A Pilot Evaluation of the Recreational Benefits Of Computers for People with Brain Injuries

Final Report

April 2001

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1. BACKGROUND TO THE STUDY

This study was stimulated by the belief that there is a substantial need for new recreational options for people with brain injuries. This need is self evident to those who work professionally in the rehabilitation of this group, such as the staff at the Brain Injury Unit, Royal Rehabilitation Centre, Sydney (where the research was conducted). It has also been noted in the literature. For instance, a recent literature review looked at the sequelae of traumatic brain.[1] The study highlights such problems as loneliness, social isolation and loss of leisure options.

A second stimulant to this research was anecdotal evidence from our own work at the Ability Research Centre with clients with traumatic brain injury. During our assessments of the computer needs of this group we noticed that carefully chosen and supported computer activities seemed to provide stimulation, enjoyment and self esteem benefits.

If it is true that computers provide a potential new option for independent recreational activity for people with traumatic brain injury, then it is also true that little work has been done in determining the best way this should be done. We note that many people with brain injury would find the standard

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1 Morton M. and Wehman P., "Psychosocial and emotional sequelae of individuals with traumatic brain injury: a literature review and recommendations" Brain Injury 9/1 1995 pp. 81-92.

computer interface confusing and frustrating.[2] We suspect that those who have tried to use computers at home may have had less than successful experiences because of this, and also because of lack of guidance regarding choice of appropriate hardware and software.

A review of the literature on computers and cognitive rehabilitation has been undertaken and is presented as the next chapter in this report. It confirms that relatively little attention has been given to the recreational use of computers for people with brain injury, although other aspects of the use of this technology have been covered.

As a pilot study the aims of this study are modest. They are:

?? To determine the benefits of recreational computer software for several people with brain injuries who choose to participate in the study. This will be done by using a case study methodology.

?? To facilitate computer access for these people.

?? To identify the types of software which these participants find most beneficial and enjoyable.

This study does suggest several areas worthy of further study. These are discussed in the concluding chapter.

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[2] This matter is examined in detail in Cress C. et al., "Cognitive Access to Computers: Selected Research, Design and Application Papers", Trace Reprint Series, Trace R & D Center, 1991.

2. A Review of the Literature on the Role of Computers for People with Brain Injury

Beginnings

The emergence of personal computers in the late 1970s and early 1980s also marks the beginning of a period of experimentation with computers to assist people with cognitive disabilities. As has been the case in many other professional areas, the arrival of computers among those involved in cognitive rehabilitation has produced diverging responses.

One of the pioneers was William Lynch in the USA in the late 1970s [3]. Such was the early enthusiasm that in 1983 the UK Government distributed Acorn BBC computers to 43 occupational therapy centres throughout the UK. This platform came to dominate the field in the UK, whereas in the USA the Apple II computer was more prominent. Initially the response was generally enthusiastic and positive:

> While there are many therapeutic modalities that will serve to reorganize and enhance the (function of damaged) cognitive processes… none compare to the potential offered by the computer. The computer may be the most powerful tool in the area of cognitive rehabilitation.[4]

Purdy was able to comment in 1989 that "the personal computer has greatly contributed to the area of cognitive rehabilitation" [5]. The benefits noted were:

- ?? To supplement a formal therapy program;
- ?? To be used to improve or maintain the current level of cognitive functioning once formal treatment has been discontinued;

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[3] McBain K. and Renton L., "Computer-assisted cognitive rehabilitation and occupational therapy", British Journal of Occupational Therapy, May 1997 60/5 199-204

[4] Bracy O.L., "Computer Based Cognitive Rehabilitation" Cognitive Rehabilitation 1(1) 7 1983

[5] Purdy M. and Neri L., "Computer-assisted cognitive rehabilitation in the home", Cognitive Rehabilitation Nov/Dec 1988, p. 34

?? To provide the injured individual with something productive to do in his or her spare time; and

?? To develop skills that could be used outside the therapeutic environment such as at school or work."[6]

Early Studies

Some early studies were promising, thus endorsing the initial positive reaction to computers. Skinner (1985) successfully used *PC Coloring Book* software to work on attention span, visual scanning, colour discrimination, sequencing, eye-hand coordination and motor planning with patients with brain injury. One patient increased her attention span from 5-7 mins to 15-20 mins. These gains were apparently carried over to over activities.[7]

Kerner's study (1985) also achieved positive results: "This study has demonstrated enhancement of memory skills in head injured individuals using memory retraining software on a Apple II+ computer".[8] Motivational benefits were noted, and generalization of skills, but the participants lost ground in many areas after 15 days.

