcome measures that included differences in walking speed at 4 (0.20 m/s, $P=.003$) and 16 weeks (0.24 m/s, $P=0.15$), Physical Performance and Mobility Exam (PPME) at 4 (1.4 units, $P=.013$) and 16 weeks (1.9 units, $P=.019$), body sway at 4 weeks (2.1 cm, $P=.008$), step test at 16 weeks (3.5 s, $P=.046$), max balance range test at 16 weeks

(36 mm, P=.002), coordinated stability test at 16 weeks (14, P=.020), and modified falls efficacy scale at 16 weeks (28, P=.009). Having "no or slight pain" (OR=5.3, P=.024; difference=0.2, P= .034) and being "able to walk unaided or with sticks or crutches" (OR=6.0, P= .018) were also

significantly improved at 16 weeks for those with CI in the intervention group compared to those in the control group. Huusko et al [15] was not included in this table as their outcome measures were not specifically related to function, ADL, and mobility

Table 3. Results of physical function, ADL ability, and mobility outcome measures.

Results	Study	
	Moseley et al [16]	Shyu et al [17]
Physical function	Between group differences of those with CI allocated to intervention group (significant changes in PPME)	No statistically significant results
ADL Ability	Significant improvements for those with CI in the intervention group were reported[a]	Significant improvements for those with CI in the intervention group were reported in both studies[b]
Mobility	Statistically significant findings in those with CI, and found statistically significant improvements for participants with CI in the intervention group compared to those in the control group[c]	Participants with CI in the intervention group were more likely to recover their walking ability compared to the control group[d]

[a]Barthel, P=.002; PPME, P=.019

[b]P=.001; an increase in Barthel score for those with CI in the control and intervention group 6 months after discharge but it is unclear if this increase was statistically significant.

[c]P=.015

[d]OR=3.49, CI=1.64-7.42, P=.001

Shyu et al [17] measured hip flexion ratio and mobility with the walking item on the Chinese Barthel Index (CBI). Results indicated that participants with CI in the intervention group were more likely to recover their walking ability compared to the control group (OR=3.49, CI=1.64-7.42, P=.001). However, no statistically significant differences in hip flexion ratio in participants with CI were found [17].

Describing ADLs as a secondary outcome, Moseley et al [16] used the Barthel ADL scale and the PPME whereas Shyu et al [17] only used the Barthel ADL scale. Both studies reported significant improvements for participants with CI in the intervention group (P=.002 by Moseley et al [16]; and P=.001 by Shyu et al [17]). Moseley et al [16] reported significant findings with both the Barthel (P=.002) and PPME (P=.019) measures.

Two studies examined whether the intervention impacted participant dwelling location over time and mortality [15,17]. Huusko et al [15] reported that the length of hospital stay for those in the intervention group with mild and moderate dementia was significantly shorter than the control group (P=.002 and P=.042, respectively). They also found that significantly more participants with mild and moderate dementia from the intervention group were living at home 3 months after discharge (P=.009 and P=.009, respectively), and continued to live independently 1 year after the operation, though not significantly [15]. In contrast, Shyu et al [17] reported that rates of institutionalization over 2 years were the same between the intervention and control group and that those with CI in the intervention group were most likely to be readmitted into hospital (OR=4.44, CI=1.53-12.89) within the 2-year timeframe. Both studies found no significant differences in mortality between the intervention and control groups. Other outcomes that were evaluated but were non-statistically significant among participants with CI included fall occurrence [16,17], and

readmission into the hospital in the intervention group at 16 weeks [16,17].

Discussion

Principal Findings

This review demonstrated that there is a current lack of outpatient rehabilitation interventions targeted towards older adults with CI post-hip fracture. Although there has been an increased emphasis on older adults with CI following a hip fracture in rehabilitation interventions, previous studies have primary focused on inpatient settings [11,20]. The three studies that met our inclusion criteria were not designed to meet the specific needs of older adults with CI, which is a similar finding to other literature reviews [21]. Rather, the authors stratified their samples and conducted a subgroup analysis of participants with CI from larger RCTs that aimed to determine the effectiveness of interventions in a geriatric population. The results of this review suggest that community-based rehabilitation post hospital discharge interventions are promising to improve various physical function outcomes, mobility, and ADLs function 1 year post-discharge from the hospital for older adults with CI. Further, there is some evidence to suggest that providing outpatient rehabilitation after discharge from inpatient rehabilitation programs can increase the likelihood of the older adults staying home and avoiding institutionalization for a short (3-month) period of time, but there is insufficient evidence to indicate whether these results were sustained for longer periods of time. Given the increased vulnerability of this patient population, and that CI as a negative prognostic factor for older adults with hip fracture immediately after inpatient discharge [22], these results are potentially significant and warrant more research. Cautious interpretation of the evidence should be exercised as there is a lack of power from the subgroup analysis.

