The IT Support for Acquired Brain Injury Patients – the Design and Evaluation of a New Software Package

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Abstract

The problems of producing a software system to assist in the rehabilitation of people who have suffered serious traumatic brain injuries are described. In addition to this primary use, therapists need the system to evaluate, monitor, and for measurement purposes. The challenges of ensuring a high level of usability by incorporating the best of graphic and HCI design into a well established software engineering methodology are discussed, as well as the details of the specific approach we designed. The software needs to be repeatedly used and enjoyed both by the patients and by the therapists. The challenges to writing software to be used by such disparate groups are significant, and there is currently very little software that has been written specifically for this user group. As we discovered, many of the standard software design paradigms are inappropriate for users suffering from brain traumatic injuries. The resulting suite of programs is now in use at a rehabilitation hospital in Victoria, and we report on their successful adoption.

1. Introduction

The facilities at the Neurological Treatment Outpatient ward at the Gorge Road Hospital in Victoria (B.C., Canada) are used very intensively. The unit for Acquired Brain Injuries, which includes all types of brain injuries, acquired either as the result of disease processes (ranging from MS, strokes, aneurysms) or following traumatic brain injuries (e.g. motor vehicle accidents).

Original software was developed many years ago by the father of one of the patients, on an old Apple IIe with, obviously, no graphical interface. The software contained the basic functionality for a set of ten activities, to be used either as part of the rehabilitation process or for assessment, and while helpful, it did not meet the real needs of the patients. Further, it is completely unusable on newer platforms of hardware and operating systems. According to Dr. Adele Hern, Director of Psychology at the Gorge Road Hospital, other North-American hospitals might be facing the same dilemma because the software was initially distributed widely, but never upgraded.

This computer-based approach was then, and it remains now, a fairly new concept for rehabilitation. In fact, at the clinical psychology level, no in-depth studies have been made of the scientific and statistical effectiveness of computer-based activities of this kind. Yet both the therapists and the doctors believe it to be very effective and have been observing its invaluable impact for many years. Therapists need such a system for a dual purpose: (a) for measurements, taken at sporadic intervals, to assess certain skills (e.g. ability to attempt a driving test); (b) for rehabilitation, evaluation, monitoring and improvement of certain skills, done over a daily basis. So any software system has to be effective for retraining certain cognitive functions, but also has to track the progress of the patients during the rehabilitation program. The software needs to be repeatedly used and give satisfaction to both the patients and the therapists.

This collaborative project aims at truly benefiting persons with brain injuries, with the three primary objectives:

1. To fulfill the needs of the therapists and the patients by writing an enhanced software package exploiting the newest multimedia interface platforms;
2. To yield a software product that can be used by other rehabilitation institutions as well as patients suffering from brain injuries working on their own.
3. To provide a genuinely satisfying experience for users.

In this context, experience is the emotional, intellectual, and/or physical reactions the user has while using the software. Producing a “satisfying experience” might seem a futile and esoteric goal for a software system but it is, in fact, critically important as the patients who use the system are engaged in a cognitive rehabilitation program not by
choice, but as a consequence of an unfortunate and tragic incident. In addition, it is intended to assess and retrain cognitive functions that worked normally before the brain injury, and this is often a tremendous source of frustration for the patients/users. The circumstances surrounding the use of the software are difficult, thus the critical importance of making it as pleasurable to use as possible, [4].

The challenges to writing software to be used by such disparate groups are significant, particularly given the wide range of severity of the injuries suffered by the patients. We use three sets of domains: (i) the software engineering design and development process using newer multimedia-based products; (ii) the demands of the human-computer interface (HCI) design and implementation, geared to a set of disparate users; (iii) the underlying choices in functionality and design reflecting the clinical psychology requirements of the rehabilitative process. We briefly report on all three of these aspects.

Our focus here is on the process of developing a new software system as a non traditional platform for clinical rehabilitation, and on the process of evaluation of the package and integration of the feedback from this special set of users: the disabled patients and the supporting therapists. The importance of certain of the design aspects is enhanced by the special needs of the user group.

