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TITLE: Computer Based Cognitive Prosthetics: Meeting Clients' Functional Priorities

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ABSTRACT:

Some patients with brain injuries have deficits, which do not respond well to conventional therapy. Four different cases are described in which the speech/language pathologist applied highly flexible computer technology to bridge functional deficits. These individualized computer systems enabled clients to achieve their self-described priority functional goals.

LEARNING OUTCOMES:
1. The learner will understand the application of computer-based cognitive prosthetics to achieve patient-specific functional goals within time constrains that are attractive to third party payers.
2. The learner will be provided with alternative therapeutic strategies for treating patients for whom conventional interventions are no longer effective.
3. The learner will be able to identify ways to maximize patient's strengths, thereby improving the patient's level of motivation and feelings of self-sufficiency.

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This presentation has 5 major themes:
- The therapist is a major component of therapy even in technology-based rehabilitation
- Computers can be prosthetic in the rehabilitation of cognitive functioning
- "dead-end" patients can benefit from computer-based cognitive prosthetics
- the speech/language therapist doesn't need to know much about computers, but does need to be as creative with this as with any other therapeutic modality
- Those people supporting the technology need to be available and responsive to the therapist

This presentation is about people – computer scientists, therapists, and patients – and how they together have fashioned technology to attain a better rehabilitation outcome. The vehicle for presenting the themes is the case study.

This work has its origins in the mid-80s when Dr. Cole, an academic computer scientist, was touring a residential brain injury rehabilitation facility as part of an office automation consultation. Many of the people were several years post injury and had little prospect of being able to live without considerable support from a caregiver. Most of these people were young. At its core, office automation involves enhancing the individual's cognitive productivity. Here was a group of people who desperately needed their cognitive productivity increased to hopefully restore enough of their pre-injury functioning to make them less dependent on others. This experience resulted in the computer scientist shifting his research direction toward computer based cognitive prosthetics.

For the past few years, the rehabilitation services described here are paid as standard (non-experimental) health care services by a broad array of payers Blue Cross. The original research with patients was supported by insurance

company rehabilitation managers who believed this approach might directly benefit the patient. This research was also supported by grants from the National Institutes of Health.

We have found the case study to be interesting and stimulating to the audience. Because of the technology's flexibility in the hands of the therapist and patient, each case is different. Patients have unique combinations of abilities, deficits, and priority functional activities. A focus on priority functional activities – in contrast to skills-oriented therapy – makes it advantageous to provide services to the patient in the home, office, or school. The case study enables the focus on small details which are so important in achieving results. This is highlighted by demonstrations of the prosthetic software, and by videotapes showing key parts of the therapy.

Details are also important in demonstrating the ways the therapist and the patient individually and together are able to fashion the technology to directly support the patient's priority activities. The prosthetic software is constantly changed. Two software-development approaches are used which requires this amount of change. One is *evolutionary design* which is an incremental approach to software development. The second is *participatory design* where the user – in this case both the therapist and patient – play key active roles in the design of their unique prosthetic system. Some software changes make the system more "user friendly." Some of these changes add new features as they become relevant to the patient. Finally, some changes are to fix bugs in the program that emerges with use.

The therapy modality has evolved incrementally in an evolutionary and participatory manner. We now do distance therapy and telerehabilitation. Our first patient we treated together was minutes from Dr. Wilt's home in rural northwestern Pennsylvania, but 350 hundred miles from Dr. Cole and his staff. Dr. Cole was forced to do technical support via modem, day or night or weekend. Dr. Wilt and the patient soon realized that there were advantages to therapeutic support by modem, which could supplement face-to-face sessions. New videoconferencing technology now makes it practical to have face-to-face sessions in the patient's home, along with using modem communication between the therapist's and patient's computers.