The paucity of studies that deliver an intervention specifically to the population with CI is concerning for a number of reasons. There are approximately 35,000 and rising hip fractures reported annually in Canada [23], and CI is present among almost half of all individuals who experience a hip fracture [7]. Yet, the presence of CI among this patient population has traditionally been a barrier to accessing rehabilitation services [4-6]. The continued exclusion from inpatient rehabilitation of older adults with CI is a concern because they are viable candidates for rehabilitation; evidence shows that older adults with CI can recover from hip fractures and return home when they are provided access to inpatient rehabilitation [24]. However, the current lack of literature evaluating outpatient rehabilitation interventions makes it difficult to determine the feasibility, acceptability, and effectiveness of relevant intervention components for older adults with CI. Our systematic review uncovers the uncertainty of a research topic and provides a baseline of evidence which can contribute to stimulating more robust research [25].

Through conducting this review, several critical insights were gained regarding the design and implementation of outpatient rehabilitation interventions. There was a consensus between the three studies that the outpatient rehabilitation interventions should begin early in the care trajectory while the participants are still receiving inpatient care, and should include discharge planning. Although it was unclear from the studies when exactly the discharge planning began, there is evidence that early initiation of discharge planning improves the continuity of care from an inpatient hospital setting into the community [26]. Maintaining continuity of care is a crucial aspect of geriatric care because older adults recovering from a hip fracture are most at risk during transitions, and inconsistencies in care can negatively impact patients' ability to maintain the progress they made in inpatient rehabilitation [27].

The other acquired insight is that an interdisciplinary team approach was a shared commonality of the interventions. Physiotherapy visits were included in all of the interventions; unfortunately, the authors poorly described the details of the physiotherapy component. The lack of information regarding the physiotherapy component of the interventions is concerning as there has been an increased emphasis on post-operative physiotherapy and occupational therapy [21]. We have defined this ambiguity as the "black box of physiotherapy". In addition, because there is no standard evidence-based care practice for this particular population in the community, it is challenging to determine the most appropriate person to deliver the therapy, in the suitable dose, frequency, and intensity, as well as identify outcome measures that are responsive and sensitive to change over time in order to compare and analyze these component characteristics. In addition to physical therapy provided by PTs, other healthcare professionals delivered additional intervention components such as cognitive therapy, home assessments, family education, and discharge assessments [15,17]. Although the effectiveness of these components was not individually evaluated within each article, it highlights the importance of implementing an interdisciplinary team. This finding is consistent with other systematic reviews in the literature that suggest multi-disciplinary interventions are beneficial when

caring for older adults, especially for individuals with CI [28,29]. The results of this review highlight the minimal amount of extant evidence that support health care professionals to provide outpatient rehabilitation interventions for this vulnerable population.

The results of this review indicate that there is a lack of clarity about what community-based rehabilitation interventions for individuals with CI following a hip fracture should involve, and that several substantive gaps require attention to move this field forward. Firstly, only one study described PTs and RNs giving counseling to family members [15]. In the transition from hospital to home, there is a shift of responsibilities to family and other informal caregivers in order to manage the needs of the older adult, thus there is a need for added support and resources for caregivers [27,30]. Future studies should provide emotional and physical support for family caregivers who assume significant roles that are rarely prepared for [31], especially as caregivers become older and may have chronic health issues themselves [32]. Prior to discharge, family members, caregivers, and community care providers are pivotal in translating concepts from an inpatient to an outpatient setting and should be included in discharge planning to increase the consistency of care after discharge. Also, further consideration on how to best leverage and support family caregivers in order to optimize patients' reintegration to the community, social activities, and other interests outside of the home is needed.

Secondly, there is a need to focus on interventions that are tailored specifically to the patient with CI. Given the debilitating and omnipresent sequela of CI, it would be reasonable to expect that those with CI generally need more individualized care than what standard care currently offers. Since it remains unknown if adapting currently existing frameworks or interventions for those whose cognitive reserve remains intact or using a framework previously developed intervention to include older adults with CI is optimal, perhaps interventions for individuals with CI need to be developed tabula rasa. The needs of older adults with CI may not be addressed by existing rehabilitation programs or standardized checklists intended for a wider, potentially healthier population. More research is required to assess the effectiveness of outpatient rehabilitation programs for older adults with CI following a hip fracture that consist of specific components focused explicitly on physical and cognitive advancements. For example, including a cognitive rehabilitation component that focuses on identifying and addressing individual needs and goals of the patient and targets cognitive functioning, while introducing compensatory methods such as using memory aids [33]. Preliminary results supporting cognitive rehabilitation suggest that more research should be done incorporating such aspects of cognitive rehabilitation with physical rehabilitation in an outpatient setting [33]. In addition, care teams need to involve older adults with CI and their families in care planning to ensure that the care and services are relevant to help them meet their needs. With respect to designing more tailored and individualized interventions, appropriate quality of life measures and a care plan based on the patients' goals and needs should be integrated and used to comprehensively evaluate intervention success. There is also a need to determine the patient profile that is most suitable for such programs; thus there is a need to

include delirium screening and more rigorous cognitive assessments to better understand if the intervention affects different types of CI. Pilot testing of evidence-based interventions using this approach is warranted and the first step to establishing a new framework applicable to this population.

