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A qualitative study on a home-based stroke telerehabilitation system

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A qualitative study on a home-based stroke telerehabilitation system

Objective: This paper reports a qualitative study of a home-based stroke telerehabilitation system. The telerehabilitation system delivers treatment sessions in the form of daily guided rehabilitation games, exercises, and stroke education in the patient's home. The aims of the current report are to investigate patient perceived benefits of and barriers to using the telerehabilitation system at home.

Methods: We used a qualitative study design that involved in-depth semi-structured interviews with 13 participants who were patients in the subacute phase after stroke and had completed a six-week intervention using the home-based telerehabilitation system. Thematic analysis was conducted to analyse the data.

Results: Participants mostly reported positive experiences with the telerehabilitation system. Benefits included observed improvements in limb functions, cognitive abilities, and emotional well-being. They also perceived the system easy to use due to the engaging experience and the convenience of conducting sessions at home. Meanwhile, participants pointed out the importance of considering technical support and physical environment at home. Further, family members' support helped them sustain in their rehabilitation. Finally, adjusting difficulty levels and visualizing patients' rehabilitation progress might help them in continued use of the telerehabilitation system.

Conclusion: The telerehabilitation system studied provides patients with home-based access to rehabilitation games, exercises, stroke education, and therapists. Based on participants' qualitative feedback, it is a promising tool to deliver stroke rehabilitation therapies effectively and remotely to patients at home.

Keywords: stroke rehabilitation; telehealth; home-based; information technologies; qualitative study

Introduction

Stroke is a leading cause of serious and long-term disability in the United States [1].

After the initial days-weeks of acute care followed by rehabilitation therapy, patients with stroke still have a long and tedious recovery process in front of them, involving return of physical, speech, cognitive, and other functions. With the advance of information technologies (IT), numerous studies have investigated the feasibility and effectiveness of new tools and their design towards the purpose of facilitating additional methods to provide rehabilitation after stroke [2-12], such as telerehabilitation, video games, and robotics.

In this paper, we explore the user acceptance of a home-based stroke rehabilitation system that is comprised of games, exercises, education, and telecommunication. A pilot study of an earlier version of this system found high compliance and significant motor gains [13]. The current system delivers treatment sessions in the form of daily guided rehabilitation games, exercises, and stroke education in the patients' homes, with no live contact with study therapists. The telerehabilitation system also offers supervised therapy sessions guided by a study therapist through videoconferencing. To explore the acceptance issues, we conduct a qualitative interview study with 13 patients who completed a six-week trial of using the telerehabilitation system.

Overall, all participants rated their experience highly on the system. Among the features that enhanced their recovery, participants particularly endorsed the video-conference capability, which provided a channel for therapists to observe, correct, and provide feedback to patients. Most patients expressed that they established a personal connection with the therapist through use of the telerehabilitation system. By doing so, they felt less isolated and more positive and connected. Effort expectancy comprised of participants' engaging experience using the system, being motivated by their own

progress and the therapist, and the flexibility of schedule and location. Furthermore, facilitating factors (e.g., physical space at home and internet connection) as well as the perception of their family members influenced their use and acceptance of the system.

Methods

We used a qualitative study design that involved in-depth semi-structured interviews with 13 patients with stroke who were enrolled in a clinical trial of arm motor rehabilitation therapy and were randomized at the University of California, Irvine to receive a six-week intervention program using a novel home-based telerehabilitation system designed to improve motor recovery and patient education after stroke [14]. All interviews and data analysis were performed blinded to all study-related assessments.

Recruitment

The study was conducted in the Greater Los Angeles Area. Participants were recruited by referral from their doctors, therapists, and hospitals where they received health care services. Participants contacted the research team if they were interested in the study. They then underwent initial assessment on the functional abilities of their upper limbs by a licensed physical or occupational therapist who was part of the research team during the screening visit. The inclusion and exclusion criteria for study eligibility are shown in Table 2.

Intervention

The telerehabilitation system is comprised of four main components: games, exercises, education, and telecommunication (Table 1, Figure 1). The system delivers treatment sessions in the form of daily guided rehabilitation games, exercises, and stroke education in the patient's home. See Appendix 2 for more details. In this trial, for subjects randomized to the telerehabilitation group, members of the research team delivered the

telerehabilitation system to the subject's home, set it up, confirmed functionality, and reviewed use of the system with the subject. Patients were assigned a guided rehabilitation program using the system for 70 minutes at a fixed time every day, 6 days per week, over 6-8 weeks.