2. Patient’s Profiles and Therapist’s Requirements

2.1 Brain Injuries. The target users are brain injured persons, who, apart from their injury, have a wide diversity of backgrounds, so nothing else can be assumed about them. Every year, approximately 50,000 Canadians and 2 million Americans suffer a traumatic brain injury, with as many as 60% caused by motor vehicle accidents. The majority of these victims are young men between 15 and 30 years of age.

While the economic costs of traumatic brain injuries are shocking, the major result of traumatic brain injuries is the lifelong, devastating consequences for the victims and their loved ones. The peculiarity of each brain injury, [6], makes it difficult to give any general characterization of the deficits of our users. Regardless of the type or the gravity of their brain injury, what occurs is a reduction of cognitive function, accuracy of response and speed of response. Simply said, a person with a brain injury takes longer to think and respond than prior to the injury. Also, most victims experience deficits in the areas of complex attention and concentration, learning and memory, integrative thinking, planning and organizing, and control over emotions and behavior.

Brain injured patients typically exhibit deficits in the following areas:

- **Memory** – specifically, new learning is affected.
- **Attention and concentration** - sustaining attention during a task, shifting attention from one task to another and dividing attention.
- **Executive functions** - analyzing and synthesizing information, sequencing and goal directed activities.
- **Perception** - difficulties in auditory and visual functions, recognition of objects.
- **Language abilities** - quality and quantity of communication.
- **Emotional and behavioral changes** - depression, impulsivity, denial of disability, passivity, dependent behavior, and aggressiveness.

The goal of the treatment is to assist the patient in successfully adjusting and adapting to everyday living after a brain injury. It not only aims to improve the cognitive functioning but also the emotional functioning and the quality of life of the brain injured patients. Cognitive rehabilitation therapy and language therapy tackle the cognitive problems. The rehabilitation of patients varies as each patient has different deficits and brings a wide range of previous skills and experiences to the process. In general, this lasts from four to six months. A typical patient needs an assessment to determine the main problems and to chart the course of therapy. Therapy then includes a number of activities, both remedial and learning types, to compensate for their deficits. The general repercussion cycle in Figure 1 shows what typically happens to a person after a brain injury.

One of the tools that is now used early in the rehabilitation process is our new software package. Computer programs for retraining specific cognitive functions began to appear in the 1980s. Surprisingly, there is still little empirical evidence for their effectiveness. Researchers consider them useful if carefully chosen and integrated into a rehabilitation program. Practitioners have seen results for themselves and continue to use them.
2.2 Cognitive psychology. Cognitive psychology is crucial to this project, since it studies how we perceive the world around us, how we store and process information. While all human beings are limited in their capacity to process information, this is a much more serious issue for our users. Some general aspects, [5], of the cognitive process require careful analysis in order to match them with the software constraints.

Perception. We perceive the world through five senses, and our perception is influenced by the accumulated knowledge in our memory. Human perception is active, patterned and selective. Active because the result of perception is conditioned by the context and by one’s knowledge and expectations. In software design, this implies that the designer’s intentions are not easily translated into an effective presentation and that the user interface must be gradually refined and tried with users in order to achieve the desired effect. It is patterned since the brain attempts to organize sensory messages into meaningful patterns and structure, and, in software design, this means that a screen can present highly complex information, given that it makes use of clear patterns, in a consistent manner. Perception is also highly selective and software design capitalizes on this characteristic (e.g. user-action elements can be color-coded, to be easily perceived).

Vision. Software design is mainly concerned with sight and hearing, with the former being more important. Vision uses five major variables, [8]: Size, Value (or intensity), Orientation, Texture, Shape Position and Hue. Each visual variable supports its own limit on the number of recognizable levels. For example, we cannot recognize more than four different orientations, but we can discern an infinite variety of shapes. The user interface utilizes those visual variables to convey a ranking of elements. Finally, the way in which people perceive size, depth, distance, brightness, color and shape has an impact on how well we respond to a particular software system, so the following have to be emphasized: recognition of familiar words, font choices, line lengths, screen contrast and color.

Hearing. Sound and vision are “complementary modes of information”. In software, sound should not simply be used for warning signals, but also to convey meaningful information about the system state.

Memory. In general, human memory is good at retaining the substance and meaning of events, rather than the details, and humans tend to remember unexpected events better than recurrent ones. Software systems cannot require users to remember transient information as they move from screen to screen or perform complex, non routine interaction with the software. Further, research has shown that names of items are better recalled from short-term memory when they are presented as pictures rather than words.