Third, we were unable to compare and evaluate which program components were essential to include in an outpatient rehabilitation program due to the heterogeneity of outcome measures, the lack of description regarding the cognitive function assessments and measures, poor participant description (eg, participants' comorbidities and baseline data, primary type of CIs), and lack of treatment fidelity monitoring in the included articles. The lack of interventions designed for individuals with CI may be due to a lack of consensus on the proper tools appropriate to measure progress among this population, highlighting the need for increased evidence-based care. Further exploration regarding the corresponding tools that are feasible for the assessment of older adults with CI, and incorporating relevant gold standards for measuring mobility, function, and ability to perform ADLs is warranted. Moreover, greater attention on the comparability of patient performance in a clinical setting versus in the patient's home would increase our understanding about which measures are best to use. Future research programs should use the same assessment, and measurement tools consistently so that studies can be directly compared to identify what components are most effective for those with CI post hip fracture.

Finally, cost or cost-effectiveness to patient care provision was not an outcome in the included studies which were conducted in Taiwan, Finland, and Australia. The cost of providing hospital care is generally the largest health care cost driver in any health care system, which favors the trend towards co-management models of care [34] or community-based treatments and programs to mitigate care costs [10]. Given the concerns regarding fiscal sustainability in public health care and the general increase in health care spending, future programs that evaluate the economic value of the intervention and include a cost effectiveness analysis are merited.

Strengths and Limitations

A major strength of this review is that it is comprehensive with the use of a librarian; we used multiple search strategies (electronic search of multiple databases, ancestry search of references) and conducted the search multiple times to ensure the most current evidence was considered. For the electronic search, we searched the databases from inception, and used several terms that are synonymous with community based

programs, such as "home-based" and "outpatient," to ensure the search was inclusive of interventions and programs. We also considered a broad range of outcomes including patient physical function, mobility, and organizational outcomes like emergency room readmissions. As with any review, the findings are constrained by the methodological quality of the included studies. Other reviews [21] considered the evidence in this area to be of "very low quality" with high risk of bias due to the lack of double blinding. However, as in many clinical trials which include the use of health practitioners to deliver the intervention, conducting a double blinded study is challenging and resource intensive which may make it impossible to accomplish in a clinical setting. Lastly, the limitation of including articles published in English and French may have excluded relevant studies conducted in other languages.

Conclusion

Based on the limited amount of evidence, our review suggests that community-based rehabilitation interventions post hospital discharge from inpatient rehabilitation show promising results to improve physical function outcomes, mobility, and ADLs function 1 year post-discharge from the hospital for older adults with CI, and to increase the likelihood of returning home for a short (3-month) period post-discharge. There is insufficient evidence to indicate the effect of these programs to keep patients at home over the long-term. It currently remains unclear what components an outpatient rehabilitation intervention for individuals with CI following a hip fracture should involve. However, our review findings suggest that interventions should (1) start early in the trajectory of care while the patient is in inpatient rehabilitation and preemptively include discharge planning discussions; (2) be designed with the inclusion of physiotherapy to address the physical component of rehabilitation; and (3) be executed by an interdisciplinary team to provide multifaceted care that continues into the community setting. Given the prevalence of hip fractures in older adults with CI, future research should focus on providing support to the family caregivers as well as including them into the care plan to enhance reintegration into the community, and pilot testing programs that incorporate the goals of the patient and family. A future program of research evaluating these interventions should consider utilizing the same outcome measures, the cognitive function assessments, and detailed participant description (eg, participants' comorbidities, primary type of CIs) in order to serve as a significant building block towards developing a consistent and expected standard of practice in community-based rehabilitation for older adults with CI following a hip fracture.

Authors' Contributions

All authors contributed to the conception and design of the study, data collection, analysis, and interpretation, drafting and revising the article critically for content, and approval of the final version to be submitted

Conflicts of Interest

None declared.

Multimedia Appendix 1

Quality assessment using the Downs and Black checklist.

[PDF File (Adobe PDF File), 238KB - rehab_v3i1e3_app1.pdf]

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Abbreviations

ADLs: activities of daily living
CBI: Chinese Barthel Index
CI: cognitive impairment
MMSE: Mini-Mental State Examination
PPME: Physical Performance and Mobility Exam
PT: physiotherapist
RCT: randomized controlled trial
RN: registered nurse
SPMSQ: Short Portable Mental Status Questionnaire

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Original Paper

Systemic Lisbon Battery: Normative Data for Memory and Attention Assessments

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Abstract

Background: Memory and attention are two cognitive domains pivotal for the performance of instrumental activities of daily living (IADLs). The assessment of these functions is still widely carried out with pencil-and-paper tests, which lack ecological validity. The evaluation of cognitive and memory functions while the patients are performing IADLs should contribute to the ecological validity of the evaluation process.

Objective: The objective of this study is to establish normative data from virtual reality (VR) IADLs designed to activate memory and attention functions.

Methods: A total of 243 non-clinical participants carried out a paper-and-pencil Mini-Mental State Examination (MMSE) and performed 3 VR activities: art gallery visual matching task, supermarket shopping task, and memory fruit matching game. The data (execution time and errors, and money spent in the case of the supermarket activity) was automatically generated from the app.

