

Research Paper

Understanding upper extremity home programs and the use of gaming technology for persons after stroke

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Abstract

Background: Many persons post-stroke continue to have difficulty using their more involved upper extremity and home programs may be poorly adhered to limiting the amount of practice an individual receives. More information on the experience of traditional home program and the acceptability of a novel home intervention was sought.

Objective: To qualitatively describe 1) upper extremity use at home, 2) previous home exercise or activity programs, and 3) the acceptability of a novel upper extremity home program, *NeuroGame Therapy* (NGT), that combines surface electromyography (sEMG) biofeedback and a commercial computer game.

Methods: A purposeful sample of ten persons with moderate to severe upper extremity motor impairment used the NGT intervention in their home for four weeks and completed nested (pre and post) one-on-one interviews. Written transcripts from the interviews were coded and themes were identified to address stated objectives.

Results: Participants reported that while use of their upper extremity in daily activities was recommended it occurred infrequently. Most participants described previous home programs as being non-specific, were often not carried out as recommended or were self-modified. Participants found NGT to be engaging and motivating, but reported minimal changes in the functional uses of their upper extremity.

Conclusion: These findings suggest that after stroke upper extremity use may be infrequent and home program approaches could be re-examined. NGT was reported to be an acceptable home intervention, but it will require further development and study to understand its value and role in post-stroke rehabilitation. © 2015 Elsevier Inc. All rights reserved.

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Seven million Americans over the age of 20 have experienced a stroke.¹ Half of stroke survivors continue to report hemiparesis at six months after stroke onset.² Many intervention approaches attempt to leverage principles of

neural plasticity,³ such as constraint-induced movement therapy,⁴ robotic assisted therapy,⁵ electrical stimulation paired with surface electromyography biofeedback,⁶ and bilateral training.⁷ Despite these and other techniques to

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address upper extremity function, the number of persons who continue to experience hemiparesis in the chronic phase post-stroke remains high. Furthermore, poor upper extremity function after stroke has been identified as a predictor of health related quality of life in some stroke populations,⁸ placing an increased importance on methods to improve upper extremity function.

Potential reasons for incomplete upper-limb recovery, beyond the extent of neurological damage, may be the limited amount of outpatient post-stroke care that is typically received and the small number of movement repetitions completed during typical outpatient sessions.^{9–11} Strategies used in clinical practice to bridge this gap are home exercise and activity programs. While commonly suggested, there is limited information on how to create home programs that address upper extremity function after stroke in physical and occupational therapy training texts.^{12–15} Such home programs range from a one size fits all approach to individualized programs^{16,17} and consist of designated exercises or activities with a recommended dosage. Those with stroke usually receive training in carrying out a program and may receive handouts or instructions to keep an exercise or activity log.^{17,18}

While home programs are commonly used and persons after stroke typically acknowledge the value of upper extremity exercise in recovery, adherence to such programs without concurrent therapy is often low.^{19,20} Such individuals indicate difficulties in completing home programs for a variety of reasons. These include lack of knowledge on how to begin or proceed with exercises, difficulty maintaining motivation, musculoskeletal issues, fatigue, lack of time, family obligations, depression, and lack of enjoyment.^{19,21}

In recent years, video gaming and virtual reality have been introduced into therapy in an effort to increase enjoyment of otherwise repetitive exercise programs and thus assist with adherence.²² Several studies have investigated the feasibility and potential effectiveness of off-the-shelf game systems and virtual reality systems in improving upper extremity motor function with some promising results.^{23–26} Only a few studies, however, have investigated the individuals' actual experiences using such video game approaches.^{27,28}

NeuroGame Therapy (NGT) is a game-based system that utilizes surface electromyography biofeedback to control a commercially available computer game for use as a home exercise program.²⁹ Given that little is known about the experience of home exercise programs for persons after stroke and that home-based gaming approaches could be effective for encouraging movement practice, it was considered important to explore user experiences of home exercise and activity programs when developing a system for home use. This study focused on participants' descriptions of their upper extremity use in daily activities and explored their experiences with previous home exercise programs, and their new experiences with NGT.

Methods

Design

This initial study of NGT was designed to collect both quantitative and qualitative data on the effectiveness and acceptability of this home approach for adults post-stroke. The quantitative study used a repeated measures design (A1, A2, B1, A3; A = Assessment, B = Intervention) and results are reported in a separate paper.³⁰ A qualitative descriptive approach as described by Sandelowski^{31,32} was used to answer questions on the nature of home programs and the acceptability of NGT. This method is a data near approach that aims to report descriptions as the participants reported them with direct quotations and minimal interpretation.³² Nested semi-structured interviews were completed at the first baseline assessment and a third assessment that occurred immediately after NGT home use.