Malachowski (1986) believed that writing is important for head trauma victims, as it assists in learning, and involves the objectification of language. It also assists with eye-hand-brain coordination. Computers were seen to expand these benefits, and were described as "invaluable composing aids for head trauma victims".[9] In one case the computer helped the patient with neatness, visual reinforcement and the ability to self correct. "The

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6 ibid p. 37

7 Skinner A., "Brief or New: Use of a Computer Program (PC Coloring Book) in Cognitive Rehabilitation", American Journal of Occupational Therapy, July 1985 p. 472

8 Kerner M. & Acker M., "Computer Delivery of Memory Retraining with Head Injured Patients", Cognitive Rehabilitation, Nov/Dec 1985 p. 28

9 Malachowski A., "Composing and Computing by the Writer with Head Trauma", Cognitive Rehabilitation, Nov/Dec 1986 p. 11

microcomputer has given her a new sense of freedom and flexibility" and she was now writing to her family and friends.[10]

Abbot (1989) also saw benefits in word processing for a patient with brain injury:

> The more Max used the word processor, the more we saw this treatment approach was beneficial to him in his daily life. We noted that it helped him compensate in many aspects of daily living, assisted him in his vocational planning and served as a compensatory device for his memory deficits…It provided him cognitively with structure, organization and served as a compensatory strategy for his memory and planning skills.[11]

The main benefits of computers were seen to be in the key areas of attention and memory. Malec (1984) saw a central role for attention in rehabilitation:

> Because of the close association between learning and the ability to sustain attention to the learning task, improving sustained attention following craniocerebral trauma may be critical to enhance other types of learning in other rehabilitation therapies.[12]

Reaction

Around the end of the 1980s several influential articles cast doubts on the efficacy of computer assisted cognitive rehabilitation (CACR[13]). The main critique was offered by Robertson (1990), who noted the poor quality of many of the published studies. Many were seen as anecdotal, with poor controls and deficient analysis of results.

> No computer cognitive rehabilitative procedures have been shown to generalise to real life and there is no existing empirical basis for the sale or distribution of any computerised cognitive rehabilitation programmes for non-research purposes.[14]

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[10] ibid p. 13

[11] Abbot N. et al., "Word Processing as a Compensatory Device in the Traumatically Head-Injured Survivor", Cognitive Rehabilitation Jan/Feb 1989 p. 37

[12] Malec J., et al, "Video game practice effects on sustained attention in patients with craniocerebral trauma" Cognitive Rehabilitation 2/4 1984 p. 18

[13] This term is generally used in reference to computer-based programs aimed at the restoration of cognitive function.

[14] Robertson I., "Does computerized cognitive rehabilitation work? A Review" Aphasiology 4, 1990, 381

Lynch also criticised the early studies, with their small groups, lack of controls and limited software. He noted that these studies make it difficult to tell whether the results are due to the software itself or the frequency, pattern and duration of delivery. The issue of input devices had been completely overlooked. The whole process has, he argues, been so boring that "Should we be surprised that so many of our patients fail to generalise the gains they demonstrate in the clinic?"[15]

While aspects of these critiques are valid, some also indicate a misunderstanding of case study methodology. They attempt to apply verification criteria that are not appropriate to this form of research.[16]

Perhaps more indicative of the mood of the time was the reaction to an article by Ross (1992)[17]. This study "may have reduced the overall use of computers within occupational therapy departments" according to Stern.[18] Yet a closer look at the study, which failed to find any cognitive gain through the use of computerised visual scanning training, makes it surprising that it can be called upon to support any conclusions about the role of computers in cognitive rehabilitation. It is part of a Master's thesis, and involved three participants. The article itself acknowledges that its results are not statistically significant, and that it is not possible to distinguish the outcomes from intervention from those arising from practice effects and spontaneous recovery. Serious methodological problems are also acknowledged by Ross, such as the failure to establish a stable response pattern by subjects during the baseline phase. Ross concludes:

> One cannot make highly accurate predictions from these data…This study neither supports nor refutes the validity of computer-based

[15] Lynch W., "Ecological validity of cognitive rehabilitation software", op. cit p. 41

[16] Yin R.K., Case Study Research: Design and Methods, Sage: CA (1994)

[17] Ross F., "The use of computers in occupational therapy for visual-scanning training" American Journal of Occupational Therapy 46/6 1992 314-322.

