Eleven Months of Home Virtual Reality Telerehabilitation - Lessons learned

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Abstract—Indiana University School of Medicine and the Rutgers Tele-rehabilitation Institute have collaborated for over a year on a clinical pilot study of in-home hand telerehabilitation. Virtual reality videogames were used to train three adolescents with hemiplegic cerebral palsy. Training duration varied between 6 and 11 months. The investigators summarize medical, technological, legal, safety, social, and economic issues that arose during this lengthy study. Solutions to deal with these multitude of issues are proposed. The authors stress the importance of choosing multiple outcome measures to detect clinically meaningful change. The authors believe that in-home telerehabilitation is the future of rehabilitation.

Keywords— virtual reality, videogame, telerehabilitation, rehabilitation, fiber optics, Internet, remote monitoring, stroke, perinatal, intraventricular hemorrhage, hemiplegic cerebral palsy, hemiplegia, child, hand, sensing glove, Java 3D.

I. INTRODUCTION

Children and adolescents with cerebral palsy who live in rural areas with no specialized rehabilitation facilities find it difficult to access the interventions they need. For patients with cerebral palsy, stroke and other medical conditions, who have life-long rehabilitation needs and live in remote areas, the only practical solution to satisfy this need is to provide therapy in the home.

Eleven months ago, we began a clinical pilot study of in-home virtual reality-based hand telerehabilitation for patients with hemiplegic cerebral palsy. Three adolescents who had moderate-severe hemiplegic CP and lived in small towns in rural Indiana were enrolled. These young adults were targeted because these hemiplegic patients have disabilities which could limit their work opportunities and activities of daily living for the rest of their lives [1, 2]. Furthermore, there are substantial societal costs due to these disabilities [2], and there are few inclusive, accessible, and affordable options for long-term rehabilitation for this age group, options which are also highly motivating. Hand function was targeted because one of the investigators had found that impaired hand use in the plegic arm was common and was a major source of disability [3]. Rutgers University did prior research on clinic-based hand telerehabilitation training patients post carpal tunnel hand surgery [4]. Unlike this earlier study, however, telerehabilitation in the home and its associated challenges was an untested territory for all researchers in the team. The purpose of this paper is to describe what the research team learned about providing home telerehabilitation to people with CP, and to suggest ways to address some of the barriers to home telerehabilitation in this population.

II. METHODOLOGY

A. System

The system developed here utilized home rehabilitation stations consisting of a 5DT 5 Ultra sensing glove (Fifth Dimension technologies, Persequor Park, South Africa) fitted to the plegic hand, a 26 inch high-definition TV, a keyboard, mouse, a PlayStation3 game console and DSL/Cable router for access to the Internet [5]. Custom games were programmed in Java3D and the systems were connected to Riley Hospital and Rutgers University as shown in Fig. 1 [5]. Communications were done via a secure shell (SSH) and access to the PlayStation3s was secured behind a firewall and password-protected.

B. Subjects

Two subjects had hemiplegic CP due to perinatal stroke, one had hemiplegic CP due to perinatal intraventricular hemorrhage, which was a complication of premature birth. Ages at study onset were 13-15 years. During the study none of the subjects received other forms of therapy or medical interventions that could affect hand function.

C. Intervention

Subjects were asked to exercise their plegic hand with the system for 30 minutes a day, 5 days a week. The subjects exercised their plegic hand wearing the sensing glove to play the games. Difficulty level was customized to the subject; each subject opened and closed his/her hand and flexed/extended his/her thumb as well as s/he could at the beginning of an
exercise session. Then subjects had to repeatedly reach their own maximum movement to earn points in games.

Practice time and changes in finger range-of-motion were remotely monitored. This system has been described in detail previously [5-7].

All three participants stayed in the study for the first 6 months, after which point one subject withdrew temporarily due to family issues. The other two adolescents have remained in the study, though one has had intermittent periods of decreased practice, also due to family issues. During the past year, the research team learned that successful in-home telerehabilitation requires engineers and physicians to work together to address medical, technological, legal, safety, social, and economic issues. It was found that multiple outcomes should be measured, as a single outcome measure sometimes failed to capture significant clinical change. After almost a year of working closely as a multidisciplinary team and incorporating the frequent feedback of the subjects, solutions were developed to some of these issues. Approaches for the remaining issues are proposed here together with suggestions for future directions for the field.