3. System Design and Functionality - Interface Design for Interactivity

Software design draws from many disciplines but focuses on specific issues. These disciplines include software engineering, usability engineering and interactive design, and each proposes multiple variations on the development process. Taking elements from these sources, our software development process has to be both feasible and appropriate for software production. The process is guided by two underlying principles: usage-centered design,
which focuses on what the users are doing and the tasks they are trying to accomplish and iterative design. The latter consists in iterating design, implementation and evaluation until the system meets predefined requirements. Figure 2 presents a schematic view of our process.

![Figure 2](image_url)

The process is divided into five stages: understanding, formal modeling, creativity, prototyping and implementation. In compliance with iterative design, evaluation is performed throughout. Formal modeling and creativity run in parallel and are completely intertwined together. It is noteworthy that the stages have no defined boundaries and tend to extend into one another.

We must determine which elements of the software, of the interface, and of the global interaction process must be adapted to the peculiarities of brain injured users. Usability is very important and in practical terms, it means that the software must be easy to use. Often, ease of use may not be preferable over high performance, but for our special class of users, it is mandatory. People perform two types of tasks when using a computer: functional tasks, which are concerned with the content of the problem, and operational tasks, which concern the means of solving the problem, in this case, interacting with the user interface to the system.[7]. It is important to target the appropriate tasks. Here, the functional tasks (“what they need to do”) are made up of the ten exercises used in treatment and assessment. Being rehabilitation activities, these tasks are expected to cause certain difficulties to the users. This is normal, and actually not under our control. On the other hand, the operational tasks (“how to do it”) present considerable potential for creating ease of use. The design effort must be concentrated on the second type of these tasks.

The ten activities were analyzed in depth: their functionality (to derive well defined software engineering specifications); their interface characteristics (to derive the HCI specifications); their cognitive psychology content (to make sure that only enhancements to the original rehabilitation goals would be introduced). For each activity observed, problems were noted, such as the patient having to remember the name of a saved file, feedback not being displayed long enough, activities that can’t be stopped before completion, meaning of options not explained, instructions not clear or inaccurate.

The cognitive limitations consequent to a brain injury are particularly noteworthy because they greatly affect the human-computer interaction. This brings back in the notion of simplicity: the design such must demand minimal cognitive resources to perform operational tasks. We discuss the possibly impaired cognitive functions, with suggestions for minimizing their detrimental effects. Sometimes a recommendation for a particular impairment may be in contradiction with what is suggested for another impairment. As in any design discipline, these conflicting demands must be resolved in the design stage of the development process.

**Visual problems:**
- Use bigger graphic elements than in common software: fonts, buttons, icons, etc.;
- Use very few colors, very distinct from one another (i.e. overemphasize the principle of contrast);
- Use sound to reinforce the visual information;
- Provide an audio version of lengthy written information such as instructions or help;

**Auditory discrimination and auditory attention problems:**
- Use sound as a complementary source of information, not as the only means of communicating a message;
- Do not overuse sound, in terms of frequency and length of the audio messages;
- Use exceptionally clear and distinguishable sounds;
- Provide means of replaying the sound, if appropriate;

**Memory problems:**
- Minimize the quantity of information that must be remembered from one screen to another: instead provide continual feedback information;
- Reduce the $7 \pm 2$ maximum elements guideline for short term memory to $4 \pm 2$ maximum elements;
A direct manipulation interaction style is used, with the mouse as the pointing device and keyboard input for patients with motor impairments.

- Avoid presenting new information rapidly, or in complex form, or in competition with additional information;
- Use familiarity and imagery for things that must be remembered;
- Do not require the spontaneous recall of information: rely instead on recognition;

**Attention and concentration problems:**
- Directly guide the user’s attention to the relevant information on the screen by structuring and grouping the elements (c.f. Gestalt laws of perceptual organization);
- Avoid simultaneous tasks (for divided attention impairments);
- Avoid lengthy written or audio information;
- Minimize the complexity of the information provided to the user;

**Executive problems:**
- Avoid wide and deep decision structures in the software so that the user is not confronted with problems of planning or depth of analysis. That is, minimize the mental effort to use the software by offering a shallow or a narrow decision structure;
- Favor narrow (and thus deep) structure over shallow (and thus wide) structure so that the number of alternative decisions is kept to a minimum at all times.