Results: Outcomes were computed using non-parametric statistics, due to non-normality of distributions. Age, academic qualifications, and computer experience all had significant effects on most measures. Normative values for different levels of these measures were defined.

Conclusions: Age, academic qualifications, and computer experience should be taken into account while using our VR-based platform for cognitive assessment purposes.

Introduction

Attention and memory are among the most common cognitive functions affected by acquired brain injuries [1]. Attention refers to the process of selecting a specific stimulus from the physical environment (external stimuli) or the body (internal stimuli) [2]. In addition to selection, this ability also depends on processes of orientation and alertness [3]. The symptoms resulting from the disruption of these abilities are related to an inability to process information automatically. Tasks that are usually automatic (eg, reading) become more difficult for patients with brain injuries, and require a great deal of effort and concentration [4,5]. The neural basis for attention may rely on different brain areas, from midbrain structures [6], to parietal regions, and the anterior pre-frontal cortex [7,8]. The ability to perform everyday life tasks may also depend on memory functions [9], which are particularly affected by pre-frontal brain lesions [10]. Memory can be defined as the ability to encode and/or recall a specific stimulus or situation. There are different theoretical and clinical models that conceptualize

memory in terms of information (declarative vs non-declarative) or temporal dimensions (retrospective vs prospective). One model of memory suggests, for example, that information can be manipulated in memory before it is used for a specific purpose [11]. This ability has been defined as working memory, which consists of multiple subsystems that store (for a limited amount of time in short-term memory), and manipulate different kinds of sensory information [12]. However, the roles of attention and memory abilities in everyday functioning go beyond these specific processes, being related to a wider range of cognitive functions called executive functions [13].

The ability to prepare a meal accurately by being able to maintain an adequate level of attention to the task, or even remembering what to buy at the grocery shop, are examples of attention or memory abilities applied to different domains of instrumental activities of daily living (IADLs) that are usually compromised, to different extents, by traumatic brain injuries [14], stroke [15], or even alcohol abuse [16].

The assessment of attention and memory functions is traditionally made with paper-and-pencil tests. Cancelation tests for visual stimuli are usually the best option to assess attention abilities, whilst the Wechsler Memory Scale is one of the most widely used tests for memory assessment [17,18]. This test assesses memory functions within different domains, comprising the following seven subtests: (1) spatial addition, (2) symbol span, (3) design memory, (4) general cognitive screener, (5) logical memory, (6)verbal paired associates, and (7) visual reproduction. In addition to the partial scores on each subtest, total scores reflect general memory ability. One of the shortcomings of such tests, however, is the fact that they do not evaluate the patient while he or she is performing IADLs. Their ecological validity is, therefore, uncertain [19-21]. The optimal way to avoid this pitfall is to carry out evaluations of cognitive performance based on IADLs. While pervasive technologies are already available to contribute to this purpose through the collection of behavioral and physiological data [22], the correlation between the collected data and the impairment of a specific domain, such as memory and attention, has not yet been established.

An emerging alternative to traditional tests is to design and develop virtual reality (VR) worlds that mimic real IADLs and record participants' performance while executing specific tasks involving attention and memory functions. One such platform is the basis for the Systemic Lisbon Battery (SLB) [23]. It consists of a 3D mock-up of a small town in which participants are free to walk around and engage in several IADLs and in ordinary digital games. While these activities are taking place, the system records for each task several indicators of performance, such as errors and execution times. In order for this to fulfill its purpose of assessment, it must be ensured that the SLB activities are valid indicators of functionality for the cognitive dimension that they were designed to assess. For the virtual kitchen, one of the activities of the SLB, this has already

been established [24] using the Virtual Kitchen Test (VKT). The VKT was designed to evaluate frontal brain functioning and was pre-validated in a controlled study with a clinical sample of individuals with alcohol dependence syndrome and with cognitive impairments. This test was developed according to the rationale of the Trail Making Test [25], which is a well-established test used to assess frontal functions. The results showed that scores from the VKT were associated with participants' performance on traditional neuropsychological tests, and discriminated between the cognitive performance of patients and controls involved in the study.

Another recent study has focused on defining normative data based on which clinical deviations could be identified for each IADL activity and/or task in the SLB [23]. In that study, 59 healthy students performed the exercises available in the SLB that address attention and memory functions. The results of that study suggested that this approach may be an alternative to traditional neuropsychological tests, but broader samples were needed to establish the normative values of performance in those tests with greater confidence. Here, our aim was to estimate normative scores for the SLB from a larger, non-clinical sample collected in the general population, as well as to test the concurrent validity of the SLB subscales with conventional neuropsychological tests.

Methods

Participants

We used a snowball method for recruiting participants. Masters students enrolled in a course on cyberpsychology were specially trained for this study and recruited family members (ie, siblings, parents, and grandparents) to participate. This ensured some demographic diversity through the participation of roughly three different cohorts of adults of both genders. These were asked to participate in a study designed to evaluate attention and memory performance while executing VR-based daily life activities. Participants were not included if they were younger than 18 years of age, had a history of psychiatric disorders, perceptual or motor disabilities or substance abuse. In addition, participants were excluded if they did not have regular access to the World Wide Web and/or if they scored below the cutoff values for their age on the Mini-Mental State Examination (MMSE) [26], which was administered prior to the main tasks. However, all participants scored above those cutoff points.

