Patient-Centered Design: Interface Personalization for Individuals with Brain Injury

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Abstract: This paper explores patient-centered design (PCD) as a methodology for personalization of software used in rehabilitation of cognitive disabilities. This methodology serves scenarios where clinical priorities, expertise, and services can be factored into socio-technical software design decisions and clinicians explicitly included in the process. The clinical context anticipates the patient's progress toward at least partial recovery and justifies clinical services. PCD builds on and integrates user-centered design (UCD) and participatory design (PD). Case studies come from work in traumatic brain injury rehabilitation.

Keywords: user interface, user-centered design, participatory design, patient-centered design, cognitive disabilities, cognitive assistive technology, assistive technology.

1 Introduction

Patient-centered design (PCD) is a methodology for personalizing software used to help individuals with cognitive disabilities. There is evidence that, for individuals with traumatic brain injury (TBI), specially designed computer software can partially restore cognitive abilities [10,11,12,25,case study 2 below], as well as serve as cognitive assistive technology (CAT). This methodology serves scenarios where clinical priorities, expertise, and services can be explicitly factored into socio-technical software design decisions. PCD places the user in a clinical context, with its focus on the individual, nuances of the condition, and prospects for treatment and recovery. PCD builds on and integrates user-centered design (UCD) and participatory design (PD). PCD is significant in that it can focus attention on clinical goals in addressing application functionality while achieving significant gains in both cognitive abilities and cognitive functioning. PD is a key element because of the key role of the user interface (UI) coupled with the user's ability to fine-tune the UI. Studies of individuals with TBI show the UI to be particularly sensitive, with small changes having a disproportionate impact on UI performance, suggesting that the UI is the principal design issue [cf. 10]. Furthermore, users, even those with profound cognitive disabilities, can guide UI design to produce highly efficient interfaces for their software. This methodology also promotes user engagement, which can have substantial clinical impact. This methodology comes out of our work with CAT and with therapists'

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treatment tools known as computer-based cognitive prosthetics (CBCP) and telerehabilitation delivery system [10].

1.2 Background

This line of research began as the design of CAT for individuals with cognitive disabilities arising from TBI. These individuals had completed cognitive rehabilitation, were dependent on caregivers, and evoked no medical expectation of a gain in cognitive abilities. There are an estimated 3.1 million people in the United States with cognitive disabilities from TBI [3]. The CDC reports that 1.7 million TBIs (including concussions) per year receive some attention, with 275,000 hospitalizations [9]. TBI cognitive rehabilitation typically has poor outcomes [4]. CAT can increase cognitive functioning by addressing an individual's actual activities in the setting where they are performed. CAT uses a computer placed in the individual's home for frequent use in performing everyday activities. The ability to highly customize software led therapists to try to treat patients with these techniques.

Personal productivity tools [13] have long been known to increase the cognitive productivity of individual users, particularly knowledge workers. These tools work at the level of subtasks and activities, which are contextual artifacts of cognitive functioning, not of cognitive dimensions themselves. In the 1980s, in pioneering what would become CAT, our research questions were: Can this software have similar results with an individual who has suffered a decrease in cognitive functioning, such as from TBI? Can software be designed that will partially restore that individual's level of cognitive productivity? Could assistive technology (AT), which increases personal productivity and level of functioning without expectation of providing a cure, be designed for individuals with cognitive disabilities?

TBI cognitive rehabilitation is an attractive vehicle for approaching these questions. Within TBI cognitive rehab, functional rehabilitation can focus on helping the individual perform everyday activities [25], providing a direct fit with personal productivity software tools. Also, the WHO definition of disability is the inability to perform everyday *activities*, due to pathology and other factors [22].

TBI produces diffuse damage across the brain, which leaves each individual with a unique pattern of damage across cognitive dimensions. Individuals who share a diagnosis have very different presentations of injury – activity tasks and subtasks that are affected – especially at finer granularity. These individuals are a heterogeneous population with unique disabilities from a shared diagnosis [4,25].

Diagnosing a TBI is done at a coarse level of granularity [4,25]. The basic question is whether there is evidence of brain injury pathology, along with suggestions of which *global* areas of cognitive functioning may be affected. Cognitive rehabilitation is largely an outpatient service, with patients coming to the clinic to see therapists at the clinic. Therapy activities themselves are based on generic everyday activities. Unfortunately, TBI patients typically have difficulty applying abstract lessons from exemplar activities (e.g., baking brownies to learn planning and organization) to their own activities; they do much better with the concrete situations of their everyday life. Seeing a patient in the clinic makes it extremely difficult for therapists to use the patient's actual activities as the context of therapy.