Sample

Participants were recruited through hospitals, clinics, support groups, and an aphasia group listserv. Each participant provided written informed consent as approved by the Human Subjects Division. All participants were at least six months post-stroke with unilateral hemiparesis and motor impairments ranging from difficulty with handling objects to no active hand movement, and had vision and hearing sufficient to complete the outcome measures and NGT. Participants were excluded ($n = 16$) if they were non-English speaking, had substantial cognitive or communication deficits, or if they had recently altered the medical management of their spasticity. Twelve participants were originally enrolled; although two withdrew secondary to lack of time to participate. Ten enrolled participants completed one-on-one interviews, one of these participants asked to withdraw from the quantitative portion of the study due to unrelated medical issues, but because he used the game system at home completed the second interview (Table 1). All names used in this paper are pseudonyms.

Table 1
Participant characteristics

Pseudonym	Age	Gender	Hemiplegic side	Years post stroke	In therapy	Digit ext. WFL ^a
Hannah	54	Female	Left	9	No	No
Michael	53	Male	Left	5	Yes	No
Harriet	67	Female	Right	3	Yes	No
Jennifer	54	Female	Right	1	Yes	No
Mary	47	Female	Right	3	Yes	No
Brad	68	Male	Right	9	No	No
Wayne	58	Male	Right	6	No	Yes
George	69	Male	Left	27	No	Yes
Gerald	69	Male	Right	2	No	No
Zac	44	Male	Left	<1	No	Yes

^a Digit extension within functional limits.

NeuroGame Therapy (NGT)

NGT is an augmented form of surface electromyography biofeedback in which the participant controls the cursor of a commercially available computer game (Peggle™) using muscle activity in the affected limb. The intervention focused on motor control of the wrist flexors and extensors of the hemiparetic limb. In Peggle™, participants aim a ball to eliminate colored pegs with increasing complexity as the game proceeds. Levels of difficulty were advanced in two ways: 1) passing into higher game levels required increased motor control; or 2) adjustments to the amount of muscle activation required to control the cursor for one or both muscles. After the second assessment, participants completed training on use of the system including how to setup the electrodes and operate the computer. If a participant planned to have a caregiver assist at home for setup of the system ($n = 2$), the caregiver was present for at least one training session. The system was setup at home for nine of the participants. Home setup was not possible for one participant and game play was completed independently in a campus setting. When at home participants were asked to use the system for 45 min five days/week over a period of four weeks. Participants were contacted by the research team intermittently throughout this period to ensure the system was working and to adjust the level of difficulty as needed.

Qualitative procedures

Participants completed two interviews, at the initial quantitative testing session and immediately following completion of NGT. The interviews were semi-structured and used an interview guide. The interview guide was developed based on the specific aims for the qualitative portion of the study. The questions in the initial interview focused on two primary areas: 1) functional use of the affected upper extremity in their daily life, 2) experience with previous home exercise or activity programs. The follow-up interview asked participants about two additional topics 1) their experience using NGT and 2) any notable changes in functional upper extremity use. (See the [Ancillary Material](#) for complete interview guides.) Interviews lasted 15 min to an hour and a half depending on the individual's responses and ease of communication. All interviews were audio recorded. Persons with expressive aphasia at times used gestures or written words to communicate during the interview. In order to capture these alternative communication strategies, the interviewer described them as part of the audiotape recording.

To ensure participants were comfortable expressing positive or negative views about NGT or their past experiences, all interviews were completed by one of two trained interviewers that were not involved with the intervention portion of the study.³³ The interview guide was followed to assure topic inclusion and impartiality. There was one instance

where neither trained interviewer was available for a follow-up interview. In this case, another researcher listened to a previously recorded interview and reviewed the interview guide prior to carrying out the interview.

Data analysis

Audio recordings were transcribed verbatim as text documents. To ensure the accuracy of the transcription, they were reviewed prior to coding by the primary researcher (EDB). Qualitative content analysis was used as the guiding method to code the data.³² In this process the aim is to summarize the data in everyday terms. The interviews, therefore, were initially coded based on the interview guide structure. For example, comments related to “Functional Use of Affected Arm” were grouped together under a single code. Additional codes were then created in order to capture key topics that were not covered in the initial coding structure, such as “Attitude” which described instances where participants expressed how they felt or thought about their affected upper extremity.