A final sample of 243 participants with a mean age of 37 years (SD 15.87), 39.5% male (96/243), and 60.5% female (147/243), was included in the study. Of the participants, 69.5% (169/243) had previous experience in using a personal computer for gaming purposes. Formal education ranged from 9 years to post-graduate level, with completed secondary-level studies (27.2%, 66/243) and ongoing university studies (23.0%, 55/243) the most frequent responses. A characterization of the participant sample is detailed in Table 1.

Table 1. Sample characterization (N=243).

Characterization		n (%)
Gender		
	Male	96 (39.5)
	Female	147 (60.5)
Employment situation		
	Student	71 (30.1)
	Working student	1 (0.4)
	Worker	144 (61.0)
	Unemployed	9 (3.8)
	Retired	11 (4.7)
Computer experience		
	None	22 (9.1)
	Basic	88 (36.2)
	Intermediate	116 (47.7)
	Expert	17 (7.0)
Video game experience		
	Never	107 (44.8)
	Occasionally	88 (36.8)
	Frequently	30 (12.6)
	More than 50% of days	9 (3.8)
	Every day	5 (2.1)
Formal education		
	Basic studies	43 (18.0)
	Incomplete high school	32 (13.4)
	High school	65 (27.2)
	University studies	55 (23.0)
	University degree	35 (14.6)
	Graduate Studies	9 (3.8)
Age, years		
	Mean (SD)	36.99 (15.85)
	Minimum	18
	Maximum	86
MMSE score		
	Mean (SD)	28.09 (3.09)
	Minimum	22
	Maximum	30

Study Procedure

Potential participants first responded to a screening protocol questionnaire. If they did not fulfill all the inclusion criteria, they were thanked and did not participate in the study. Participants fulfilling the inclusion criteria were given the MMSE test, but their results on the MMSE were only analyzed after their participation in the main task. Both the MMSE and the screening protocol used to assess the other criteria were administered in paper forms. Interviewers then ran Unity Web Player and asked participants to sign in to the platform with a pre-established code so that we could, if needed, establish an epigenetic relation between participants. Before performing the main tasks, participants carried out a familiarization task to ensure that they had the necessary skills to navigate and interact

in a mediated 3D environment, but this task did not include the tasks on which they would be assessed.

The main tasks were carried out on the SLB [23], a VR platform for the assessment of cognitive impairments based on serious-games principles and developed on Unity 2.5. It consists of a small-city scenario, complete with streets, buildings, and normal infrastructures (eg, shops) used by people in their daily lives. The SLB is freely available online [27]. To ensure a more immersive environment, tthe SLB scenario is populated by computer-controlled non-playable characters (NPCs), which roam across the city. Besides the house, which is the spawn point (the starting point of the player in scenario), and in which the users can engage in most of the home-based daily activities (ie, personal hygiene, dressing, meals), this "city" has a supermarket, an art gallery, a pharmacy, and a casino. The assessment tasks are performed in all these settings. The tasks to perform in the SLB range from memory tasks to complex procedures, and the platform is undergoing a constant process of development to optimize and expand the set of tasks included.

In this particular study, participants performed three different tasks. The first (fruit-matching) is a short-term memory task consisting of a matching tiles game in which participants had to complete 8 trials of matching pairs of fruits. The second (supermarket) is a working memory and attention task, and took place in a supermarket scenario where the participants were instructed to buy 7 products (a milk bottle, a pack of sugar, a bottle of olive oil, a pack of crackers, a bottle of soda, a bottle of beer, and a can of tuna) for the lowest possible expense (€25 maximum) in a minimum amount of time. The third (art gallery) is an attention task, and took place in an art gallery. Participants had to match missing pieces in three different paintings into their correct place. These three tasks are illustrated in Figure 1.

The avatar was spawned in the bedroom, where the participant had to complete the first task. The other tasks were performed according to a protocol that was provided on screen just before signing in. All activities were listed in the protocol, together with the indications to roam the virtual city. For each task, performance indicators were automatically recorded, for each code, in a file (*.txt) that was later exported to Microsoft Excel.