Rehabilitation tools have continued to be based on manual tools like 3-ring binders, Post-its, generic flashcards, and forms. While computers are widely available in rehab clinics, computer software is rarely designed to be a therapist's tool. Computation appears ideally suited to addressing the cognitively disabled individual's everyday activities, and supporting Functional Rehabilitation. As CAT, computation lets the patient deal with concrete instances of activities. Its applications can be highly customized to each individual's needs. TBI presents an opportunity and challenge for a computational approach to support rehabilitation. The opportunity arises from decades of experience in supporting cognitive activities of users. The challenge is that the cognitive deficits that produce disabilities in everyday activities can also impair the ability to use computer software. Also, a software solution must not be so burdensome as to require substantial therapy time.

An early model of interface performance may be helpful in understanding the challenge presented by disability, adapted from Card, Moran, and Newell [7]. See figure 1. There are 3 clusters of independent variables: (1) user characteristics, which include cognitive functioning and disabilities, (2) task characteristics, and (3) system characteristics, which include UI design and functionality. These clusters then predict (1) state-to-state transition time, (2) work time per unit, (3) length of productive working time, (4) number of errors, (5) ease of error recovery, (6) training time per feature, and (7) training information remembered.

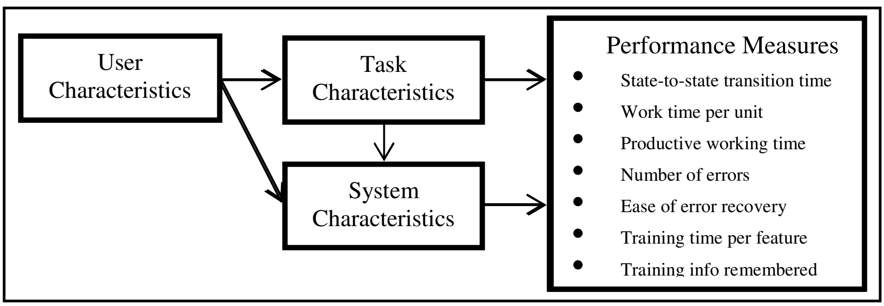

Fig. 1. Performance measures and predictor variables used in evaluating interface designs

Performance is a function of user, system, and task characteristics. Systems are designed for people with a certain level of assumed abilities. If the individual's characteristics are lower (U↓) and performance levels are to be maintained, then the system design needs to fit the user better (S↑), e.g., through a better-fitting UI. This means that for individuals with U↓, a higher quality UI is required and more emphasis needs to be placed on UI design. As we will see below, for individuals with cognitive disabilities, i.e., U↓, the UI is extremely sensitive to even small changes in UI design. In the case of an individual with a unique set of deficits and abilities, a better-fit system design requires personalization. The task component suggests that different tasks may require different designs for functionality or interface or both. The model doesn't provide guidance on *how* to achieve a better fit, but the model does provide a means of *evaluating* an interface design and comparing designs.

2 The Patient-Centered Design Model in the Brain Injury Context

PCD derives from our work on TBI rehabilitation treatment of cognitive disabilities where one-of-a-kind software systems have provided substantial independence to the individual [see 10]. PCD incorporates some features of UCD and of PD and also addresses clinical issues. In PCD, the focus is on the individual patient, on rehabilitation treatment plan objectives, on the skills of the therapist in treating the patient, and on using the patient's abilities.

There are 3 types of actors who participate in PCD: clinicians, individuals with cognitive disabilities, and software designers. In our implementation of PCD, clinicians apply functional rehabilitation, which uses everyday activities as the context of therapy. Patients are treated in their homes via computer workstations with a TBI telerehab delivery system combining CBCP software and videoconferencing.

The first step in the design process involves UCD in the selection of patient priority activities, which become the context for cognitive rehabilitation therapy. These are activities that have required caregiver support since the injury. A therapist elicits a set of priority activities and upcoming events from the patient. The clinician evaluates the activities for their therapeutic appropriateness, including their relationship to upcoming events, and selects one for the initial intervention. A criterion for the initial intervention is that the patient be able to achieve success within a week or 2, unusually fast for rehabilitation. The Initial Intervention centers on a particular concrete activity that can be well specified, and simplified, in contrast to a generic activity that involves many contingencies. UCD uses patient participation and engagement in therapy sessions and in the setting of target activities as major motivators and elements of rehabilitation.