[18] Stern H. et al., "Computers in Neurorehabilitation: What Role do they Play Part 1", British Journal of Occupational Therapy, 1999 62(12) p. 549

> remediation in the achievement of performance-based occupational therapy goals.[19]

Other articles around this time indicate a change in the mood, especially by therapists, regarding the use of computers for people with brain injury. This could be regarded as defensiveness on the part of therapists who, as with many other occupations and professions, saw computer technology as a threat. Several articles retreated from the contention that computers may help restore cognitive functioning, and instead confined them to the role of providing tools for therapists. This was the approach of McGuire (1990)[20]:

> They are capable of highly controlled presentation of stimuli in a standardised format and can record data more accurately, consistently and objectively than can a therapist or observer. They can then analyse and record these data in a permanent record which is easily accessed. The stimuli presented can be attractive, bright and colourful, helping to engage and focus the patient's attention…the computer is infinitely patient...is able to present a variety of tasks according to the patient's needs and abilities, at a level which will challenge but not frustrate the patient. Feedback can be provided immediately in a clear, consistent and non-judgemental fashion. The patient is able to work at his or her own pace in a non-threatening environment, and can make mistakes without feeling any of the humiliation which may occur in interpersonal situations. (303-304)

But he notes that computers offer no substitute for the personal relationship the patient can develop with patient.[21] The role of the therapist was thus preserved.

Re-assessment

The early 1990s provided an opportunity for a more sober assessment of the aims and issues involved in the use of computers for people with brain injury. A fairer evaluation of the role of computers was able to take place at this time.

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[19] Ross F., op. cit p. 320

[20] McGuire B., "Computer-assisted cognitive rehabilitation" Irish Journal of Psychology 11/4 1990, p. 306

Several critical factors have provided a backdrop to this period of re-assessment. The first was the recognition that it is virtually impossible to distinguish any gains in cognitive function derived from CACR from natural recovery. "The most fundamental obstacle arises from individual differences in spontaneous recovery from head injury".[22] Natural recovery occurs at different rates for different patients, and this makes research in this area very difficult.[23]

A second factor in the re-assessment of the role of computers has been brought about by changes in the world of computers. There has been a growing sense of inevitability that computers have a role of the rehabilitation of people with brain injury, as they have established a role in almost every other sphere of work.[24] But also the types of changes in computer capabilities and features have been seen as favourable for their use in cognitive rehabilitation.[25]

A final and possibly most significant element in this re-assessment in the 1990s has been a more careful definition of aims. Are we really seeking to use computers to restore cognitive function, or are we using them to help people adapt to their new circumstances? Subsequent studies have followed one or other of these two streams.

Computers and the Restoration of Cognitive Function

There are those who remained committed to the task of using computers to achieve demonstrable restoration of cognitive functioning among patients

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[21] ibid

[22] Chen S. et al., "The effectiveness of computer-assisted cognitive rehabilitation for persons with traumatic brain injury" Brain Injury 11(3) 1997 p.198

[23] See also Pepin M. et al., "Efficiency of Cognitive Training: Review and Prospects", The Journal of Cognitive Rehabilitation, July / Aug 1995, 11-12, Gauggel S. and Niemann T., "Evaluation of a short-term computer-assisted training programme for the remediation of attentional deficits after brain injury: a preliminary study", International Journal of Rehabilitation Research, 19, 1996 pp. 229-239; Malec J., et al, op. cit.

[24] See for example Stern op. cit., 1999 (549), McBain & Renton op. cit., p. 203

[25] McBain & Renton op. cit., p. 203

with brain injury. They believed that we need to be more specific in targeting areas of cognitive deficit, and be more careful in the selection of suitable patients, in order to achieve positive results.