Data collection methods

We conducted interview studies in order to gain an in-depth understanding of patients' experience of using the telerehabilitation system. We contacted participants after they completed all trial components. We conducted interviews with 13 patients who completed the study and were randomized to the telerehabilitation group. All 13 participants (see Table 3) who were contacted agreed to participate in the semi-structured interview. Among them, nine of the interviews were conducted at participants' homes where the devices had been installed, and four interviews were conducted at the university enrolment site. Nine patient participants were accompanied by one caregiver who helped clarify or supplement the answers.

After obtaining informed consent from participants to take part in the current qualitative research study, we interviewed them and asked questions about their history of stroke and treatment, motivation in participating in their study, experience in using the telerehabilitation system, and intention to use the system in the future. With participants' permissions, we audio recorded the interviews. Participants were informed that they could discontinue the interview at any time. Each interview took around one hour. Subjects were provided \$25 as compensation for their time.

Data Analysis

All interviews were transcribed verbatim. We removed identifiable data and replaced patient names with pseudonyms to protect participant's privacy. We input the transcripts

into DeDoose, a web application for qualitative data analysis.

We analysed user acceptance of the telerehabilitation system based on the Unified Theory of Acceptance and Use of Technology (UTAUT) [15], a model of information system/information technology acceptance and use. The model describes four factors that would influence a user's attitude, behavioural intention and use behaviour of an information system or information technology: performance expectancy, effort expectancy, social influence, and facilitating conditions. We present findings about these four factors when patients used the telerehabilitation system. Based on the results of open coding related to UTAUT about using the telerehabilitation system, we report the themes and sample interview quotes in the next section. We used pseudonyms to protect patients' privacy.

Results

Performance expectancy

In the context of health information technology, we define *performance expectancy* as the degree to which the patients believe that using the system enhances their health conditions in physical, mental, and social/emotional aspects.

Perceived improvement in physical abilities

Overall, patients reported different levels of improvement in their physical conditions after the six weeks of study therapy. Some participants demonstrated their enhanced dexterity, strength, and endurance by comparing how their arms functioned at the end of therapy in contrast with what they were like before therapy. For P1, she mentioned *that "my arm started getting a little stronger I could reach more you know in and I practiced I started reaching for the refrigerator with my right hand and door knobs."*

Among all the components of the system, all participants rated highly their experience using the videoconference, which provided a channel for therapists to observe, correct, and provide feedback and encouragement. First, participants emphasized that they were able to obtain feedback from the therapist on their exercise. During the session, the therapists would go over many games and exercises with the patients and watch participant movements, and they could verbally correct exercise performance, make adjustments, and answer questions. Afterwards, offline, therapists could adjust game choices or game difficulty parameters (e.g., game speed, duration, or difficulty level) to adapt to a patient's progress and preferences. For example, P7 appreciated that the therapist could watch her doing the exercises and correct them when necessary: "*I enjoy giving clarification on how to do the exercises. I can see you can't do that well put your hand in your whatever and she would tell me this is the alternate way. She would tell me start from the shoulder or whatever. If I could not do each exercise, she would watch, give some little corrections ...*" Participants also liked that video-conferencing provides a visual feedback to the therapists to adjust the games and adapt to their preferences.

Perceived improvement in mental well-being

Some patients also experienced enhanced cognitive skills through playing games. As the caregiver of P3 helped add: "*It was a great help mentally.... He was confused in a few things. He started your program, I noticed he started to become better... For example, what day is today? Monday? Remember? What month?*" In addition, the education component also helped them learn about stroke that they were unaware of before. For most of the participants, the questions were rated as easy but nonetheless also helped them exercise their cognitive abilities. Some participants reported enhanced memory after playing the games.