Both UCD and PD involve observation of the present system to establish user requirements. This is done in the user's setting because few users can communicate with the necessary accuracy and level of detail. In addition, the analyst will notice artifacts that provide useful information. In the case of PCD, observing the current system helps identify tasks and subtasks that the individual cannot – and *can* – perform, giving clinicians an inventory of contextualized abilities. When a computer is used to help perform an activity, the analyst will observe the individual's use of the software and identify failures. From this data will come user requirements, consisting of required functional features and insights into interface design. The individual generally feels successful when able to perform subtasks, and for that reason, PCD excludes those subtasks from the user requirements.

There is a 2-pronged strategy for collapsing the time needed to train the patient in use of the software. The first strategy is to strip down functionality to what is needed this therapy session only and was inspired by Carroll's training wheels concept [8]; Leung et al. [16] use multilayer interfaces to reduce learning time. Fewer features mean (1) fewer commands necessary and (2) reduced application and interface complexity. Also, with unnecessary functionality removed, the individual is freed from learning how to use features that will not be needed until later. The second strategy is to make the interface intuitive to that individual user, by using PD to allow the user to design the interface, especially the details. In this strategy, the user's mental model is factored into the UI, making it intuitive to that individual.

Usability testing is a key component of PCD and comes from PD. Our studies – and clinical work – have shown that the UI is the key design component of the application. Small changes in a UI, seemingly innocuous, can make the difference between what can be successfully used and what cannot.

Usability testing procedures are modified for the individual cognitively impaired user rather than a panel of users [10]. There is a structured testing session to obtain quantitative data and then an unstructured testing session, which provides the most valuable information. Here the user can make design suggestions at both a gross and fine level of detail. The individual shapes the UI to overcome specific cognitive disabilities. The need to refine the UI was found across the range of deficits, from profound to high-functioning, and frankly was surprising. What was equally surprising was the ability of *profoundly* impaired individuals to make key suggestions for the design of their UI [11]. They seem to have excelled at fine-tuning the UI. The resulting designs exceeded the capabilities of highly trained designers. As one observes a patient making suggestions for the UI, it is not always clear exactly what the patient is optimizing, and the patient may not be able to articulate it. What is clear is that something is being optimized. Results of the usability testing are cycled into the next iteration, which undergoes usability testing again.

This process greatly increases the design effort in the UI. The *rationale* for this effort is the degree of users' cognitive impairment, typically several standard deviations from the mean of several cognitive dimensions ordinarily involved in UI use. The *justification* for the effort rests in the outcome of the intervention.

Roll-out involves installing the system in the patient's home, on the patient's desk. The therapist and the patient (and perhaps a family member) will have selected a clinically appropriate place in the home for the patient's desk and workstation.

After the patient begins using the application, it is likely that some additional changes will be necessary or desirable. Although the software underwent usability testing, the testing was not performed under real operational and workflow conditions.

PCD requires enhancements. CBCPs have stripped-down functionality. The patient, realizing that additional features could be valuable, asks the therapist to have the features added. The CBCP software suite offers extensive functionality, so in all likelihood the functionality for any given feature merely needs to be activated, although case study 2 below involves new applications. However, the feature's interface must be designed. The patient and therapist develop the UI for the feature, and how it fits into the existing interface, perhaps in consultation with a UI designer.

2.1 Case Study 1: Essence of Text Editor

The patient was high functioning, competitively employed, and looking for another job. He continued to have deficits in memory, attention, concentration, reasoning, and problem solving; cognitive rigidity; and reduced frustration tolerance that sometimes led to outbursts. He also had handwriting problems. He was trying to write a short cover letter for his resume in response to a help wanted ad. He would write out a draft and start editing it, and the paper would tear as he tried to erase a word; an outburst would ensue. College-educated, he had been a professional in a government agency before his accident, and he knew how to touch-type.

User requirement. The immediate task was to compose, edit, and print a single cover letter. The functionality needed was default font and line spacing, and a print command. The user needed to be able to insert and delete words, both of which would rely on cursor control. Inserting words could be accomplished by keeping the keyboard in insert mode. Deleting words could be accomplished by backspacing.