Coding was first completed by the primary researcher and verified by a second researcher (BD) with extensive experience in qualitative analysis. Any disagreements regarding a particular use of a code were discussed until a consensus was reached. Codes were then organized into themes under three broad categories: 1) affected upper extremity use, 2) perceptions of past home exercise or activity programs, and 3) experiences and perceptions regarding NGT. To ensure that the findings were an accurate representation of the participants' views, paraphrasing took place during interviews and member checking was completed with three participants via telephone calls after data analysis was completed. Participants expressed no disagreements with the interpretation of the data.

Results

Pre-intervention interview

Participants had been asked to describe how they used their affected arm/hand in daily activities in order to understand their functional ability. Two themes emerged regarding upper extremity use in daily activities: 1) that it was infrequent; and 2) that participants felt they should be doing more. Nine participants were able to name at least one functional activity in which they tried to use the affected limb, such as turning on and off light switches or incorporating the affected limb into dressing and cooking activities. However, most participants felt that the use of their affected upper extremity was rare. For example, Harriet said “*I have tried to use it with opening doors or hanging – using it to hang up clothes ... the thing of it is, is that it's very [frustrating] ... Most of the things I do, uh, with my left hand.*” Mary stated, “*I really can't do a whole lot with it though. I can't you know get a cup*

or anything like that ... I don't use it." George echoes these sentiments saying, "Unless I really have to u-involve both hands I, I do everything with the right [less affected upper extremity]." This appeared to be independent of their level of function as participants with severe impairments as well as those with more moderate impairments reported limited functional use of their affected upper limb and hand.

Despite participants reporting infrequent use of their upper extremity, several participants reported that they felt they should be trying to use it more frequently. Michael stated, "I'm um chagrín to say that I don't use, I don't try to use it as much as I should." Zac reported "[I] Probably need to be trying to make it do more than it is ... What I mean I should be trying to make myself eat with it I guess. It seems like that's something I should-probably about time to be ... forcing the issue on that." Some participants while recognizing that they could use their upper extremity more expressed that they were just learning to use it or were unsure of how to use it. For instance, Mary stated "... And you know the one lady said, she said, 'You need to use it,' And, I'm like but how do I use it?"

Home exercise/activity programs

Three themes emerged regarding previous experiences with home programs. Two themes characterize home programs as: 1) non-specific and 2) self-modified. The final theme reflected barriers that participants reported in implementation of their home program. Although participants' views varied greatly, it appeared that most programs consisted of active and passive range of motion exercises, strengthening exercises, and a few included functional activities. While most participants could recall some exercises or activities that they were instructed to do at home, only a few participants recalled how often they should complete them or the number of repetitions they should do, even though six participants reported receiving handouts. Wayne reported several activities that he did, but when asked how much or how often they were to be done he stated "No, she didn't say how much." In addition to non-specific recall of exercise or activity programs, most participants (7/10) either lacked a strategy to or reported difficulty in incorporating home exercise/activity programs into their daily routines. For example, George reported that he did not have a schedule for this but rather "it just happened whenever." When Hannah was asked about how her home exercise program fit into her routine she stated, "Well it didn't. That's what I'm telling you, it didn't. (short laugh) You know, I get home and I'd get busy being a mom and a ... office manger and trying to handle some part of my household." There were a few participants, Bruce and Gerald, who reported a routine with dedicated time to daily upper extremity exercise.

A second theme was self-modification of their home program often independent of advice from therapists. Two participants reported substantially changing their programs because they did not feel that the programs were working.

Gerald after not having much success with his home electrical stimulation only once a day stated, "I read up on it [the]. Research, uh, research procedure. And they had it three times a day" and reported adding two additional electrical stimulation sessions to his routine. Hannah also took steps to leave her home program when it stopped working "... I hired a personal trainer. And, um, so there's this series of exercises ... my daughter found on the Internet ... And they said, if I do these levels [of exercises], I get to [level] three and I'll be able to use my arm and hand." Other participants reported efforts to add new activities to existing programs as they felt it was warranted. Jennifer reported finding a place to continue her work, "I set myself up in a gym after, um, when therapy ran out ... And, um, that gives me a designated place to go to do what I'm supposed to do."

