Lessons Learned and Challenges Discovered in Developing Cognitive Technology for Individuals with Brain Injury

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Abstract
Dynamic accessibility can apply to individuals with diagnosed disabilities as well as individuals who become temporarily impaired. This presentation will review our extensive R&D activities developing software for individuals with cognitive disabilities from brain injury, and suggests this work can be useful in designing dynamically accessible systems.

Keywords
Cognitive disabilities, cognitive assistive technology, user interfaces, patient-centered design, participatory design.

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H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous. H.5.2 [Information Interfaces and Presentation]: User Interfaces – User-centered design; K.4.2 [Computers and Society]: Social Issues – Assistive technologies for persons with disabilities.

Introduction
Issues raised by situational impairment apply to individuals with a diagnosis of disability, as well as those who don't. Since the 1980s, the Institute for Cognitive Prosthetics has focused on developing tools to restore function of individuals with cognitive disabilities from brain injury. This work – substantively and methodologically – can partially serve as guide posts for Dynamic Accessibility. Individuals with brain injury experience significant shifts in abilities within a day and between days, typically more pronounced than the broader population.

For reasons of research design, traumatic brain injury (TBI) was selected as the target disease for exploring cognitive disabilities. For decades, cognitive rehabilitation has had poor clinical outcomes, leaving 6.1 million people with life-long cognitive disabilities. This leaves a sizable number of individuals and families who could potentially benefit from cognitive assistive technology (CAT). CAT would help individuals perform their everyday activities.

Some clinicians observed that our CAT could be used as a treatment tool in cognitive rehabilitation, with the potential of achieving a partial recovery. The most widely used approach to cognitive rehabilitation is Functional Rehabilitation, which uses everyday activities as therapy context. Computer applications support the performance of everyday activities, with a wealth of domain knowledge about everyday activities.

TBI causes diffuse damage across the spectrum of cognitive dimensions, making each injury unique. A Universe of One [2] scenario, software needs personalization for interface and functionality from a software suite spanning the broad range of patients' potential activities. In contrast most commercial CAT applications are developed to address a single activity or cognitive dimension [8]. The challenge has been to design software that is immediately useful and which requires virtually no patient training. Patient Centered Design (PCD) achieves that performance [4].

Key Findings

Patient Centered Design: adapting Concepts from software development methodology to CAT

Techniques from participatory design (PD), user-centered design (UCD), and usability testing were adapted to software development. These incorporate clinical treatment factors and the methodology is called Patient-Centered Design [3]. Usability testing has quantitative and qualitative procedures.

The importance of a very-good fit UI

An early finding is that the user interface (UI) required a very good fit in order to be acceptable. This applied to individuals with profound/severe deficits as well as those only mildly impaired. Seemingly innocuous changes in the UI can have a substantial impact on usability.

PD is particularly important in UI design. The individual user – even with profound cognitive disabilities – is able to inform UI design in a reasonably efficient manner. These users typically excel at fine-tuning the interface.

TBI patients will often have instances of greatly reduced capabilities. Serendipitously, we were able to capture one of these instances, which showed how good-fit software was able to substantially increase her level of functioning during the duration of the software use. A video will be shown at the workshop. This may have implications for situational impairments.

There are 2 sides of the disabilities "ledger".

The individual has deficits, which cause inabilities to perform some everyday activities. Additionally, the individual has abilities which are available for "work-arounds", often identified by the individual. Some abilities also seem to have a contextual quality. Abilities rarely get more than a mention in clinical assessments.

Unexpected abilities are often revealed exploring the individual's activity settings. See the Anomalies below.

There is no substitute for intensive work with users. Deficits and disabilities are concepts describing categories. Individuals with a diagnosis typically have deviations from the archetype, and additionally will have relevant abilities. Study the individual user, not a proxy, not a SME, not a caregiver.

Design benefits from:
User-Centered Design – a focus on the individual's priorities to address. Too often AT provides working non-solutions, leading to AT abandonment.

Participatory Design – The user has probably given a lot of thought to the impairment, and has insights into design solutions.

Maintain predictability – when events begin to go awry, changes in device behavior may add to the problem.

CAT was designed that substantially increase cognitive functioning
Software was designed consistently that increased the cognitive functioning of individuals with brain injuries, both in research studies [6] and with clinical practice patients [5,7]. There were 2 key factors: 1) PD by users on the UI, and 2) user engagement, especially in clinical patients whose treatment was generally 6 months or longer. In cognitive rehabilitation therapy, the initial version of an application is stripped down to provide only the features needed for the first day or 2 of therapy. User engagement began with PD in the application design, especially with the UI. Patients were encouraged to ask for changes in their software that would enhance ease of use. Afterward, functionality and interface changes were only made when the engaged user asked for them. This gave users a sense of ownership over their application – it was directed at their priority activity, and it used the UI they designed. It also gave them locus of control. Their computer system is something they can control.

To be useful to the individual, cognitive prosthetic software needs to address the range of that individual's activities and tasks, i.e., those tasks that the individual can no longer perform without caregiver assistance. A Cognitive Prosthetic Software Suite was developed, which included a major component to customize a patient's system in minutes [4].

Anomalies in behavior
Ethnographic techniques, coupled with system logs, have helped discover what we have called anomalies of behavior: behavioral exceptions to the conventional wisdom – explicit or implicit – of some group.

The anomalies below are important to the goals of the workshop. Anomalies are a term that can be used for situational and other changes in abilities. The anomalies below describe strengths of the individual, which PCD can identify. Can we design intelligent systems which will also be able to identify these?

The substantial abilities of individuals with severe/profound cognitive disabilities
An anomaly discovered in our initial work [1] was the substantial ability of an individual with several profound cognitive disabilities, to contribute to the design of her UIs, especially in fine-tuning the designs. Unexpected abilities are frequently found. A case study will be

presented of a college student who, after a TBI, was headed for a sheltered workshop, but who was able graduate college, because of software developed with PCD, coupled with excellent therapy.

What is hard is easy, and what is easy is hard

A general approach to presenting new material in teaching, training, and therapy is to start with easy material, and work up to difficult material. Material is graded. If an individual can't do well at the easy material, they typically are not offered a chance to do the more difficult material. A small but significant percentage of our users are described by this anomaly.

Islands of deficits in seas of abilities, and *islands of abilities in seas of deficits*

Abilities and deficits are typically clinically measured at coarse levels of granularity, while people's actual behavior is at a fine level of granularity. These granularity differences explain important behavioral differences. Islands of Abilities in Seas of Deficits underestimate an individual's abilities. Islands of Deficits in Seas of Abilities explain why patients unexpectedly fail at some activities.

User engagement

User engagement is an important to therapy outcomes, and has been associated with brain plasticity in the use of clinical software [10]. Madson et al [9]has used it to stimulate autistic adolescents to develop new ways of using clinically relevant software, and Morris et al [11] has used it to harness autistic children's obsession and redirect their enthusiasm to clinically desirable activities. Our group's success in achieving increases in cognitive ability, and increases in functioning is based in part on achieving user engagement.

Contribution to the workshop.

My contribution to this workshop involves a fine grained knowledge of patient outcomes with technology, of research methods, and of clinical settings and culture.

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