Figure 1. Systemic Lisbon Battery (SLB) subtests. City spawn point (top left); gallery (top right); supermarket (bottom left); and memory game (bottom right).
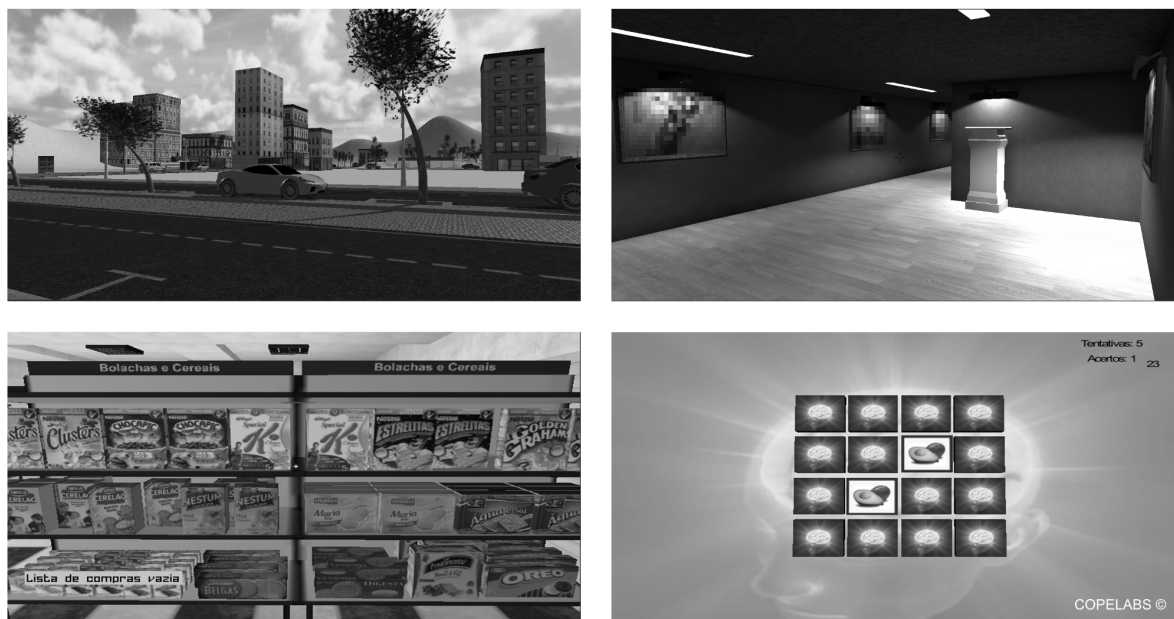
Outcome Measures and Statistical Analysis

Basic cognitive performance was assessed with the MMSE [26] in a validated Portuguese version [28,29]. The MMSE is a brief screening test that assesses aspects of mental function related to cognition. Higher scores on each measure indicate better cognitive functionality. We used the cutoff values for the Portuguese population established by Guerreiro and colleagues [28], according to level of education: 22 for 0-2 years of schooling, 24 for 3-6 years of schooling and 27 for 7 or more years of schooling.

IADLs-related cognitive performance measures were based on the execution times and number of errors in the three SLB tasks (fruit matching memory task, supermarket memory and attention task, and art gallery attention task). We verified the correlations

between these to avoid measurement overlap. In the case of the supermarket task, in which participants were instructed to go for the cheapest solutions, we also added the amount of cash spent on listed products. In all cases, lower scores indicate higher cognitive performance.

The main goal of this study was to establish normative values for three subtests of the SLB. Given what is known on the effect of demographic variables (ie, namely age and education) on measures of cognitive performance, it was important to identify their effects and establish normative values separately for different levels of age and education. Since the SLB was developed as a VR application, controlling the effects of video game and computer experience was also a necessary goal. Finally, we were also interested in understanding the relations

between the results of the different subtests, as well as between the different subtests results and MMSE.

Demographic effects on performance were tested with non-parametric statistical analyses (Mann-Whitney and Kruskal-Wallis tests for independent samples), since the distributions of the performance measures did not pass the Kolmogorov-Smirnov test for normality. For the same reason, we computed correlations using Spearman's rank order correlation (ρ).

Inferential statistics were carried out using IBM SPSS v.20 (IBM Corp. USA). For every statistical analysis, we considered a CI of 95%, so statistical results are reported as significant when the P value is lower than .05. Although this was not an experimental study, the main conclusions of this study were based on inferential statistics, which required a priori power analysis to estimate the sample size needed for proper statistical analysis. This procedure was conducted in G*Power (v3.1) with Cohen's r effect size for non-parametric Spearman's r_s tests [30,31]. Given an expected effect size of .30 (medium) for a .05 significance level (alpha) in two-tailed testing with a power (1-beta) of .80, the required sample size for this study was 167 participants.

Results

Means (SDs) for both errors and execution time for the three subtests are reported in Table 2. For subtest 2 (supermarket), the descriptive statistics for money spent are also reported. Finally, CIs for the 95% level are also provided for each subtest. The correlations between execution times on the three different tests were all positive and moderate: gallery–memory game, $r_s(128) = .371$, $P<.001$; gallery-supermarket, $r_s(127) = .312$, $P=.001$; memory game – supermarket, $r_s(116) = .360$, $P<.001$, suggesting that time-performance on the different SLB tasks is evaluating interrelated cognitive performance constructs. The inter-correlations between execution times and errors *within* each subtest were also all positive and moderate: gallery, $r_s(125) = .300$, $P=.001$; memory game, $r_s(103) = .341$, $P<.001$: and supermarket, $r_s(129) = .510$, $P<.001$; which is what we should expect. However, none of the correlations between error rates in the different subtests were significant, which is a result that needs some discussion. In addition, the predictably negative correlations with task scores on the MMSE were all either weak or non-significant.