Case Study 1

LS, a 45-year-old female, presented with multiple cognitive deficits as a result of a bilateral frontal lobe and subcortical closed head injuries sustained in a MVA in November 1980. Additional injuries included near severation of the right arm 2 inches above the elbow, bilateral round oval window fistulas and inner ear fractures resulting in hearing loss in her right hear, severe and debilitating vertigo, pronounced right-sided body weakness, and right visual field cuts with floaters. She progressed slowly in the intensive rehabilitation program because of vertigo and over-responsiveness to sudden motion or noises. She became ambulatory and was discharged; however, she exhibited cognitive and receptive and expressive language deficits. She functioned fairly well and lived independently but was often incapacitated by bouts of vertigo that did not respond to pharmaceutical intervention.

In the summer of 1985, a total right labyrinthectomy was performed resulting in total loss of hearing in the right ear but overall reduction in vertigo. By this time her language and cognition had improved to the point that she began to take college courses. She was referred for cognitive retraining and language therapy in 1991. She had received no speech/language therapy or cognitive therapy post MVA. Limitations in written expression had delayed her progress in college. She was unable to judge the relative importance of ideas, to sequence ideas, to remember multi-stage instructions, and to apply correct grammatical constructs, including punctuation and spelling. She was unable to select a topic from among multiple alternatives and to disengage from random development of an idea once she had "gotten into set." Residual pain and limited movement of the right arm, right visual field cuts, visual tracking problems, chronic fatigue, and pain limited her manual writing. Cognitive and linguistic problems prohibited the successful use of conventional word processing programs. Traditional and nontraditional therapeutic approaches utilized by the speech/language pathologist from 1991-1993 were only minimally successful.

In the fall of 1993, LS was evaluated at the Institute for Cognitive Prosthetics. In January,1994, following extensive neuropsychological and speech/language evaluation, LS began work with a word processor for DOS (pre-Windows 95). As a result of the collaborative efforts of the speech/language pathologist and the computer programmer, specific software adaptations were utilized, including limiting functions to save, retrieve, print, new document, and exit; allowing for long file names (up to 60 characters); and customizing the grammar checker to address her particular grammar and punctuation errors. The program collected all versions of a document and detailed usage data. LS mastered the use of the software in 4 sessions. LS and the speech/language pathologist worked on-line using remote control computer software on a system maintained by the Institute. They worked approximately 4 hours per week for

five months . Hardware and software programming problems identified by both the SLP and the computer technician were solved and additional software adaptations were made to address LS' visual and perceptual deficits and to accommodate her increased capabilities. Because of these interventions, LS was able to produce a finished product that reflected her command of the subject matter and of written composition. Use of the computer was less physically demanding.

In May 1994, LS satisfactorily met the college's language competency graduation requirement by writing a 500-word paragraph on a specific topic within a specified time limit. LS graduated in 1994 and within a few months was employed by the county Area Agency on Agingas a case manager of pre-admission assessments. As a volunteer she wrote funding proposals that generated revenue for social service agencies.

Case Study 2

DR, a 50 year old female, presented with Broca's aphasia and cognitive deficits as a result of a left cerebral hemorrhage with craniotomy in 1995 The client had intensive inpatient rehabilitation with minimal improvement in physical, cognitive, and language function. DR developed an extensive home program to improve her physical functioning as well as language expression and reading. Neuropsychological and speech/language evaluations in May, 1997 at the Institute revealed major problems in the areas of oral and written language expression and lesser problems in attention, memory, executive functioning, and stress management. DR's deficits interfered with her ability to function effectively in daily activities.

The Institute provided a customized word processor. The initial word processor had the following functions: save, retrieve, print, new document, and exit. The computer program collected all versions of a document and detailed usage data. As the client's proficiency in the use of the computer improved, additional features were added, such as cut and paste, creating folders for organizing documents, saving alternate document versions, editing (font size, centering, etc.), and grammar checking. The speech/language pathologist and therapists at the Institute worked online at least once a day using a remote control computer program maintained by the Institute and videoconferencing. Technical assistance for the speech/language pathologist and the client were available from the Institute seven days a week, virtually 24 hours a day.