User interface design. Because of the user's cognitive rigidity, a decision was made to mimic typewriter mode: Courier font, 12 point, single space. It was also proposed to implement the print command ("Print this page") with a color-coded function key. The print command would give feedback to the user in a text box that would appear on the screen. The user would design the function-key print command and the confirmation text box in the unstructured phase of usability testing. The results of the design session would be added to the application and undergo another cycle of usability testing.

Results. User training took about 10 minutes and mainly involved use of the cursor. This intervention succeeded in the first hour of use. The therapist worked with the patient in creating and revising the letter. The patient was able to make inserts and deletions as he wanted, and he was able to print the product. He kept a hard copy of the letter for his files. He went on to write additional letters, using the previous letter as a template and printing out hard copies. Shortly afterward, he asked to have a multiple-document text editor; save and retrieve features and interface were added.

This application served clinically important goals and was a major success despite its limited functionality. It served the patient's initial and important goal and is thus an excellent example of PCD. Note that the patient solved the problem of how to write additional letters by deleting and inserting. From a software design perspective this approach would be considered inadequate by most standards, but as a therapy tool for that patient, it was exactly what was needed.

This application also made the patient active in the rehabilitation process. It addressed what he saw as a priority activity, he helped to design the UI, and he made requests for added functionality. His comments revealed pride and ownership in the application and system. That application served as a gateway to other applications and increased the individual's self-sufficiency.

2.2 Case Study 2: Patient and Therapist Contributions to Design

This case study focuses on several aspects of patient involvement in design and novel use of software. This case study is also important for its outcome, which was considered extraordinary by the rehabilitation professionals who had treated the patient in the rehabilitation hospital.

This college senior suffered a traumatic brain injury when struck by an automobile. Serious medical complications further reduced her cognitive abilities. She had cognitive rehabilitation as an inpatient and outpatient. It was expected that she would need daily caregiver support, and work in a sheltered workshop was anticipated. Return to college seemed impossible despite her supportive family.

Early on, the patient needed scheduling software to remind her of daily activities, but she tended to forget an event even if she had looked at the calendar earlier and had a reminder displayed on the monitor. Therapist and patient asked if a reminder could be sent to her. This involved a major modification of the scheduling application, including a store-and-forward message system because none was available from pager carriers.

User requirement. The initial user requirement was to have a feature added to each calendar entry whereby a message composed by the patient would be transmitted at a specific time to an alphanumeric pager that she would carry. In discussions with the patient, it was decided that the messaging would be part of the appointment-scheduling form. A widget would activate several fields for the message, including the text of the message and the time for delivering the message.

User interface design. Operationalizing the notification time involved several options, including a specific time and a time offset (minutes before the event) from the appointment time; the patient chose the offset time. The UI testing let the patient specify the field labels and field placement; she chose a check-box to activate the function.

Several alphanumeric pagers were obtained for testing.

Results. The patient quickly became proficient in clicking the check-box and in composing the message with considerable care, often editing it several times. Unfortunately, the approach failed for 2 main reasons. First, the paging service was not sufficiently reliable, and messages could take minutes to an hour for transmission. More important, the pager was multimodal with soft keys, which meant that the function of a specific key changed depending on the active mode of the device at the time. None of the pagers would allow modification of the user interface. The patient had difficulty reading multipage messages and also had difficulty finding the message list. Basically, the interface failed because of both the number of errors and the inability of the user to recover from the error condition.

User requirement – redesign. The message-sending concept seemed sound, but the equipment was clearly inadequate. Cell phones could provide an immediate connection and so seemed more promising. A cell phone message could be transmitted either as text-to-speech or as a sound file recorded in the patient's voice. The patient found the idea of sending herself a reminder in her own voice very attractive and engaging.

None of the communication carriers had a store-and-forward audio file capability. Fortunately, our application designed for pagers could be easily adapted for delivering sound files via cell phone. An added feature would be recording the message composed in the text box. In design/testing sessions, the functionality would involve recording, reviewing, rerecording, and saving the audio file.

User interface design. The UI was dual: the user's interaction with the on-screen form and with the cell phone. The user phrased the labels for commands. On testing, we were able to incorporate the commands easily. She was also able to record, revise, and save the sound files. However, the sound files often had a pause at the beginning and end of the recording, which the user disliked. Rather than placing the burden on the user to coordinate speaking and recording, it was decided to automatically edit the recording, removing the silences at the beginning and end of the file. The patient approved of this solution. As for the cell phone component, the patient decided that it was satisfactory to answer the phone and press a key to begin playing the recording.