Bergman (1991), for example, argued that we must look at pertinent neuropsychological weaknesses (such as inattention, visual neglect) and use this information in the design of a computer prosthesis:

> Although a neuropsychologically unguided design process may serendipitously create some helpful features, the potential is great that it will become a scattered, inefficient and trial-and-error exercise…will place undue stress on the brain-injured user.[26]

Lynch (1992) proposed that a battery of psychological tests (especially targeting reaction times and memory) should be used to determine the suitability of patients for CACR and to pinpoint the goals of a program.[27]

Mazaux (1998) saw developments in brain imaging as offering prospects for more precise rehabilitation after traumatic brain injury, and sees computers as able to complement face-to-face therapy.[28]

Several studies have achieved positive outcomes. In one study by Ruff (1994) software called *THINKable* was used by 15 patients with severe traumatic brain injury. The attention and memory remediation modules of the program were used by each patient for up to 20 hours. The study concluded: "Significant results were documented on the computerized tasks, psychometric measures and on patient and observer ratings of everyday behaviours of attention and memory".[29]

Another successful study was that conducted by Thomas-Stonell using remediation software:

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[26] Bergman M., "The necessity of a clinical perspective in the design of computer prostheses" Journal of Head Trauma Rehabilitation 1991 6(2) p. 103

[27] Lynch W., "Selecting patients… Part 1" op. cit.

[28] Mazaux J. & Richer E., "Rehabilitation after traumatic brain injury in adults" Disability and Rehabilitation 20(12) 1998 pp. 435-447

[29] Ruff R. et al., "Efficacy study of THINKable in the attention and memory retraining of traumatically head-injured patients", Brain Injury 8(1) 1994, p. 3

> Significant group differences were found on several of the standardised assessment battery test scores suggesting that the remediation modules are an effective enhancement to traditional rehabilitation and education programs. Skill improvements were not instrument specific… but generalised to noncomputer-based activities as measured by the standardised assessment battery…anecdotal reports suggest that skill improvements from the remediation program generalized to classroom activities.[30]

Chen (1997) summarised a number of studies that used the Psychological Software Services Package to achieve specific gains. Gains were made in 9 studies, but no gains in 4 studies. Chen noted that the successful studies had longer treatment duration (3-6 months) and posed the possibility that "variations in the duration and intensity of therapy may have accounted for differences between these outcome studies".[31]

Gianutsos (1992) took a slightly different approach, by arguing that computers "permit the establishment of home-based computer-augmented rehabilitation programs, which allow aggressive pursuit of restoration of function in through exercise and practice".[32] While also acknowledging the compensatory role of computers (such as using word processing to compensate for a poor memory), she sees benefit in seeking restoration first:

> A good argument can be made for beginning therapy with restoration as a goal, even when the goal might be remote. There is value in having pursued restoration, even when it does not occur … computer technology facilitates the pursuit of restoration of cognitive functions. Whatever the outcome, if the individual has been given an option and decides how far to pursue it, the result should be positive psychologically. [33]

Such an approach sees value in the *pursuit* of restoration, regardless of the outcome.

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[30] Thomas-Stonell N. et al., "Evaluation of a computer-based program for remediation of cognitive-communication skills", Journal of Head Trauma Rehabilitation 9/4 1994 p.33
[31] Chen op. cit p. 198
[32] Gianutsos R., "The computer in cognitive rehabilitation: It's not just a tool anymore Journal of Head Trauma Rehabilitation 7/3 1992, 26-35 p. 26
[33] ibid 29-30

The results from the restoration approach have been mixed. Yet such an outcome should not be unexpected from its very methodology — positive results will only come if specific areas of cognitive functioning are targeted, patients are carefully chosen, appropriate software used and for a long enough period.

Generalisation of skills, however, will always be an issue with the restoration approach, where the software used tends to focus on drill and practice rather than real life situations. As Rizzo notes, restorative approaches involve "overemphasis on the brittle performance of overly learned functional behaviours, with a neglect of the underlying cognitive abilities required for the flexible problem solving needed to handle normally occurring variations in real-world circumstances".[34]

Computers as a Compensatory Strategy

The other approach since the 1990s has been to use computers to help people learn skills they can use in everyday situations. In these studies there is no attempt, nor any need to attempt, to demonstrate improvements in cognitive functioning. It is a case of helping people with brain injury to better use the capabilities they have.[35]

One of the earliest proponents of this strategy was Glisky (1992).[36] She describes the compensatory or alleviation approach as "training patients to perform specific functions in everyday life that they would otherwise be

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[34] Rizzo A., et al., "Virtual Reality and Cognitive Rehabilitation: A Brief Review of the Future", Journal of Head Trauma Rehabilitation 12(6) 1997 p. 4

[35] See Pepin op. cit., (1995) who postulates that "everyone is able to learn in varying degrees" and that this "does not require any specific inferences from the underlying neurological mechanisms" (8)

[36] Glisky E., "Computer-assisted instruction for patients with traumatic brain injury: teaching of domain-specific knowledge" Journal of Head Trauma Rehabilitation, 7/3 1992, pp. 1-12;

unable to perform because of the memory problems".[37] She notes the promising role of a computer in this role for the patient at home:

> Various kinds of information relevant to everyday activities -- listings of addresses and phone numbers, scheduled daily activities, information about home finances or budget, instructions for carrying out household chores, medication regimes, special dates, and so forth -- can be stored in a computer database and retrieved when necessary. Used in this way, a computer essentially functions as a memory prosthesis, providing a reservoir of facts that might otherwise be unavailable to patients with memory deficits.[38]

Several other studies have reported on the successful use of portable computer devices as memory aids for patients with brain injury.[39]

However the main focus of Glisky's own research was on the teaching of domain-specific knowledge, which she regards as an alternative compensatory strategy:

> The studies reported in this article had demonstrated that TB I patients with memory and learning deficits are capable of acquiring considerable amounts of complex knowledge and skills relevant to important domains of everyday life. Although their learning is slow compared to normal, patients are nevertheless able to acquire complex computer tasks such as data entry, database management, and word processing, and to use them to enhance independent functioning both at home and in the workplace. In the reported studies, the microcomputer played a major role.[40]

Many other studies have followed Glisky's approach, seeking ways in which computers may help people learn skills necessary for coping with everyday life. This has had the effect of broadening the debate about computers and their role in assisting people with brain injury. Lynch coined the term *ecological validity* to describe "the extent to which performance on a training

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[37] ibid p. 2

[38] ibid pp. 6-7

[39] See for example Lynch W., "You must remember this: Assistive devices for memory impairment" Journal of Head Trauma Rehabilitation 10(1) 1995 and Kim H. et al., "Utility of a microcomputer as an external memory aid for a memory-impaired head injury patient during in-patient rehabilitation" Brain Injury 13(2) 1999.

[40] Glisky op. cit p. 10

activity predicts performance on a target task that is considered relevant to the patient's adaptive functioning".[41] He saw this as an alternative to using computers for restoration of function. They can be used "purely as prosthetic devices allowing the patient to accomplish a specific treatment or vocational objectives".[42]

Reid (1995) argued that assistive technology is not just about the enhancement of specific functional capacities. Rather, it has "a more general and much more powerful goal: social inclusion".[43] Social inclusion is taken to mean full and meaningful inclusion in all relevant contexts. Assistive technology, including computers:

> permits children with disabilities following traumatic brain injury to function in many different environments, achieve greater academic success, and participate within the community rather than growing up in social isolation.[44]

This study fits in well with the compensation approach.

A study by Birnboim (1995) used a computer to help patients understand their own thinking processes.[45] A program was used to teach and train patients how to analyse their strategies and then apply them in real life situations. "Patients come to realise that problem solving, which was an automatic skill before their brain damage, now requires constant monitoring efforts".[46]

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[41] Lynch W. op. cit. (1992) p. 36

[42] ibid p. 44

[43] Reid S. et al., "Computers, assistive devices, and augmentative communication aids: Technology for social inclusion" Journal of Head Trauma Rehabilitation 10(5) 1995 p.81

[44] ibid p. 89

[45] Birnboim S., "A Metacognitive Approach to Cognitive Rehabilitation" British Journal of Occupational Therapy 58(2) 1995 pp. 61-61

[46] ibid p. 63

Perhaps McGuire's conclusion is salutary: that computers "appear most competent in aiding the learning of particular skills or information sets than regenerating complete areas of cognitive functioning".[47]

On the whole, the use of computers as a compensatory strategy for people with brain injury has been a liberating one. It has opened up creative pathways for the use of computers. No longer has the role of computers been sidelined by the elusive requirement that restoration of cognitive function be demonstrated.

Other Frontiers

The distinction between restorative and compensatory approaches to the use of computers for patients with traumatic brain injury does not exhaust the important developments of the 1990s. Several other themes have emerged.

The first is the recognition that software used in cognitive rehabilitation must be *user friendly* and *age appropriate*. Jarvis (1990) noted the drastic consequences that can flow from 'unfriendly' software:

> Patients will probably react in whatever maladaptive way is most characteristic for them. Some may experience increased feelings of inadequacy and depression, some may increase demands for dependency on the therapist, and others may 'project' the blame onto the computer. In any case the 'unfriendliness' of the software is likely to reinforce the patient's maladaptive responses.[48]

As previously mentioned, Lynch was critical of the boring nature of much of the software used in CACR.[49]

The problem of age appropriateness of software is well known among therapists. McBain (1997) noted the growth in special needs software, but identifies "problems in using this software with adults. Often patients with

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[47] McGuire B., op. cit, p. 306
[48] Jarvis P., "The Importance of Patient Friendliness in CACR Software" Cognitive Rehabilitation Jul/Aug 1990 p. 24

head injury find that educational computer programs are not age-appropriate and, therefore, not fully motivating".[50] Software that is age appropriate for adults is usually too fast and too cognitively demanding for those with brain injury.