The specific goal of speech/language therapy was to improve the client's written communication skills and her reading speed and comprehension. DR demonstrated limited writing output with significant problems formulating grammatically correct sentences. She exhibited speech poverty, over-reliance on concrete words, confusion regarding the use of prepositions and pronouns, and an inability to understand and use abstract words and figurative language. DR read slowly and laboriously. Gaps in the continuity of what she read arose because she was unable to recognize some words and was dependent on silent mouthing of phonemes; as a result, her comprehension and recall of information were significantly compromised.

In addition to conventional therapeutic interventions for oral and written language expression and reading comprehension, the therapist took advantage of the intact visual imaging skills in the right hemisphere to help the client understand grammatical structures, including prepositions, pronouns, and abstract words. DR's assignments consisted of making daily journal entries, writing short autobiographical paragraphs, completing worksheets, reading articles, and answering questions about these articles using complete sentences. The speech/language pathologist observed the client working on the assignments as well as reviewing the finished products. The client developed a list of common grammar and punctuation errors that she used as a cueing device when writing. Reading comprehension exercises were aimed at exercising her ability to fact find as well as her ability to reason out more subtle aspects of meaning. As the client's writing improved, the assignments included developing a resume and cover letter, as well as producing written instructions for original craft items which she hoped to market. The computer was also utilized to help the client prioritize daily activities, schedule daily activities, and develop grocery lists incorporating comparative shopping using newspaper advertisements. The client's own writing samples were used as a tool for language improvement. DR's ability to recognize errors in syntax improved, and she engaged in successful self-correction using grammar check. DR used the word processor to finish detailed descriptions of procedures for completing complex multi-step personal projects, including crafts and exercise programs.

At the end of six months, DR had achieved her short-term and long-term goals. All strategies combined resulted in improved independent functioning and increased productivity. As DR became aware of her significant gains, she spoke of an improved self-image and a greater degree of optimism. At Christmas, she sent her therapists self-

generated cards using PrintShop Deluxe. The messages were personalized and written in complex sentences using both descriptive and abstract language.

Case Study 3

JH, a 51-year-old female, presented with severe cognitive and language deficits secondary to sudden onset on September 1, 1990 of central nervous systems vasculitis with accompanying multiple bilateral lesions. The client received extensive inpatient rehabilitation as well as outpatient speech/language therapy. Her former speech/language pathologist referred her to the Institute. The client continues to suffer from significant deficits in the areas of short-term memory, word finding, writing and reading which have thus far prevented her from returning to a productive and active lifestyle. The client has had a housekeeper six days a week since her return home. Pre-morbidly the client was a practicing attorney with a Master's degree in Nursing.

The evaluation was designed to gather detailed baseline data to identify remaining areas of functioning that would be viable for use with a computer based cognitive prosthesis. The evaluation included interviews with the client and her husband, observation of the patient in her home environment, administration of the Western Aphasia Battery, review of medical documents and the analysis of a videotape prepared by her former speech/language pathologist. During the evaluation at her home, the client emphasized her frustration with her extensive functional deficits and her inability to read. She described herself as being very depressed and disinterested in the activities around her. She did, however, display a strong motivation to improve her current functioning and to participate more fully in the life of her family.

The evaluation revealed an inability on the part of the client to generate responses to questions. The client often repeated herself. Results of formal testing revealed deficits in writing. She identified letters of the alphabet, numbers, and single words. She had limited, but functional reading skills. She was unable to write her name and address. Semantic and phonemic paraphasias were noted during oral reading and conversation. Although the client had functional expressive speech and language, she displayed functional deficits in the following areas: understanding and expressing complex ideas, word-finding, short-term memory, sequencing, following complex directions, and initiating and planning activities. These cognitive and linguistic deficits have seriously interfered with the clients' ability to function independently and effectively in daily activities. Because of the severity of her deficits, she has required constant and continual repetition and reinforcement to carry out daily activities and to participate in cognitive rehabilitation.