D. Outcome measures

Subjects were evaluated at the beginning of the study and after 3 months of intervention using several standardized occupational therapy instruments: grip strength using dynamometer, pinch strength using pinchometer, and general hand function using the Jebsen and Bruininks-Oseretsky tests of hand function [8, 9]. Subjects also received evaluations of forearm bone health using a DEXA scan and peripheral quantitative CT scan. In addition, changes of range of motion measured by glove sensors were collected remotely throughout the study. One patient received a third set of occupational therapy and forearm bone health evaluations at 10 months.

E. Identifying and addressing barriers to telerehabilitation

The Indiana University and Rutgers University members of the research group had weekly teleconferences to discuss research problems and how to solve them. Each week the Indiana University research assistant summarized the previous week’s problems in a report that was emailed to all team members before the weekly meeting. Additional communications occurred by phone and email as the team worked on problem-solving each week. The information reported here describes what the team learned during the past 11 months of weekly meetings.

III. RESULTS: ISSUES ENCOUNTERED AND HOW THEY CAN BE ADDRESSED

Changes in activities of daily living (ADL) have been described previously [5].

A. Medical Issues

1) Medical issues can limit use of equipment, or make it difficult

a) Spasticity: Medical issues can limit a subject’s ability to use the equipment. This study found that hand spasticity was more of a barrier than anticipated. The 5DT Ultra 5 glove is made of elastic Lycra material, with fiber optic sensors on the back of each of the five fingers to detect changes in global finger flexion/extension. A “practice session” was held to test out the equipment before installing systems in the subjects’ homes. It was not realized that the subjects’ hands were so spastic that they found it difficult to don the glove even though the palm was partially open and the glove was elastic (Fig 2). Afterwards the subjects were asked to practice donning regular winter gloves in the weeks before system installation. In the early days of the study, glove donning took as much as 30 minutes- and then the subjects were expected to play the games for another 30 minutes! Two of the three adolescent
subjects eventually achieved the ability to don gloves unassisted by their parents. If this intervention is going to work in a larger population, subjects should be able to don gloves with minimal assistance, in under 5 minutes.

b) Sensory Impairment: Two of the three subjects in this pilot study also had visual difficulties related to their CP, a field cut in one case and decreased peripheral vision in the other. A large screen high-definition TVs was used as game monitor to maximize the subjects’ ability to see the games they played. Unfortunately, some of these subjects also have sensory limitations, such as hemi-neglect [10]. Future telerehabilitation interventions will require an extensive baseline neurological exam in each patient to determine which senses can be utilized for game feedback. In future studies, subjects may require large sensorial substitution, replacing a degraded visual channel with an enhanced haptic one. Haptic (force feedback) interfaces such as the Falcon [11] or the Phantom Omni [12] have become less expensive, thus predominantly haptic-based training, when needed, may be possible at home.

c) Epilepsy: Some subjects requiring telerehabilitation, such as subjects with CP, may also have epilepsy. Videogame epilepsy episodes can be induced by low-frequency flashing lights in the game, increased excitement, or even the game monitor [13-16]. Photosensitive epilepsy has been documented for Pokémon cartoons as early as 2001[17]. One European study found that playing games on a 50Hz TV was more likely to provoke seizures than playing games on a 100Hz TV [14]. Two of our three subjects had epilepsy that was well-controlled on one medication, and they had a history of previous videogame play without problems. Nonetheless, the custom rehabilitation games developed for this study avoided flashing lights, explosions or violent scenes. No epileptic episodes occurred during the study. It is suggested that researchers may want to use caution in including subjects with uncontrolled seizures or known videogame-induced seizures in studies of telerehabilitation using videogames. When off-the-shelf (web downloadable or CD) video games are used, the practitioner should consult the warning label that many game companies now include on their product. Physicians need to determine if content is appropriate for the envisioned therapy, and patient group.

2) Medical issues may limit rehabilitation potential: As reported in our previous work, the three subjects had more improvement on gross motor skills than fine-motor skills [7]. All three patients had extensive areas of perinatal cerebral injury affecting motor pathways and it is unclear how much fine motor improvement will be possible in these patients. While the home telerehabilitation field pushes the boundaries of the field, that there are, in all likelihood, some limitations to the potential of telerehabilitation. While researchers continue to see how far telerehabilitation can go in restoring function or creating function that was never there, caution is suggested when counseling patients on what could be possible.