Results. Use of the cell phone feature allowed the patient to remind herself, rather than having a family member remind her, with 2 important results. First, the family could see that she no longer needed their reminders. Second, the patient appreciated hearing the reminder in her own voice.

Epilogue. The cognitive rehabilitation therapy provided with this technology increased both the patient's cognitive abilities and her level of cognitive functioning with the supportive technology. It was decided that a return to college was a reasonable goal to attempt but would require passing several academic-achievement exams. The therapist and patient proposed a multimodal concept-learning application that would combine tactile, visual, and audio components. The application was built, and refined both before and after rollout. It proved successful in helping her relearn academic material. She was readmitted for her senior year, which she successfully completed in a year, and graduated. Her therapist provided cognitive rehabilitation in the form of academic support during both periods. The therapist was certain that the recovery would have been impossible without the use of the software and its design.

3 Discussion

Cognitive technologies as catalysts of clinical gains in cognitive abilities. Cognitive technologies for individuals with disabilities seem to have 2 modes of action. The first is like a power wheelchair, bridging deficits so that the individual can use existing abilities to increase level of function. The second increases cognitive abilities, producing actual clinical gain. Merzenich et al. exploited brain plasticity in developing software to treat an auditory processing disorder [18]; repetition and patient engagement were both factors in patient success. In case study 2, a former college student headed for a sheltered workshop was able to graduate from college with a combination of intensive therapy and cognitive technology. Similar results were achieved in physical and cognitive dimensions in a young stroke patient [12] and to a lesser extent before brain plasticity had entered the neurorehabilitation clinical literature [11]. The ability to produce clinical gains suggests that some cognitive technologies would benefit from clinical expertise, both with therapy and with involvement in the personalization of software. Case study 1 shows how the most limited functionality was able to advance therapy goals. PCD can promote clinical gains. This focuses attention on clinical goals and expertise.

Contributions of TBI patients to the design of their UIs. The UI seems to be *the* key design issue for individuals with TBI, predicted by the diffuse cognitive damage caused by TBI, and the cognitive load of learning new interfaces. PD has been widely used for developing CAT functionality and contributes to UI design with older populations [1,16,23,24], developmental disabilities [5], aphasia [cf, 19], and autism [cf, 17]. To be useful, UI design for TBI requires personalization. Clinicians and UI designers lacked fine-granularity cognitive-performance data to inform UI design. Fortunately, TBI patients were particularly adept in identifying problems in a proposed UI design, and especially at fine-tuning their own UIs. In our implementation of PCD, the individual with a brain injury could best inform UI design, and was given that responsibility.

Promoting user engagement. Cognitive rehabilitation aims to increase and restore cognitive activity. User engagement aims at increasing cognitive activity as well. The implementation of PCD discussed in this paper is designed to promote patient engagement in several ways. Patients become engaged because their priority activities are the context of cognitive rehabilitation. Patients become engaged because their software contains ideas they individually have proposed, especially the UI, the most visible part of an application. Users are encouraged to suggest additional functionality to help deal with an activity in their near future. The engaged user also often develops personal new uses for applications, evidence of expanding cognitive activity. These uses of the software that haven't been taught constitute invention on a personal scale. This personal invention helps increase the individual's level of cognitive functioning and activity. Both help reduce the level of disability – especially in priority areas – and help the individuals get back into their lives. Madsen et al. [17] encouraged autistic adolescents to develop new uses of a technology tool, and Morris et al. [20] cleverly used interface design to engage autistic children by incorporating objects of their obsession into software with therapeutic goals.

The abilities of individuals with severe and profound disabilities. PCD can be a powerful tool, providing the opportunity to see a range of behaviors. Often PCD will provide a view of behavior opposite from conventional wisdom. Disabilities are typically easy to see, but abilities may not show themselves very often. Too frequently a disabled individual lives down to the level of people's expectations. PCD provides the opportunity for individuals with disabilities to be themselves, and for people who work with them to understand that many dimensions are uncorrelated or poorly correlated with each other. Our initial (and first computer science) study in cognitive disabilities [11] reports an individual with several profound deficits, coupled with substantial abilities. Case Study 2 reports on a person with some severe and moderate cognitive deficits. Both were involved in developing the UI, as well as developing new uses for her software. An individual with profound disabilities is limited, as were our expectations of ability to do PD. However, we were surprised at the ability to provide instructions that made the UI virtually intuitive. We were also surprised at her ability to develop new uses for the application, e.g., to check the accuracy of information stored in her new computer because the information in her previous computer was corrupted.

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