Perceived improvement in social-emotional well-being

Some patients also reported that they felt more socially connected after using the system. Some considered talking to the therapist as a way to socially connect with others. They described becoming more isolated after their stroke, often caused by their limitations in mobility. However, the video-conferencing allowed them to talk to their therapist and therefore feel more connected. As the caregiver of P2 added: *“being alone here in the house with nobody but me and the dog, she would enjoy another woman coming ... and I think she really enjoyed that.”* Through socially connecting with others, participants experienced more positive mood. Most patients expressed that they established a personal connection with the therapist through use of the telerehabilitation system. By doing so, they felt less isolated and more positive and connected.

Effort expectancy

Overall, participants considered the system easy to learn and easy to use because of the engaging exercise experience provided by the games, the external and internal motivation in using the system, as well as the convenience of conducting the exercises at home.

Perceived engaging experience

All participants agreed that playing games made the rehabilitation experience more enjoyable. In particular, participants liked the variety of the games they had been exposed, such as poker, shooting, and driving games. For example, many patients liked the game “Shooting Ducks” because they like doing action games, and some liked the driving game because the skills could be adapted to real life when they eventually returned to driving. Some liked poker because they used to play poker in their daily lives and it helped them gain a sense of recovering towards prior hobbies. As P7 mentioned, *“I like to drive because I had to work a little bit to get in, ... I really like the blackjack because I think it*

did better there than it did Vegas. And the poker was fun even though I don't play poker.”

Through choosing and playing a variety of games, participants perceived the exercises to be more engaging compared with conventional repetitive rehabilitation exercises.

Motivation to conduct the exercises

Patients reported both external and internal motivation for performing their exercises. Externally, communicating with therapists three times a week held patients accountable for conducting the exercises. Several patients mentioned that even though they were aware that their previous rehabilitation therapy exercises, prescribed prior to study participation, were essential for recovery, sometimes they had been too tired or busy, and therefore in the past they had tended to skip sessions at times. However, during study participation, they knew that a therapist would connect and talk with them, and so they felt more obliged to complete their assignments, including in comparison to working with the system by themselves. Internally, witnessing their progress over time helped participants maintain continued use of the telerehabilitation system. In particular, they noticed the progress when they could play the games faster, easier, and with higher scores, when they observed improvement in conducting their activities of daily living, and when they received evaluation and feedback from their therapists. Overall, the external and internal motivation that drove patients to stay in the telerehabilitation program reduced their perceived effort for engaging in this rehabilitation program.

Convenience in home-based rehabilitation

All patients commented that being able to conduct rehabilitation at home has made rehabilitation much more convenient compared with having to travel to a healthcare professional. They could also adjust the time in using the system, which is more convenient than scheduling a specific time with their therapist. The convenience in

location and time also made it easier to for patients to have higher doses of therapy compared to that achieved when having to travel to a therapist at a scheduled time. As P2 reported: *“it was very convenient. You could go over there in your robe or pyjamas and do it if you didn't want to get up at 8 o'clock in the morning and get ready to...”* Using home-based rehabilitation systems also saved effort for some caregivers. For example, C7 compared her experience as a caregiver in the telerehabilitation system with sessions with the therapists in person. *“I would go with her to watch what was being done and what the goal was, how it was supposed to be, sort of continuity of care. In other words, I could learn enough to watch what she was doing at home.”* Therefore, the home-based telerehabilitation system saved users' effort in traveling to the therapists at specific time and freeing caregivers from accompanying them.

Facilitating conditions

Some participants also wished that they could have better facilitating conditions in terms of technical issues, physical space, and schedule. Three participants reported minor technical issues at the beginning of the study but appreciated that they were able to receive support in time. For example, P7 reported that the camera used for video-conferencing occasionally fell, which made them frustrated. Being provided a channel where they could always reach out for technical support was considered essential for both patients and caregivers. Physical space is the second facilitating factor raised by the patients. Two patients mentioned that they had limited space in their homes. Therefore, despite of all the benefits of the telerehabilitation systems, they found it inconvenient at times. The third facilitating factor is the time. Two participants mentioned that even though they were able to receive larger dose of therapy compared with visiting the therapist, they also reported time constraints. For example, P4 mentioned he had to suspend some daily tasks

if he was going to use the telerehabilitation system for six days a week. He wished for a less intense schedule, such as two days a week.