JH was furnished with a Computer-Based Cognitive Prosthetic (CBCP) with minimal functions. Text could be typed in using 24-point type. The document could be printed using a single function key. The cursor modified in color and width for easier detection. The therapist had hidden function for editing, saving, and retrieving a document and beginning a new document. Sessions were held via teleconferencing using a remote controlled computer program.

Goals included improving reading comprehension, developing functional writing skills, increasing verbal output, and planning and implementing a daily schedule of activities.

Reading materials were scanned into the computer in 24-point type. The patient read the material aloud and answered questions related to content. Because the client was unable to find letters on the keyboard, strategies were developed to acquaint the client with the keyboard. The patient dictated letters and descriptions of daily activities, which the speech/language pathologist typed. Therapy consisted of five 60-90 minute sessions per week for a period of six weeks. The patient was given assignments to complete between sessions.

By the end of the sixth week, the client was able to identify the letters on the keyboard with 70% accuracy. She was reading 3-4 paragraphs aloud and answering questions about content and meaning with 95% accuracy. She was able to read items from Readers' Digest which required the understanding of double entendres and figurative language. She described her weekend activities at length and dictated autobiographical passages consisting of up to 15 sentences. She was able to recognize errors in typing and reading and engaged in self-correction. The client was attempting to complete assignments and expressed a desire to learn more of the functions of the computer. She was able to follow the therapist's directions to edit, save, close, and retrieve a document as well as to begin a new document.

Most significantly, the client began to take more interest in the activities around her. She looked forward to her sessions and expressed her satisfaction with her accomplishments. She began to initiate conversation with the therapist and to inquire about the therapist's families and activities. JH began to express her sense of humor and commented on decreased feelings of helplessness and hopefulness and her improved emotional and psychological status. She began to express her awareness of a sense of purpose and recognition of her emerging positive self-image.

Case Study 4

ES is a 15-year-old female who was involved in a MVA on October 19, 1995. She was in a coma for approximately three weeks. After six weeks of intensive inpatient rehabilitation, she was discharged to her home. ES's physical deficits included tremors in the left hand and leg, oblique visual field palsy, and diminished energy. ES's mother assumed the role of tutor and "wrap-around" when ES returned to school the following month. ES received voice therapy as an outpatient but underwent no further language or cognitive therapy. ES has always attended a Catholic school and was identified as a gifted student. Before the accident, ES had received inquiries from Johns Hopkins University regarding her interest in early admission to their undergraduate program in mathematics. Pre-morbidly ES was an outstanding athlete. She was involved in activities in her school, church, and community.

Although ES successfully completed the sixth grade, graduating with honors, she and her family became aware of deficits in the areas of attending, reading comprehension, and memory. Her physical problems continued undiminished. ES was referred to the Institute and was evaluated there on December 22, 1997. The focus of the evaluation was to gather detailed cognitive and language baseline data. The evaluation included a home visit, interviews with family and client, analysis of the interview video, and review of medical records. Although ES was quite verbal when responding to questions, she did demonstrate occasional word-finding difficulties and tangential, rambling speech The evaluation revealed that ES experienced functional problems in the following areas: attending and concentrating, memory, language, and executive functioning. Specifically, ES was slow to respond to others in conversation, was unable to do any multi-tasking (e.g., following lectures and taking notes), was unable to integrate material from multiple sources, and was easily distracted by external stimuli. ES reported studying and reviewing at length for a test and then "drawing a blank" when the test was administered. ES has difficulty expressing a complex thought completely or succinctly and often is unable to identify the main topic in a paragraph. ES has difficulty completing tasks. A therapeutic plan was designed and implemented to enable ES to perform learning tasks more efficiently, to read and comprehend more efficiently, to write with improved organization and topic maintenance, to minimize external distractions, to reduce frustration, and to continue assessment.

