Computer-Based Cognitive Prosthetics: Assistive technology for the Treatment of Cognitive Disabilities

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1. ABSTRACT

Traumatic brain injury and stroke leave many individuals with cognitive disabilities even after much therapy. For over a decade, our multidisciplinary group has been conducting a research and clinical program. The focus of our efforts has been restoration of individual's functioning through technology enabling them to perform some of their priority everyday activities. Our approach has been three-fold: 1) the application of theory and methods from computer science; 2) the design of one-of-a-kind prosthetic systems to bridge deficits, and 3) therapy integrated tightly with prosthetic technology. Research incorporated the single-subject case study approach – widely used in brain injury rehabilitation – with studies being partial replicates for grouping data. Results have been significant and substantial, with an increase of function being the rule rather than the exception. An important finding is that our evaluation techniques of patient abilities tends to show greater abilities than show in clinical testing. These abilities can be used in participatory design to greatly enhance the clinical outcome. Also, the impact of small deficits on behavior seems to be significantly greater than one would expect. Resolving or bridging small deficits can have considerable behavioral impact.

1.1 Keywords

Cognitive Disabilities, Cognitive Prosthetics, Usability testing, User interfaces; User studies; Personal Productivity Tools, Learning Disabilities; Health care applications.

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2. INTRODUCTION

2.1 Diseases and etiology

Traumatic brain injury, stroke, various forms of dementia, and other neurologic disorders produce acquired cognitive deficits which often block the individual's ability to return to their previous activities and fulfill the previous social roles. These disorders typically damage functioning in a number of cognitive dimensions. In the case of traumatic brain injury, damage is diffuse across cognitive domains. Rehabilitation of cognitive deficits has not been nearly as successful as rehabilitation of physical deficits. About 2 million people a year have a brain injury, and about 10% of those have long term cognitive deficits which interfere with their everyday functioning.

2.2. The structure of everyday activities

We have adapted a user model for the cognitive portion of people's activity performance. An activity is composed of a long sequence of cognitive actions by the brain. Some of these actions occur in parallel, while others are sequential. Some of these actions take place in timeframes of less than a second and some over several minutes. A failure in one step of the process is sufficient to impede the activity, and leave the individual unable to complete the intended activity. This has significant implications for rehabilitation of cognitive disorders.

When rehabilitation is not able to address all of the subtasks involved in an activity, the individual continues to be partially disabled. This has been the case for many individuals with acquired cognitive deficits from traumatic brain injury and stroke. These conditions, particularly TBI, tend to affect a number of cognitive dimensions.

When the cognitive dimensions that are needed to use computer systems are the same as those damaged by the disease process, there is an obvious problem. The "cure" cannot rely on compromised cognitive dimensions. Prosthetic computing systems must be "user friendly" to the disabled user. For us, this means that prosthetic systems must be easy to learn, produce a minimum of errors during use, and the recovery from the error condition must be easy. Applying these concepts, we have developed an approach with some success in restoring the performance of patient-priority activities.

3. MAJOR COGNITIVE DIMENSIONS

Cognitive processing involves a broad range of activities involved with "thinking." Cognitive dimensions are intimately involved with the performance of everyday activities. Significantly, these dimensions are intimately involved in learning how to use computing systems, and using them. In attempting to turn to computer technology to overcoming cognitive disabilities, one is confronted with a cure which is intimately involved with the condition it seeks to address. The most widely accepted dimensions in neuroscience are as follows :

Executive Function which includes diverse areas such as problem solving, planning, self-monitoring, task sequencing, prioritization, and cognitive flexibility.

Memory which subsumes facets such as short-term, long-term, verbal and visual, procedural, declarative, and implicit memory.

Orientation and Attention including freedom from distractibility, focused attention, and divided attention.

Visual-Spatial Processing which includes perception and integration of visual information in space.

Sensory-Motor Processing

Language including expressive and receptive language, repetition, prosody, and speech rate, and fluency.

Emotions encompassing control of and expression of emotions, detection and understanding of emotions, and frustration tolerance.