B. Technology Issues

1) Freezing of the system: Several times the PlayStation 3s “froze” and the subjects had to repeatedly shut down the system to reset it. Many of these problems were due to a lack of sufficient random access memory (RAM) needed to run Linux and the custom games. Sony did not intend researchers to engineer around the programming in the PlayStation. Neither does Sony allow access to the powerful graphics chip in the console. The only computational recourse open to this project was the multi-core IBM processor in the PlayStation 3 and its PowerPC unit. The Rutgers part of the team has decreased freezing frequency by using the Yellow Dog version of the Linux operating system [18]. This version of Linux is specifically developed for the multi-core IBM chip, and has a smaller RAM requirement, or “memory footprint,” than other Linux OS versions used earlier in the study.

2) Simple Game Scenes: Another technology issue stemming from the lack of permission to use the graphics chip was the rendering of game scenes in software on the PowerPC. As a consequence, the scene complexity (number of polygons, textures, lighting) was reduced in order to maintain an acceptable level of graphics refresh rates. Fig. 3 shows a sample of game scenes [5]. The rather simplistic nature of the custom games used in the study may certainly diminish the enthusiasm of the casual game player, however it was not found to be an issue with the study subjects.

3) Loss of power/Internet connection: Indiana tends to have very strong storms that can knock out power and communication lines for a few days. This happened several times during the pilot study. However, the system used in this study is set such that exercises can be done if there is power in the home, even if communications are down. Once the Internet connection is restored, data are automatically uploaded to the clinical server. Thus no clinical data are lost as long as the PlayStation 3 was used. Thus, brief lapses in training due to situations beyond control did not appear to prevent continued improvement. In the future surge protectors will be provided for subjects, since harmful lightning-generated voltage surges cannot be prevented.

4) Glove malfunction: The SDT Ultra 5 gloves [19] were designed for use by people with intact hand function. Within this pilot study the gloves were tested to and beyond their limits due to use by patients with extremely flexed and spastic fingers. It was subsequently noted that these gloves tend to malfunction after about 3-4 months (see medical issues, spasticity-above). It was found that one problem was due to the sensors being pulled out of their finger “guides” when the gloves were tugged on too strongly. This problem is being addressed by writing an instruction manual for future patients on how best to get the glove on and off their plegic hand. In this and other IT-based rehabilitation system it is necessary to maintain training despite hardware malfunctions. The prudent approach is then to have duplicate systems on the premises, or close at hand, for a possible “hot swap.” In this project it was suspected that the gloves will get a more rigorous use than they were originally designed for. Thus two identical gloves were
budgeted for each subject, as well as money for repairs. When a glove wears out, the patient will immediately get a second glove, and the first glove will be sent for repair. If the second glove wears out, the subject will receive the repaired first glove. It was found that apparent decrease in function detected by remote monitoring, without decrease in function by report, is an early indication of glove malfunction. In general, manufacturers would have to increase the ruggedness (mean-time-between-failure) as well as the repair turn-around if widespread medical use of such gloves is to be successful.

C. Legal Issues

In the United States, the Electronic Communications Privacy Act and the Health Insurance Portability and Accountability Act (HIPAA) serve to protect the patient’s privacy [20] by limiting who has access to medical records. This legislation raises many concerns with regards to telerehabilitation. Other countries vary in their laws protecting patient privacy and protecting access to electronic medical records. The present study used secure shell connections (SSH) and firewalls to prevent outside access to recording of videogame exercise sessions. Both the Indiana University School of Medicine and Rutgers University institutional review boards approved the existing data safeguarding measures as part of the research protocol. Furthermore, the data collected was not generally considered medically sensitive (practice time and range of finger movement). However, one could envision a scenario where hackers were highly motivated to break into the records of a public official or celebrity undergoing telerehabilitation in order to judge the rate of recovery. To safeguard against illegal entry into the database, all experimental data was stored under patient aliases, and their
true identity was never stored on the clinical server. As the sophistication and potential of telerehabilitation develop further, the security of telerehabilitation-generated records and the protection of patient privacy will need to develop as well.

Apart from data privacy and protection against eavesdropping on electronic records, telerehabilitation poses other general legal issues. One specific issue is that of liability in case of accidents or harm to patient stemming from telerehabilitation. It is possible that therapist liability insurance may limit the geographical location of practice. One potential problem stems from patients practicing in another state, or even (in the future) in another country. Such legal issues will have to be resolved if telerehabilitation is to gain momentum.