Participants during the course of the pre-intervention interviews also reflected on what made it difficult to continue with prescribed home programs. One common barrier was the level of frustration that was present as they tried to use their upper extremity. Michael stated, "if you get frustrated and discouraged with what you're trying to do you just won't do it." Hannah echoed this sentiment stating, "... but that's another thing an' I get so frustrated and then I'm just a ball of tears and ... It doesn't seem worthwhile to make myself that upset." Two participants also reported that pain limited home exercise, while some stated that cognitive or behavioral issues limited their participation. For example, Mary stated, "Well it's because I don't remember ... So, I mean, someone has to come over and physically say, 'Hey, we're gonna do this.'" Whereas Zac commented, "I would say, you know, one of my biggest issues [is] ... initiation ... And it's particularly obvious when it came to those exercises."

Post-intervention interview

NeuroGame Therapy experiences and impressions

After completing the 4-week NGT intervention, participants provided feedback on acceptability, perceived effectiveness, as well as challenges and suggestions for improving this approach as part of upper-limb rehabilitation.

NeuroGame Therapy acceptability

Most of the participants in the study found NGT to be engaging and enjoyable. Brad concisely stated, "[The] game just was awesome." Michael commented that "And it's exciting ... when I can ... actually make something happen with my brain with my affected side." A few, suggested that the game was not cognitively challenging and did not motivate them. Bruce stated, "It's just all pinball." Harriet commented that, "playing games ... just doesn't motivate me. I understood why the purpose of the game and what the benefit of the game, but at the same time it wasn't something I enjoyed doing, to be honest with you." In addition, some participants, including those who found the game enjoyable, suggested that making the game more age appropriate would be beneficial. Although

participants had different perspectives on the acceptability of NGT, when asked directly if they would recommend it to others, nine out of ten reported that they would. Six out of ten participants reported including the game into their daily routine. For instance, Hannah had it setup at the office and reports, “*So it was easy to form a routine about when I would do it because I have a lot of cheerleaders there.*” Others, however still struggled to form a consistent routine. As Michael stated, “*I was fairly erratic ... Routine for me is difficult just to begin with.*”

NeuroGame Therapy perceived effectiveness

While the game was generally acceptable and used, very few participants reported any substantial changes in the functional use of their affected upper extremity. Others did report more subtle changes in movement after using the program. For example, Brad stated, “*[This] was the first time I’ve got some movement.*” A few also reported that they were incorporating their affected upper extremity in daily activities in new ways. Michael who had more severe impairment reported that, “*When one’s in a grocery store, pushing a shopping cart, most people do it with both arms or both hands, and so I’m trying now to make sure I rest my affected arm on the shopping cart handle ... just at least it would start to emulate or simulate a more normal approach to ADLs.*” Similarly Jennifer also reported that she was trying new uses of her affected upper extremity, “*I put on my sweatshirt and my jacket and it there, the sleeve was up above my arm here and it was, like, elastic there so it was kinda stuck up there. And it took me a long time, but I used my hand and stuck it under the elastic and said, well, pull the sleeve and that took me a long time and it’s a stupid accomplishment but I thought, it took a lot.*”

NeuroGame Therapy: challenges and suggestions

Participants talked about challenges with NGT and improvements they would suggest for the system. Each participant encountered at least one instance of technological malfunction that required troubleshooting. Some of the issues that were faced included: 1) following the necessary steps to exit the game and shutdown the system 2) correctly placing the electrodes 3) charging the system battery 4) home setup that was different from the lab training. In addition to technical challenges, two participants reported difficulties with fatigue and found it more taxing to engage with the game when tired. For example, Jennifer reported that “*I’m really over-worked or over-tired, I find it harder to get the, the strength and finding it.*” Finally, two participants reported that during the game they experienced minor pain not requiring medical attention. Hannah reported pain in her shoulder and upper trapezius “*for a couple days and then it calmed down,*” while Jennifer experienced some discomfort, stating, “*I played so hard ... I hit [my elbow] out of the chair too.*”

Participants also made some suggestions for improving implementation of the system. One suggestion made by two participants was that the length of time that participants

used the system should be increased. Gerald stated that he wanted “*more time, uh, just, 30 days is not time enough.*” Mary concurred, reporting, “*Four weeks might not be enough to see results.*” While two other participants suggested that functional use of the arm be incorporated into the program possibly through guidance from a therapist. Harriet commented that she would like “*some exercise that would incorporate the use of the fingers so, you know ... it should have some more meaning.*” Michael thought that collaborating with occupational or physical therapists would assist in providing ideas such as, “*if I could gain wrist extension I might be able to improve the following ... for me.*”

Discussion

Key findings highlight the difficulties and opportunities in augmenting or improving home programs in general and the uses of NGT specifically. Participants were able to identify activities during which they used their affected upper extremity, but reported that these activities occurred infrequently and were challenging. Participants described that they should be trying to use their arm more everyday. But they were provided with home programs that they often recalled as non-specific suggestions, were done infrequently, and were at times modified to varying degrees. Finally, while participant’s described their experience with NGT as enjoyable, only a few noted changes in upper extremity movement, while some did discuss experiencing an increased awareness of their affected upper extremity.