**Physical problems:**
- Account for patients who cannot use the mouse due to motor impairments (many patients suffering from such problems can use the keyboard, when it is equipped with a special guard);
- Minimize the number of gross motor movements (e.g. movement back and forth between the keyboard and the mouse) to avoid fatigue;
- Minimize the number of transitions from gross motor movements to fine motor movements (e.g. typing or positioning the mouse on a target);

**Emotional and behavioral problems:**
- At all costs, avoid situations in which the user feels “trapped” in a screen, because it could easily trigger frustration;
- Keep things simple, again to avoid frustration or anger.

Our final design concepts for the system are described below in point form.

- The primary new (very successful) idea is to use a “game” metaphor. This suits the application well since it can be thought of as consisting of ten games. This metaphor helps to make the software fun yet challenging, just like a game. It avoids anxiety for the patients as regular assessment exercises can, and it is familiar in its layout. It is the enforcement of the game metaphor that provides the delight of the experience.
- Windows are not used and the information is presented on the full screen. This decision is guided by the study of brain injuries. Windows can be useful to view multiple sources of information on the screen at once and to manage those views. However, this counterproductive here as we need a sequence of single screens. In addition, the use of windows hides some information and complicates the interaction for persons with brain injuries.
- On-screen, contextual help is available and easily accessed at all times during the execution of the program, even during an activity. Providing genuinely useful on-line help is a challenging and multi-faceted task.
- There is no such thing as a user error. The software should be as helpful as possible when the user plays with the interface. To keep the user in the “right track”, feedback messages are displayed when unexpected user actions occur.
- All controls are visible on the screen (e.g. there is no menu bar to hide the menu choices). This is also guided by the study of brain injuries. Hiding choices under a menu bar requires users to remember that some options are available even if they are not visible. This draws on memory. We have to minimize the cognitive load.
- Whenever an option is not available, its control simply doesn’t appear on the screen. Some systems make options lighter or grey when they are not usable. This could be confusing so we simply avoid it.
- All controls are grouped in a “control bar”. This allows the user to always go to the same location to perform any action. It might take a little while for the user to have the reflex to look at the “control bar” but it becomes very handy, once the habit is installed. To conform to the previous decision, options are constantly added and removed from the control bar. The context determines which controls are shown on the screen. Some controls remain even during ongoing activities.
- Various sounds, including speech output, are used for feedback and positive reinforcement after a good performance. Also, to maximise the chances that the user perceives the various messages, speech output is used concurrently to written output. The sound option can be easily turned off from any screen.
- Consistency is enforced. Various features are added to
every exercise in order to bring consistency across the software. The options are harmonized as much as possible. For instance, the number of repetitions is an option for every exercise. Also, the try feedback, the execution feedback, the execution results and the scores are unified. The control bar always keeps the buttons in a consistent location. The look and behavior of the buttons and other controls are coherent. A color coding is applied to all screens. Clearly, consistency does not limit our ability to use innovation, but rather encourages us to use it carefully and in a disciplined manner.

- Feedback about the performance in the activities is very important for the user, so it is distinctly displayed. A try feedback is displayed after each attempt (activities with more than one try). Also, an execution feedback is always displayed once the activity is performed. The user’s execution result and scores are not displayed automatically but they are shown on demand. In addition, the scores can be printed at any time during a session.

- During a session, scores are only temporarily recorded. At the end of a session, a screen lets the user decide whether the scores for this session should be saved.

An administration module is provided to the therapists. It is used to:

- Register new patients (add their name to the list presented on the first screen)
- Deregister a patient
- Display and/or Print the scores of a patient
- Set various default values for the activities’ options. Default values can be applied to a single patient or to a group of users.
- Collect global statistics over time for one patient or for a group.