Malpractice insurance normally excludes coverage for unlicensed activities [21]. It follows that physicians or therapists supervision of telerehabilitation services in a state in which they are not licensed becomes problematic. This puts the burden on therapists and physicians to make sure they are licensed to provide therapy or medical care in every state in which their patients reside. Furthermore, since telerehabilitation involves information technology as a conduit of medical care, liability may be shared by the technologist, not just the therapist. Programmers or engineers may or may not have liability insurance, and may not even realize they are at risk of lawsuits.

D. Safety Issues: The Patient and The Equipment

In the U.S., the Food and Drug Administration (FDA) must assess the safety of new medical devices before institutional review boards will approve studies. The home telerehabilitation system presented here was assessed as a minimal risk device, as patients do not appear to be at any significant risk of harm during use. However, concerns about the safety of the equipment used in the study did exist. One patient who was being assessed for possible participation in the pilot study was not included when it was found out that a parent was a relapsed drug addict with multiple arrests. The possibility that the parent would steal and pawn the equipment became a concern. Indiana has been going through difficult economic times, and there are increased rates of drug abuse (particularly crystal methamphetamine) in rural areas. As a consequence, all subjects participating in the study were cautioned not to advertise the presence of the study equipment in their homes, so to lower the risk of theft. Subjects were also cautioned not to eat or drink while using the equipment, and to keep it all, particularly the glove, away from small children and animals. This addressed the possibility that the $1200 custom-built sensor gloves would become a chew-toy for the family dog!

E. Personal and Social Issues

The subjects in this study went through periods of decreased practice due to boredom with the games, other after-school activities, school exams, family stress over parental job problems, family stress over parental illness, parental reluctance to spend time helping the subject don the glove, and unclear reasons likely related to adolescence. While games were modified following subjects’ input and new games were developed to address the boredom issue, a lot of researcher time was invested to even find out that other problems existed. A key finding in the pilot study is that remote electronic monitoring is not enough; humans must be heavily involved in remote monitoring. Human contact and human understanding are key to the success of telerehabilitation.

Related to remote monitoring is the issue of compliance to the prescribed home therapy. Current medical practice has little or no monitoring of exercises actually done by patients at home. Remote monitoring has the potential to improve patient compliance. In fact the best result (the most constant practice) was obtained by a combination of parent involvement and electronic monitoring.

F. Economic Issues

It was found at the beginning of the study that none of the three subjects’ homes had the high-speed Internet connections required in this telerehabilitation setup. One home had no Internet service at all, the second family could not afford to upgrade its existing dial-up Internet. Thus the research team had to subsidize the Internet connections needed out of grant funding. As the economy enters tumultuous times, it is expected that the lack of adequate Internet bandwidth in patients’ homes will be an increasing problem. In the future, installing telerehabilitation systems in schools and community centers could increase access in economically disadvantaged areas.

G. Outcome Measures, and Their Limitations

Initially, chose outcome measures were range-of-motion, pincer strength, grip strength, the Jebsen Test of Hand Function [22] and the Bruininks-Oseretsky Test of Hand Function [23]. The Jebsen test measures unilateral hand function, while the Bruininks-Oseretsky includes measures that require simultaneous use of both hands. In this pilot study, reported in detail elsewhere [5-7], at 3 months of telerehabilitation there were improvements in the Jebsen test in all 3 subjects, but no significant improvements on the Bruininks-Oseretsky. The Bruininks-Oseretsky test showed improvements in the subject who continued practice almost continuously for 11 months [6]. Meanwhile, the parents of one patient started to report changes in practical hand function within 4-6 weeks after starting therapy. Their daughter started to pick up objects with the plegic hand, using it spontaneously without thinking about it. Another parent started to notice changes in plegic hand use when questioned. Researchers realized that the subjects were developing meaningful changes in hand function that were however not being picked up by the Bruininks-Oseretsky test. Standardized, validated measure of ADL changes will be used in future studies [24].

IV. CONCLUSIONS

Medical, technological, legal, safety, social, and economic issues arose when initiating and running a pilot study of in-home telerehabilitation with virtual reality videogames. Some of the issues faced by the team- such as glove breakdown and subject boredom- were related to the unprecedented length of the study. Despite these issues there were positive outcomes of
the therapy for all three subjects. In-home telerehabilitation increases the accessibility of rehabilitation, and has the potential to become inexpensive with large scale production. The research team found that regular scheduled videoconferences and additional phone and email meetings were invaluable and catalyzed timely problem solving. A multidisciplinary approach combining medical and engineering input was also found to be highly helpful. This research team believes that home telerehabilitation is the future of rehabilitation and looks forward to working with our colleagues to overcome all remaining barriers.

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