Among psychologists and neuroscientists, there are a number of different classification approaches to cognitive dimensions. But, what can be generally agreed upon is that cognitive functions are not unidimensional. Rather they are comprised of many distinct operations comprising a larger network and are expressed differently depending on the particular situation. Cognitive dimensions are constructs, methods of classifying a phenomenon for some research purpose, and necessarily represent a simplification of a process. These dimensions often are related to diagnosis, and to the design of diagnostic tests (Lezak, 1995; Kolb and Whishaw, 1990; Bigler, 1988).

4. COMPUTER SCIENCE CONCEPTS UNDERLYING COGNITIVE PROSTHETICS

Several concepts from office information systems and from human computer interaction have been particularly useful. First and foremost is the relatively old concept of computer technology augmenting cognitive and intellectual activities (Englebart 1964). It was then a small step to postulate that computer technology could be useful for cognitive disabilities.

Computer science has had very well developed models of activities applied to individuals, workgroups, and organizations. This has been critical to the evolution of software development methodologies, and to understand why systems fail. An activities-oriented model is very well suited to overcoming rather than curing disabilities.

Office information systems, including decision support, has distinguished among activities that are well structured, semi-structured, and relatively unstructured. These distinctions have turned out to be very important as we have gained more insight into the abilities which remain even with people who have profound deficits. This helps prevent situations where there is an impulse to address disabilities providing more structure and support than the individual actually requires.

Usability becomes a fundamental concept and requirement. In the mind of the general public "user friendliness" is an attribute of a device. As specialists, we understand that usability describes a relationship among user characteristics, task characteristics, and device characteristics. There are multiple and conflicting performance criteria. What is "user friendly" to an individual with cognitive disabilities (and to the larger population) in one circumstance can be user hostile to the same individual in other circumstances.

Finally, implementation details are critically important. Many of these details are at a considerably finer level of granularity than most therapists encounter in their personal and professional lives.

5. RESEARCH APPROACH AND DESIGN

The broad objective of our work has been to help disabled individuals achieve greater self-sufficiency. The research design has been a complex one. Since each individual's combination of cognitive abilities and deficits is virtually unique, single-subject case studies have been a major tradition in brain injury rehabilitation (Barlow and Hersen, 1984). That approach was adopted.

Control was achieved by using each subject as its own control. A subject selection criterion required that subjects be beyond the time period in which spontaneous recovery can be medically expected. For TBI this period is 18 months, and for stroke 9-12 months. After that time, rehabilitation could produce increases in the individual's level of function, but the rate of increase was slow. Eventually, the rehabilitation progress plateaued. Individuals used as research subjects have had cognitive rehabilitation, and have plateaued for those rehab goals which were the object of the study.

Increases in functioning following the commencement of our treatment are attributed to our treatment. Subjects have plateaued for the rehabilitation goals addressed. Baseline data shows that the individual is not able to perform a target activity self-sufficiently prior to the intervention. The activity is always described in functional terms; often the activity is also described in terms of the cognitive dimension(s) which the individual is not able to perform. Prosthetic software is designed to bridge the functional deficits. Considerable usability testing is involved in preparing prosthetic software for the patient. Then the system is installed in the individual's home, and the treatment begins. The treatment consists of therapy coupled with the use of prosthetic software. After the initiation of treatment, the prosthetic software is fine-tuned for both functional requirements as well as interface features. The intervention is deemed a success when the individual is able to perform the target activity self-sufficiently.

5.1 Interface standards

Usability is particularly important for individuals with cognitive deficits. The original standards that were adopted are:

- state-to-state transitions without confusion
- errors recovery can be achieved
- individual capable of performing all relevant subtasks in real time
- less than 3 half-hour training sessions required

5.2 Computer Platforms

When our work began in 1986, two major requirements were an open system architecture and interface simplicity. The two platforms considered were IBM PC and the Mac, and the PC was selected. Early systems' platforms were the IBM PC under DOS, with the DesqView operating system extension. Application software was developed with Clipper and third party function libraries. Some functions were developed with Microsoft C. The current platform is Windows 95 with application software developed with Visual Basic 5 plus third party controls.

6. SOME KEY CASE STUDIES.

IE

A 50-year-old woman was involved in a minor automobile accident. Initially she suffered bruises, but over the next few days developed a number profound cognitive problems. She had a profound short-term memory loss, an inability to sequence subtasks in an activity, and was also diagnosed with a "left neglect" (inability to process information on the left side of the visual field). She also had an apraxia, which interfered with some fine motor skills in her left hand. For 3 ½ years she had received extensive therapy, but was still cognitively impaired to the point of needing a full-time aide. For 2 years, she had been given twice-weekly training on a checkbook program and a word processor, but was unable to use either without someone standing over her. She had over a dozen therapists serving her, including our collaborator, a clinical psychologist.