Table 2. Descriptive data on virtual reality-based subtests (N=243).

	Mean (SD)	CI 95%	
		Lower bound	Upper bound
Memory game execution time	40.66 (8.94)	37.29	40.91
Memory game errors[a]	7.85 (2.47)	7.43	8.49
Supermarket execution time	435.98 (202.37)	394.31	477.66
Supermarket errors	7.19 (9.59)	5.22	9.17
Supermarket money spent[b]	10.56 (3.88)	9.76	11.36
Gallery execution time	155.55 (105.12)	119.79	155.20
Gallery errors	10.64 (18.47)	5.94	13.39

[a]Number of incorrect hits.

[b]Money spent in Euros used to purchase the pre-defined list of products.

In order to test whether there were effects of socio-demographic characteristics and computer and video game experience on performance in this set of subtests of the SLB, and thus if separate normative values should be established for different levels of each of those variables, we carried out a series of tests. Since most of the outcome variables were non-normally distributed, we used either the Mann-Whitney or the Kruskal-Wallis tests, respectively, for two or more groups.

The test for computer experience (Table 3) indicates effects on execution times in both the fruit matching memory task ($\chi^2_3=12.485$, $P=.006$), and in the art gallery attention task ($\chi^2_3=9.351$, $P=.025$). In the memory task, specialists performed significantly faster than participants with no experience ($P=.008$), basic experience ($P=.001$), and intermediate experience ($P=.012$). In the art gallery attention task, specialists also performed significantly faster than participants with no experience ($P=.012$), with basic experience ($P=.006$), and with

intermediate experience ($P=.036$). In fact, participants with a lot of computer experience were typically much faster than other participants in performing the tasks, suggesting that computer experience should be taken into account when assessing performance based on execution times.

As for academic qualifications, tests results show one significant effect on performance as measured by number of errors in the art gallery attention task ($\chi^2_5= 22.024$, $P=.001$). Here, the significant differences were between participants with only basic studies, on the one hand, and on the other, those who had completed high-school ($P=.000$), had or were attending university ($P=.013$), or had university degrees ($P=.006$) (Table 4). This task thus seems to be tapping into some cognitive skill that is learned in the high school system. There were no significant effects of gender, video game experience, TV viewing-hours per week, VR knowledge, 3D experience, or 3D knowledge, on any of the cognitive performance indicators.

Table 3. Subtests results by computer experience.

	Level of computer experience, mean ranks				
	None	Basic	Intermediate	Specialist	χ^{2a}
Memory game execution time	72.68	74.96	61.98	24.00	12.485[b]
Memory game errors[c]	38.00	52.08	60.78	45.89	5.581
Supermarket execution time	84.40	68.25	60.40	54.50	4.619
Supermarket errors	75.40	66.30	60.87	74.69	2.132
Supermarket money spent[d]	81.75	61.91	63.53	74.75	3.067
Gallery execution time	75.90	71.31	60.85	29.86	9.351[e]
Gallery errors	82.70	62.49	61.86	45.67	4.476

[a]Chi-square of the Kruskal-Wallis test.

[b]$P<.01$.

[c]Number of incorrect hits.

[d]Money spent in Euros used to purchase the pre-defined list of products.

[e]$P<.05$.

Table 4. Subtests results by academic qualifications.

	Level of academic qualification, mean ranks						
	Basic studies (9[th]grade)	Incomplete high school	High school	University attendance	University degree	Graduate studies	χ^{2a}
Memory game execution time	67.23	75.33	67.09	59.04	57.65	44.00	4.774
Memory game errors[b]	42.36	64.97	60.54	50.39	51.41	42.17	7.694
Supermarket execution time	76.54	55.82	57.88	55.09	76.90	50.33	9.731
Supermarket errors	76.48	56.94	59.97	57.61	64.62	69.58	5.130
Supermarket money spent[c]	77.71	67.44	59.97	55.13	65.29	41.25	8.269
Gallery execution time	67.32	68.33	59.21	60.95	58.06	69.83	1.761
Gallery errors	84.00	73.88	46.35	54.00	54.53	52.00	22.024[d]

[a]Chi-square of the Kruskal-Wallis test.

[b]Number of incorrect hits.

[c]Money spent in Euros used to purchase the pre-defined list of products.

[d]$P<.01$.

Age was significantly, albeit only weakly or at best moderately, related to reduced performance, as measured by execution times on the different tasks: art gallery attention task $r_s(127) = .312$, $P<.001$; fruit matching memory task $r_s(139) = .172$, $P=.049$; supermarket memory and attention task $r_s(127) = .184$, $P<.001$), as well as by the MMSE $r_s(242) = -.147$, $P=.022$. We tested the effects of age cohort on performance in the different subtests of the SLB (execution time and errors for both gallery and memory game) by dividing the sample into four cohorts according to age quartiles (Table 5). Results indicate significant effects for both gallery execution time ($\chi^2_3=14.733$, $P=.002$) and gallery errors ($\chi^2_3=10.400$, $P=.015$). Older participants took longer to complete the task and made more errors. Post-hoc comparisons show significant differences in the gallery execution time measure in the comparisons between the <23 years age group and both the >49 and 35-48 age groups. With respect to gallery errors, the most significant differences were between the 23 to 34 and the >49 age groups. The age effect for the memory task (execution time) was just beyond the margin of significance ($P=.052$), so we did not analyze post-hoc differences.