ES uses a notebook computer programmed with MS Word 7. Data analysis of the work product is completed daily. Because of the tremors in ES's left hand, she finds it difficult to use the keyboard accurately and efficiently. For that reason, a speech recognition program was supplied. Because ES now learns more efficiently through auditory rather than visual input modalities, a speech synthesis program was installed. Effective utilization of these technologies will enable ES to prioritize and organize her daily activities, to complete her homework more efficiently, and to plan more hopefully and realistically for her future

ES has trained extensively with two speech recognition programs. Since the goal of 95% accuracy in speech recognition was not achieved using DragonSystems Naturally Speaking, IBM Via Voice has been installed. The speech/language pathologist has worked with the patient at her home or via the remote control computer program six to eight hours a week for ten weeks. In addition to supervising ES's training, the therapist has helped the client to develop more effective learning strategies using the computer and to prioritize her personal and academic needs. She has worked with the parents to develop and implement an academic support network in the school.

To date the goal of 95% accuracy in speech recognition has not been reached. Several factors have contributed to this: difficulty in finding a microphone of above average quality, necessity for training the client to read or dictate with appropriate enunciation and speed, questionable "user friendliness" of the program for individuals with below average voice quality, and the inconsistencies of the program's operation. In comparison with the other individualized computer based cognitive prostheses, this adaptation requires that the therapist be proficient in the use of the program. A therapist-client relationship based on mutual trust and confidence is essential. Frustration with the technology on the part of the therapist or client will have an immediate negative impact on the therapeutic process causing an unwillingness to continue on the part of both individuals. In this case, however, both the therapist and the patient have

become more tolerant of the technology and have learned to deal with their frustrations more productively. Other benefits can be noted. ES has learned to recognize and accept her need for intervals of rest and to maximize her time and energy so that she can lead a more active life. She is excited and challenged by the prospect of learning this innovative technology and is convinced that it will enable her eventually to achieve her long-term goals. The therapist has realized that accepting the technical difficulties and mastering the art of troubleshooting has reinforced the client's determination and desire to persevere.

Discussion

The four patients described here were no longer making substantial progress using conventional speech/language pathology therapy modalities, and had no other realistic therapy options. These cases are all of our joint cases up to this point and were not specially selected for presentation.

The SP/L therapist did not need to have much knowledge or interest in computer technology. However, it is very important to be able to see how this technology can be used as a therapeutic tool. It is necessary for the therapist in general terms to describe how the therapeutic intervention should work, without being concerned about the programming considerations. For their part, the individuals supporting the technology need to have a deep understanding that the therapist is on the front line and will need support, sometimes with no notice. It is important that the technology be "user friendly" for both the therapist as well as the patient.

Part of our clinical success is attributable to the ability of the CBCP approach to address the patient's priority activities. Addressing priority activities has been a means of motivating the individual. Prosthetic technology is able to bridge deficits, enabling the therapist to address rehabilitation issues out of traditional sequence. CBCP technology enables "Out of Sequence" rehabilitation.

The success of our approach rests in large part on the attention to detail. This is particularly important in the customization of prosthetic software as well as the identification of cognitive deficits which need to be bridged. It was important to assure that the interface performed well from beginning to end, and that the individual could perform the target activity. Design problems appeared during and after the CBCP was introduced and those problems needed to be identified and resolved.

It is significant that many individuals who are successful at clinic-based rehab develop difficulties when performing the target activities in their own environment. Context-specific deficits may be the explanation for this success in one place and failure in another.

This argues for working with the patient in the setting where they will perform their activities. Thus the individual's home, school, or office is a much more preferable site for delivering rehabilitation services than is the clinic.

Telemedicine enables the delivery of CBCP services by a therapist into the home. Coupled with videoconferencing technology, speech/language pathologists can work face to face with their patients. Therapists are able to give guidance and structure to their remote patients. This can be done on an as-needed basis, for short periods several times a day. There are considerable advantages for the patient with this kind of delivery system.

Success at performing an everyday activity often can be subverted by relatively few deficits which themselves are relatively small. The impact of these deficits seems out of proportion to their role in the process. Prosthetic software can bridge these deficits. The analysis done by software designers and analysts is well suited for locating these deficits. It is remarkably easy for us to bridge these deficits and enable successful performance of priority functional activities by the patient.

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