She wanted to be able to pay her bills, because she knew that responsible adults pay their bills, and if she paid her bills she would be a responsible adult. Later we discovered she also wanted to be able to write on a text editor. Still later, a rudimentary daily schedule was developed.

The initial application was a check-writing application. The goal was to develop only the necessary functionality, with an interface which met several requirements:

- able to pay her bills at any time without the active involvement of caregivers.
- no confusion in state to state transitions
- easy for her to learn to use
- no errors that she was unable to correct

There were many usability testing sessions, which focused on each component, and then on modules. It took about 10 months to build, and required creating or changing over 1000 interface and functional parameters.

The computer system including a printer and a dedicated phone line for a modem were installed in the patient's home.

After installation and initial use, modifications were made to the software. There needed to be modifications to the interface and system functionality which became evident only after a period of use by the patient. Some of these user requirement changes were needed to achieve system performance standards. Other changes were requested by the patient, some of which increased user satisfaction. An important class of changes is enhancements which increased the functionality of the patient's system. These are suggestions by the patient which will increase the utility of the prosthetic software. Some increases will be suggestions for new features to existing software. In other cases, new types of activities will require new application software.

Three additional major modules were added to the patient's system. One was a primitive text editor, which had print, save, retrieve, and exit features. Another was a schedule which contained some daily information, including the time and menu of lunch and dinner.

Several outcomes are significant. First, The software was prosthetic, it provided cognitive support for specific subtasks which the target user was unable to perform. She no longer required a caregiver for assistance in these activities, although caregivers were necessary for other activities. Second, the system was a multi-functional prosthesis in that there were several different prosthetic applications, and several different types of personal activities which these systems supported. Third, this individual with a profound memory loss was able to learn how to use the interface with less than 3 half-hour training sessions. Fourth, considerable customization was necessary to be successful. Fifth, customization was most successful when applied to the specific instance, rather than based on broad principles. For example cognitive chunks of different portions of the software seemed to be of very different sizes. This case was reported in [16] and [17].

EV

A high achieving 34-year-old woman had a series of strokes, which left her with substantial physical and cognitive deficits. These deficits included: executive dysfunction; poor information retrieval; visually guided constructional difficulties; unilateral neglect with shifting laterality, dominantly left-sided; slowed information processing; impaired ability to manipulate several pieces of information simultaneously; impaired visual and verbal memory for new information; impaired language, including reading and word retrieval; impaired arithmetic skills; and bilateral, right more than left, spasticity and dystonia resulting in spastic circumductive gait and spastic contracture in all muscles of her right upper extremity.

The initial intervention goal was for her to be able to express herself in writing, using an editor with a password. Software usability testing was difficult because her test-retest reliability was poor; similar results were seen in her neurological evaluation. Although neurologically compromised individuals can show very substantial variation in performance, this case stands out as having the most variation unrelated to fatigue. The resulting design was simpler than that of the individual with the profound memory deficit, Case IE above. This was surprising because EV's memory appeared to be considerably stronger than IE's. The initial design had menu commands Print, Save, Retrieve, and Exit implemented as Function-Key commands. Three punctuation marks were implemented as remapped lower-case keys. Document names could be as large as 60 characters, but typically were just a few words. Documents were automatically saved, and when the user did not give the document a name, a default name was used. After a few months, a cut and paste feature was added at the patient's request. Two other major applications were added. One was the American Heritage Dictionary. This had both a dictionary/definition feature and a thesaurus feature. This provided intellectual stimulation as she "surfed" words and their definitions. A second application was a paint program, which required the introduction of a mouse (Kinsington "Mouse" trackball). After about 6 months she attempted but failed to learn Adobe Illustrator.

After two years, she began using off-the-shelf software: Microsoft Word and America Online, and Netscape Internet Explorer. She is able to use the most basic features of Word. She spends a substantial amount of time using the Internet using AOL chat rooms and email.