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Table 5. Kruskal-Wallis non-parametric comparison of Systemic Lisbon Battery (SLB) performance by age cohorts.

	Age cohort in years, mean (SD)				χ^2
	<23	23-34	35-48	>49	
Gallery execution time	105.31 (57.36)	135.98 (69.96)	173.70 (130.58)	186.08 (103.22)	14.733[a]
Gallery errors[b]	5.69 (9.20)	3.22 (3.93)	9.91 (16.50)	19.46 (26.45)	10.400[c]
Memory game execution time	36.85 (9.19)	43.01 (7.43)	42.45 (8.19)	40.58 (9.51)	7.721
Memory game errors	8.21 (2.49)	7.86 (2.11)	8.061 (2.46)	7.33 (2.62)	.544

[a]$P<.01$.

[b]Number of incorrect hits.

[c]$P<.05$.

Discussion

Principal Findings

Neuropsychological research has exposed the limitations of traditional paper-and-pencil neuropsychological tests for the assessment of cognitive functioning. A major critique is that those tests do not replicate cognitive functions used in the activities of daily living. A more ecologically valid emerging alternative is to use VR-based applications to test executive functions and related cognitive functions such as memory and attention. One of these applications is the SLB [23], a free online application and cognitive test, which provides a highly immersive and motivating experience with a first-person view that mimics IADLs.

The main objective of this study was to identify normative values for this application to be used as baseline in clinical studies. Our results indicate that performance on VR-based IADLs as measured by execution times is enhanced by education and computer experience, whilst age decreases performance. According to these results, we propose that normative values for execution times on VR-based IADLs be separately established for different levels of each of these variables. Conversely, we found no effects of gender, which is reassuring in that it indicates that the SLB has no gender bias and normative values do not need to be adjusted to gender. In addition, the moderate positive correlations between execution times suggest that the different subtests are tapping into different but associated cognitive functions, which is what we would have expected. The same pattern was not found for errors, which is probably due to floor effects on all of these, as we are dealing with a non-clinical sample for which errors are all relatively low. However, error rates on each of the tasks are correlated with the respective execution times, which indicate they are not random. Correlations between task performance and MMSE are mostly non-significant, which is probably due to a ceiling effect on the MMSE itself, also typical of non-clinical samples.

If we take into account these differences, these results indicate that VR-based assessments of cognitive functions using tasks that reproduce activities of daily life, such as the SLB, may be useful to assess cognitive functioning during the execution of activities of daily living, although a larger study comparing normal with clinical samples, and evaluating the comparative performance and within-subject correlation between results of the SLB and traditional neuropsychological tests is still needed. Moreover, it is important to note that it is possible to have these applications available anytime, anywhere, and to everyone with the advent of pervasive technology through mobile devices, which will make their use easier and more accessible than current conventional treatments. It is therefore urgent to test their validity and establish normative data for varied populations.

Limitations

The data was recorded on a variety of personal computers and several volunteers participated in the data collection. Thus, it was impossible to guarantee homogeneity of conditions, in particular in what concerns the influence of screen types, interfaces (eg, mouse), and of the person running the tests. The over-65-years sample size was too small to draw firm conclusions for that age group. In addition, we did not assess whether prior training could impact on performance, as all participants underwent training before the assessment. Finally, the fact that we were assessing a non-clinical sample probably explains the floor and ceiling effects in the error rates and MMSE, even though this is an essential step for every assessment and/or training battery validation that is focused in working with both clinical and general populations.

Conclusions

The assessment of cognitive functions is traditionally made through non-ecological pencil-and-paper tests. However, interactive and immersive platforms options like virtual reality apps, which mimic real-life activities, are increasingly available. Nevertheless, such options require establishing normative data for healthy populations, which can be used to assess cognitive problems in (potentially) clinical populations. This study follows this aim by identifying normal levels of cognitive performance in a non-clinical sample, using assessment measures based on VR versions of IADLs chosen for their demand on memory and attention functions. Age, level of education, and computer experience all appear to contribute to performance with this tool, which implies that normative values have to be adjusted to all these variables.

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Acknowledgments

Authors' Contributions

Pedro Gamito designed the study and wrote the main part of the manuscript. Diogo Morais and Sara Correia carried out statistical procedures and analyses. Jorge Oliveira wrote the literature review. Paulo Lopes prepared the evaluation protocol. Felipe Picareli and Marcelo Matias developed the 3D app. Rodrigo Brito revised the text and the presentation of results.

Conflicts of Interest

The authors owned and have developed the SLB app, but this app is freely available and the authors will not profit commercially from it.

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Abbreviations

IADLs: instrumental activities of daily living
MMSE: Mini-Mental State Examination
SLB: Systemic Lisbon Battery
VKT: Virtual Kitchen Test
VR: virtual reality

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