Findings from this qualitative investigation are consistent with Barker and Brauer’s exploration of persons after strokes’ views on upper extremity recovery,²¹ in that both groups expressed an understanding of the importance of arm and hand use and were trying to incorporate their affected limb into daily activities and routines. The barriers for engagement in home programs are both numerous and somewhat distinct from those previously cited in the literature.^{19,21} Our participants reported frustration, fatigue, and cognitive barriers (memory and initiation) in addition to more commonly mentioned barriers such as lack of enjoyment, motivation, and musculoskeletal issues. These findings suggest that persons after stroke value the opportunity to continue recovery, but likely need additional encouragement to carry out a home program.

Most participants reported having received instruction with prior home programs, but the training that they recalled was vague. The non-specific nature of the home exercise programs may have made it difficult to incorporate these activities into a daily routine. Furthermore, after participants stopped receiving direct therapy services, it appeared that they had developed or modified their own home program routines. This suggests that programs carried out at home should continue to be monitored in order to ensure that the approaches being used are appropriate and that the person is following through and not

encountering difficulties. To remedy this, home activity/exercise programs may need to have a more intensive focus during rehabilitation with continued follow-up and monitoring via telephone or the Internet to ensure carryover and enable more effective self-management. Current research on telerehabilitation suggests that these techniques may be a viable option to extend therapy services.^{34–36}

While several participants reported that NGT was more engaging and enjoyable than their previous home programs, only a few participants were able to identify changes in their upper extremity use after NGT. This is consistent with the findings in the quantitative results of this study, which indicated small positive changes at the level of sEMG, but not at the level of functional activity.³⁰ While quantitative measures did not detect changes in upper extremity ability, several participants reported an increased awareness of their affected upper extremity and increased attempts to use it in daily tasks. This may indicate that engaging in a home program like NGT could help a person after stroke attempt to use their affected upper extremity, yet individuals likely still need assistance in identifying which activities are most appropriate for continued practice.

Based on feedback from participants, there are a few concepts to consider for incorporation into current approaches taken with home programs for persons post-stroke. Participants reported that being both engaged and successful motivated them to continue with NGT and this appeared to reduce, although not completely eliminate, frustration. Home programs, therefore, may be more readily adopted if the individual can be successful in the program without direct assistance from a therapist. Another item to consider when establishing a home program is how to incorporate a home program into their daily routine, to aid in adherence. Participants' feedback also highlighted the importance of choosing from a variety of games to engage participants. Therapists who develop home programs may then want to ensure that there are several exercises or activities that a participant can choose from in order to increase engagement.

Study limitations

A limitation of this study is that while participants were screened for severe cognitive impairments, several of the participants admitted challenges with memory and therefore their report of previous home programs may have been non-specific due to poor recall and not due to lack of instruction. Another limitation to this study was the small and variable sample. While the participants provided valuable information, a larger sample could have provided further insight and perspectives. In future qualitative research, recruiting and enrolling a more homogenous sample, possibly based on time post-stroke and/or current participation in therapy, may be advantageous. Also, the use of video recording in future studies to capture participant responses especially for persons with expressive

aphasia would allow for a more robust analysis. Continued qualitative investigation with rehabilitation therapists and family members of stroke survivors would provide a more complete understanding of how home activity/exercise programs address the needs of persons after stroke.

Conclusion

Adult participants with hemiparesis following stroke were interviewed about home exercise/activity programs in general and the use of NGT specifically. They reported difficulty using their hemiparetic upper extremity for functional activity, but understood that using their affected upper extremity was an important part of continuing motor recovery. Most participants had been provided with a home exercise program in the past, but had difficulty recalling details about it, performing it frequently, and often modified it without guidance. Participants found the NGT program enjoyable, but encountered challenges related to the use of the system and experienced minimal carryover to functional hand or upper-limb use. While we investigated only the viewpoint of the therapy recipients, these findings provide valuable perspectives for researchers and clinicians to consider when developing home activity/exercise programs that adults will perform as part of continuing stroke recovery and adaptation.

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Supplementary data

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