This case is significant for the profound impact of the intervention on patient functioning. Perhaps the clearest evidence of this is her change in reading. She went from being able to recognize half the words on a line when double-spaced to recognizing 95 percent of words single spaced. She also went from having a reading endurance of about 2 paragraphs to being able to read 100 pages in a day. Other changes included an improvement in spelling and grammar, a substantial reduction in impulsivity, an increase in concentration, an ability to grasp "finger food" such as a sandwich and chips, and increased ability to dress herself. All of these occurred over a period of two months.

This case is also significant because the patient has ultimately successfully moved from our highly customized software to commercial software. The first attempt at commercial software in the first few months after commencement of treatment was a failure. Two years later there was success. At least some of the difference should be attributed to an increase in cognitive functioning. Some of the difference can also be attributed to acquiring computer knowledge and skills. This case was reported in [13].

CS

A 61-year-old man, who was a very successful senior executive, sustained a head injury in a bike accident. As a result of his closed head injury, CS suffered a right subdural hematoma and right-to-left transfalcine herniation. He underwent a right frontal craniotomy for drainage of the hematoma, placement of a ventriculostomy shunt and intracranial pressure monitor. Following the hematoma evacuation, he was left with persistent left-sided weakness and CAT scan showed infarction in the distribution of the right middle cerebral artery. Neurological examination and neuropsychological assessment revealed that CS suffered anterograde and retrograde amnesia as well as impairment in prospective memory. He also exhibited problems with attention and concentration, visual-spatial processing, and global executive dysfunction.

There are several aspects of this case are significant. First, the CBCP worked for an individual as the initial outpatient treatment. This requires that design and customization be produced in a timeframe of hours to days, fast enough to be used on an individual whose cognitive functioning was changing rapidly. Second, the initial application was directed toward a very narrow functional requirement, one which is subsumed by many scheduling and daily-diary applications. It is significant that the patient wanted only minimal functionality. Third, it was an anomaly that he was able to perform extremely demanding cognitive tasks while unable to perform other tasks which were much simpler cognitively. He could negotiate projects involving millions of dollars, which were both intricate and difficult. However, he was unable to organize his own bills, and he found supermarket shopping too cognitively demanding do successfully. This seems to be non-monotonic, and appears to be significant clinically.

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This study posed two broad issues. First, could CBCPs be effective in increasing the level of functioning for what therapists consider plateaued and dead-end patients. Second, can the design of CBCPs be automated so that prosthetic software can be quickly customized. Third, to what extent can cognitively disabled individuals participate in the design of their prosthetic software. In an NIH-funded study, 7 of 9 plateaued patients were able to achieve a priority activity in between 1 day and three weeks of use. For 3 of the patients, 23 systems and versions were produced over a 12-week period. A total of 21,000 lines of code were generated (some of it automated), Changes were made to 389 software components (functions). Participatory design has many benefits with CBCPs. Patients can often provide solutions to functional and interface problems with their systems. In this study, patients made 46% of functionality design/redesign recommendations, and suggested 42% of the interface changes. Participatory design is particularly useful in resolving relatively fine-level implementation details. Early cases in this study were reported in [10] and [12], as well as [11], [13-15].

RR

This woman in her mid thirties was 2 years post TBI, and was referred by her occupational therapist. The patient scored in the highest range on occupational therapy functional evaluation scales in the clinic. Yet this woman was failing in a number of everyday activities in the home setting. This included an inability to keep appointments for herself, and for her young son who required ADDH-type school services following the same accident. Other problems involved inability to follow recipes, and difficulties in organizing and paying bills. She was also unable to do her crafts which had been a creative outlet for her before her accident. Neuropsychological evaluation revealed problems in memory and en executive functioning, primarily in planning and organization.

The initial intervention was a daily schedule application with minimal but sufficient features. Initial features included setting a schedule item, adding a memo to the item providing details, printing the day's schedule, moving to another date, and exit. All items were scheduled, and there was no "To Do" list. The prosthetic software was quickly designed. The computer and printer along with a modem and dedicated telephone line were installed in her home. Her therapist worked with her daily, guiding her in the structure of her day. These therapy sessions involved talking on a voice line and working on the computer with remote control software. She achieved success in using the application to help keep her on task within the first week.

Next a simple text editor was added. Again, it was quickly designed. In less than a week, she was using the text editor to organize her and her son with relatively simple lists.