Social influence

Three participants mentioned social influence when using the telerehabilitation system. Besides caregivers, social influence mainly came from family members. For example, For P2, *“I have a son who comes in and out of the house about once a week and he was thrilled over anything that I was getting to help. And they have the children that are ten and twelve at that time. And the kids were really good because they realized it was grandma’s therapy and they didn’t bother it.”* Even though the system was used by a single user and not in a social model, our participants reflected that being able to receive attention from their friends and family motivated them to continue engaging in their therapy using this system.

Behavioural intention

We asked about their behavioural intention: whether they will continue to use the system in the future. Most participants agreed they would want to use the system in the future. However, participants also expected a number of improvements to the system to enable long-term usage, particularly improved ability to adapt game difficulty and to show progress over time.

First, participants expected that the difficulty of the games and exercises could be adapted to their progress over time. As our participants reflected, they had experienced improvement after using the system for six weeks. If they were to continue using the system in the long run, the system would need to keep challenging them. For example, P1 mentioned: *“You get to a point where you feel really easy so there had to be more*

goals that we had to meet because if you're not improving then you know there's no sense in doing it over and over again.”

Second, participants wished to visually see their progress over time. As mentioned earlier, participants were motivated when they subjectively experienced progress or their caregivers observed the progress. However, they also wished to view their data in the long run. Being able to see the progress over time could motivate them to make continuous improvement.

Discussion

This article reports the findings of a qualitative study of a telerehabilitation system for patients to conduct upper limb therapy sessions at home through therapy games, exercises, videoconferencing with therapists, and education. We conducted interviews with 13 patients who had completed a 6-week trial with the telerehabilitation system. We qualitatively analyzed the data in four aspects that determine a user's acceptance towards a technology following the UTAUT technology acceptance model: performance expectancy, effort expectancy, social influence, and facilitating factors. We further present users' intention and suggestions when considering theoretical use of the system for a longer term. Finally, drawn from the findings, we discussed three implications in designing technologies that facilitate stroke rehabilitation: design for individualized rehabilitation plan, design for engagement, and design for the home environment.

Acknowledgements

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Conflicts of interest

Dr. Cramer has consulted for MicroTransponder, Dart Neuroscience, Roche, Neuroolutions, Regenera, Abbvie, SanBio, and TRCare.

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Appendixes

Appendix 1: Definition of constructs in UTAUT model

Performance expectancy: the degree to which an individual believes that using the system will help him or her to attain gains in job performance.

Effort expectancy: the degree of ease associated with the use of the system.

Social influence: the degree to which an individual perceives that important others believe he or she should use the system.

Facilitating conditions: the degree to which an individual believes that an organizational and technical infrastructure exists to support use of the system.

Appendix 2: procedure of the clinical trail

Subjects received a total of 36 treatment sessions, half supervised and half unsupervised.

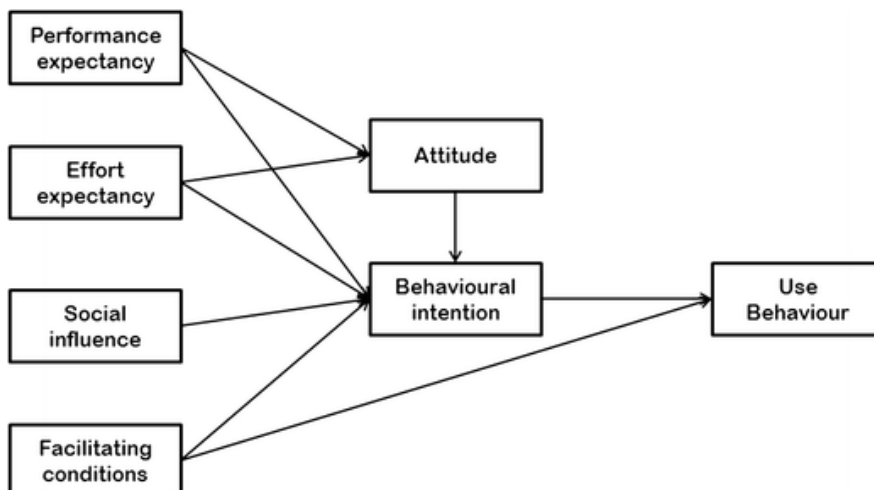
At the beginning of each supervised session, at the agreed upon time, a treatment therapist at the study site initiated a videoconference (Figure 1) with the subject's telerehabilitation system. The treatment therapist then supervised the subject, using a structured approach, for a 30-minute period during which the therapist observed the patient performing assigned home-based telerehabilitation exercises and tasks, answered questions, reviewed the treatment plan, and on selected days performed brief study assessments. After 30 minutes, the therapist disconnected from the videoconference and the subject completed the remaining 40 minutes of therapy guided by the telerehabilitation system. The 18 unsupervised therapy sessions were performed by the subject at home using the same telerehabilitation system but with no contact with a study therapist. Instead, all 70 minutes of therapy were guided only by the telerehabilitation system. Each unsupervised session began with five minutes of stroke education that was focused on prevention, recognition, response, and management of stroke. This was followed by games and exercises that had been assigned by the treatment therapist previously, offline.