4. Implementation and Evaluation

Initially, we had decided to implement the system in the object-oriented programming language Java, which was relatively new at the time. Our choice of this specific programming language was motivated by its object-oriented nature and by its multi-platform and web capabilities (see [2] and [3] for the advantages of the object-oriented approach), but its low level demands caused too much time to be spent on unnecessary graphical details. We turned to the multimedia authoring system Macromedia Director 6. With its film metaphor, Director allows us to produce GUIs easily and quickly. Lingo, the scripting language in Director, can be used to program the GUI and the system’s backend. Lingo is not purely object-oriented, but it presents some object-oriented features which are very useful when developing a complex system like ours. With Director, we developed prototypes that were refined and iteratively became the real system.

The first version was installed on two of the computers at the Gorge Road Hospital. The therapists were given a demonstration and they started a notebook for comments and questions on each activity. Once the therapists were comfortable with an activity they would introduce patients to it. The therapists were able to get initial feedback from their patients that had the most patience and highest functioning level. The characteristics of the patient population unfortunately made it impossible to administer a formal survey. Other patients made comments on their own, or the therapists made note of the areas that gave them difficulty, the functions they did not understand and the patients’ response to the program. Over time, all of the improvements and clarifications were incorporated.

At the opening of the application, after typing in a name to be identified, the game board is loaded, with the ten activities depicted in a very simple fashion by a game board with squares surrounding a central panel (similar to a Monopoly board). This game metaphor proved to be a winning strategy, as it combined the ease of use, the simplicity and the effectiveness of functionality which were deemed critically necessary (see above), and enabled the interface issues to maintain a consistency throughout, eliminating a major source of frustration. Moreover, the game board itself provided a connection of personal familiarity for patients and reduced their anxiety level.

Once an activity is chosen, a screen of instructions appears with option choices; some games are so intensive that they allow only one repetition, while others can be customized, together with the therapist, for speed, repetitions, length, difficulty. The “Back”, “Help”, “Exit”, “Scores” buttons are always in the same locations on the board and directly accessible, and are integrated within the functionality. For example, if the Help button is pressed while an activity is running, the timing clock continues to count. This implies that the patient’s time score will be higher, a perfectly valid case. As the patient progresses, the Help button will be used less often, improving the score, and avoiding the patient’s attention from wandering during the pause in the activity.

The therapists took extensive notes on the daily use of the system and some patients were also able to comment.
The main changes made as a result of feedback were in the following categories:

- Change colour choices to less brighter shades.
- Ease of adjustment of font sizes – extremely useful for vision problems.
- Ease of adjustment of range of difficulty levels through the interface enables patients to make the changes as well as the therapists.
- Game metaphor – easily understood by all, even with the most varied background of users.
- Help and Instructions – their uniformity was enhanced even more.
- Scoring feedback – many changes were made here providing the easiest possible interface to both patients and therapists to check scores at any point in time, with a fine or coarse grain window, which was truly appreciated.
- The main feedback notes were that patients actually had to be allowed, upon request, to continue activities beyond the allotted time, as they found the pleasant interface an enormous change from their regular expectation; most of all, many patients were able to use the software on their own after a few sessions, something never achieved before. It is hoped that this new level of enthusiasm will enhance their recovery process and make it much less frustrating than formerly.

The program has been accepted with enthusiasm by both the therapists and patients. The program required alterations, but the design process was successful in creating a product that met the needs of both the therapists and patients. The patients seem to enjoy using the program and are able to navigate through it easily. Figure 3 below shows two screen shots: the left one is of the main game board, while the right one is of the Number Search activity (they need color to look appropriate).

5. Conclusions

We describe the development of a software system to assist in the rehabilitation of those who have suffered serious traumatic brain injuries. Although the user group is potentially quite large (over two million people a year in North America), very little investigation has been carried out on the specific needs of this non traditional user group, and we explore the real challenges in designing any software system for such a set of users. It is shown that it is critical to incorporate the best ideas of graphic design and HCI into the development process if we are to ensure the high level of usability for the system. This is absolutely crucial when many of the users will be suffering from a lack of ability to concentrate, diminished memory capacity and similar difficulties as a result of their injuries. Further, they are not using the software system out of choice, and are often aware of the serious deterioration in their abilities caused by the brain traumatic injury. The system is now in use and evaluation at the Gorge Road Hospital in Victoria, and we report on the acceptance process, the evaluation undertaken and the very positive reaction to the system by both the therapists and the patients.

6. References


Figure 3