This case focuses on a person who was not so disabled that she required a caregiver, but who was sufficiently disabled that she was unable to successfully perform typical everyday activities. Often these "high functioning" individuals are difficult for traditional rehabilitation programs to treat. For this patient, rather minimal functionality was used very extensively to provide organization and structure. We were struck how the simple text editor enabled her to provide a well-organized list, when compared to pencil and paper methods. One of the major advantages is the ability to end up with a well-structured linear list or outline even though the individuals thought process jumps around. Word processors uniquely enable the individual to move around the document and thus are able to support a disorganized thought process.

CASE STUDY: DR. T.

Dr. T was in his early-50s when coworkers became aware that he had profound memory and organization problems in the hospital. His was a fast-paced hospital based practice, and he was unable to track the status and treatment of the several patients in his care at any minute. Neurologic evaluation initially suspected Alzheimer's but the diagnosis was changed to dementia of unknown origin. He then resigned from his position.

On clinical testing, he was unable to remember any new information after 30 minutes. He needed to be reminded of activities and appointments during the day. A scheduler with a pager was customized. As a doctor he was used to carrying a pager so people could call him. Now, he would use the pager to remind himself of his activities. The pager enabled him to send himself an 80 character alphanumeric message. It was interesting that he was able give himself this short cue which would enable him to perform a more complicated task. His schedule software had basic features of adding a scheduled item, providing extended details of the item, setting the time and message of the optional page, printing the daily list which included the item, the details, the beeper time and beeper message.

He was able to achieve success in performing his scheduled activities in less than a week. He used this over a period of about 6 months, after which his functional memory had improved, but was still in the impaired range. The improvement was attributed to his substantial reduction in cognitive load following his retirement.

This was significant because of the beeper's ability to initiate action at locations away from the workstation. This kind of capability is now a standard component of our capabilities, and is being used by a wide range of patients. This case was described in [25].

7. DISCUSSION

Our research has shown that under exacting conditions, computer software can be a cognitive prosthesis. As such, the technology bridges deficits for the individual in performing specific activities. A clinical delivery system has been developed to treat individuals with a range of neurological disorders that cause cognitive deficits: Traumatic brain injury, mild brain injury, stroke, brain aneurysm, anoxia, and brain cancer. These results take on clinical significance because the process is now accepted by insurance companies as a conventional rather than experimental mode of treatment.

The exacting conditions required for effective cognitive prosthesis construction have been achieved by is the construction of one-of-a-kind hardware/software systems. Customization focuses on the patient's unique combination of activity priorities, cognitive and physical abilities, and cognitive and physical deficits. Exacting conditions have required the attention to detail. It was important to assure that both the interface and the underlying application performed well from beginning to end, and that the individual could perform the target activity. Design problems appeared during and after the system were introduced and those problems needed to be identified and resolved.

Part of our clinical success is attributable has been 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. This means that the individual does not have to go through a retraining regimen, where easier skills are relearned, which then become the basis for addressing more complex skills. The technology has been able to be designed to bridge those skills which the individual lacks. The patient need not endure extensive preparatory retraining, and the therapist can address rehabilitation issues out of traditional sequence. In this way, CBCP technology enables "Out of Sequence" rehabilitation.

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 possible for us to bridge these deficits and enable successful activity performance

From the beginning of our empirical work, we were able to notice anomalies in cognitive dimensions. Cognitive dimensions of profound disability often contained small pockets of abilities. Also, cognitive dimensions with largely intact cognitive performance often had pockets of deficits. The anomalies were visible at the very fine level of granularity which characterizes the detailed stages of software development. 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, cognitive rehabilitation therapists can work fact to fact 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.

Cognitive disabilities are topics which are under-represented in computer science research. This is unfortunate because there is a richness of problems, and an opportunity for so many computer science fields to make a contribution. The cognitive disabilities area had seemed to present problems which were difficult to successfully address. It is hoped that the research and clinical outcomes of our work will encourage others to work in this field. Our lab has internships for students, and opportunities to collaborate with researchers and clinicians.

Finally, our work in the area of cognitive deficits is extremely rewarding. Many of the people we have treated have had disabilities for years. The detailed nature of our work insures that systems staff has personal contact with our patients. There is a special satisfaction that we get in helping these people become more independent.

8. ACKNOWLEDGMENTS

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