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Figure 1. An example of a patient interacting with a treatment therapist using the telerehabilitation system during a supervised session.



Figure 2. The Unified Technology Acceptance Theory (UTAUT) [15].



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Table 1. Key components of the telerehabilitation system.

- Table
- Folding chair
- Computer with monitor, microphone, and speakers
- Verizon wireless modem
- Myo Band
- Wiimote in a pistol-shaped holder
- PowerMate
- PlayStation 3 Eye Move Controller
- Joystick
- Logitech Trackpad
- Standard rehabilitation therapy devices for the upper extremity

Table 2. Inclusion and exclusion criteria for patients enrolled in the study program.

Inclusion Criteria:

1. Age \geq 18 years at the time of randomization
2. Stroke that is radiologically verified, due to ischemia or to intracerebral hemorrhage, and with time of stroke onset 4-36 weeks prior to randomization
3. Arm motor FM score of 22-56 (out of 66, higher is better) at the Screening Visit
4. Box & Block Test score with affected arm is at least 3 blocks in 60 seconds at the Screening Visit
5. Informed consent signed by the subject
6. Behavioral contract signed by the subject

Exclusion Criteria:

1. A major, active, coexistent neurological or psychiatric disease, including alcoholism or dementia
2. A diagnosis (apart from the index stroke) that substantially affects paretic arm function

3. A major medical disorder that substantially reduces the likelihood that a subject will be able to comply with all study procedures
4. Severe depression, defined as Geriatric Depression Scale Score >10
5. Significant cognitive impairment, defined as Montreal Cognitive Assessment score < 22
6. Deficits in communication that interfere with reasonable study participation
7. A new symptomatic stroke has occurred since the index stroke that occurred 4-36 weeks prior to randomization
8. Lacking visual acuity, with or without corrective lens, of 20/40 or better in at least one eye
9. Life expectancy < 6 months
10. Pregnant
11. Receipt of Botox to arms, legs, or trunk in the preceding 6 months, or expectation that Botox will be administered to the arm, leg, or trunk prior to completion of the 30 Day Follow-Up Visit
12. Unable to successfully perform all three of the rehabilitation exercise test examples
13. Unable or unwilling to perform study procedures/therapy, or expectation of non-compliance with study procedures/therapy
14. Concurrent enrollment in another investigational study
15. Non-English speaking, such that subject does not speak sufficient English to comply with study procedures
16. Expectation that subject cannot participate in study visits

17.Expectation that subject will not have a single domicile address during the six weeks of therapy, within 25 miles of the central study site and with Verizon wireless reception.

Table 3. Demographic data of interviewed patient participants

ID	Gender	Side of stroke	Age	Accompany	Interview location
1	Male	Right	67	N/A	Home
2	Female	Left	72	Spouse	Home
3	Male	Left	80	Spouse	Home
4	Male	Right	62	Spouse	Home
5	Male	Right	84	Spouse	Home
6	Male	Right	82	Spouse	Home
7	Female	Right	63	Elder sister	University
8	Male	Right	86	Spouse	Home
9	Male	Right	77	Spouse	Home
10	Male	Left	75	Spouse	Home
11	Male	Left	52	N/A	University
12	Male	Left	55	N/A	University
13	Male	Left	63	N/A	University

Figure captions

Figure 1. An example of a patient interacting with a treatment therapist using the telerehabilitation system during a supervised session

Figure 2. The Unified Theory of Acceptance and Use of Technology (UTAUT) [15]