The matter of *computer access* has also been given some prominence in the 1990s.[51] Lynch identified neglect of this issue as one of the problems of earlier studies of CACR software.[52] O'Leary (1991) observed that "For the person with traumatic brain injury, access to a personal computer may be improved through the use of positioning, adaptive aids, adaptive hardware, and adaptive software".[53] She mentions a range of adaptations, most of which are still relevant:

- Adjustments may be required to monitor height or keyboard position.
- Mobile arm supports, slings or splints may help.
- Trackballs may be useful.
- Software such as Sticky keys and word prediction can assist.
- Mouthsticks, headpointers, infrared controllers and on-screen keyboards may all be useful where control by head movement is required.
- Screen enlargement or large monitors may assist.
- Auditory and visual cues can be modified to increase attention and sensory input. [54]

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[49] Lynch W., "Ecological Validity" (1992) op. cit.
[50] McBain & Renton op. cit., p. 203
[51] Levine S. et al., "Performance considerations for people with cognitive impairment in accessing assistive technologies" Journal of Head Trauma Rehabilitation, 7/3, 1993 pp. 46-58; O'Leary S., "Computer access considerations for patients with traumatic brain injury", Journal of Head Trauma Rehabilitation, 6/3 1991, pp. 89-91.
[52] Lynch W., "Ecological Validity" (1992) op. cit. p. 41
[53] O'Leary S., op. cit., p. 91
[54] ibid

Other developments since that time have also proven useful. These include speech output, multiplay CD-ROM drives, large animated cursors and joystick mouse devices.

A third important development in the 1990s has been the use of *virtual reality* in cognitive rehabilitation. Put simply: "...information gained from experience in a VE [virtual environment] can transfer to the real world... in a simulated world disabled people can enjoy experiences that would otherwise be denied them".[55] From a therapist's perspective virtual reality enables one to "assess a patient's ability to perform everyday functions...without endangering the patient and without sacrificing strict control over the test situation".[56]

Virtual reality also offers the possibility of overcoming the distinction between restorative and compensatory techniques. As Rizzo explains:

> It may be possible for a VR application to provide systematic restorative training within the context of functionally relevant, ecologically valid simulated environments that optimise the degree of transfer of training or generalisation of learning to the person's real world environment. [57]

These three themes have their own importance and relevance, whether one favours the restorative or compensatory approaches to CACR. They will become increasingly important as technological change continues to accelerate.

The Computer as a Motivator

When one reads the literature on the use of computers in cognitive rehabilitation, and the major themes that have unfolded over the past 20

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[55] Wilson P. et al., "Virtual reality, disability and rehabilitation", Disability and Rehabilitation, 19(6) p. 218

[56] ibid p. 217

[57] Rizzo op. cit p. 4. See also Grealy M. et al., "Improving Cognitive Function After Brain Injury: The Use of Exercise and Virtual Reality", Archives of Physical Medicine and Rehabilitation, June 1999, pp. 661-667.

years, one can't help but notice a most persistent sub-theme. Studies frequently suggest that computers give people with brain injury greater *confidence* and *self esteem*, and that they provide positive *motivation*. This conclusion has emerged, even in studies that showed that no cognitive improvement arose from the use of computers.[58]

One study described the methods used to enable a 54 year old stroke victim to use a computer. After eight months it was noted that he was "brighter and he appeared more tolerant of his disability". He was able to write letters and stories, and this improved his self esteem. Further, "the patient believed that working on the computer improved his memory and quickened his mind. It also enabled him to pursue his leisure activities for hours at a time without losing his concentration". [59]

Sietsma (1993) studied 20 people with TBI who had mild to moderate spasticity in the upper extremity. The results from a rote arm-reach exercise were compared with those from using a computer-controlled game. "Results indicated that the use of the game elicited significantly more range of motion than the rote exercise".[60] Further, "The flashing lenses and sounds of the Simon game provided motivating feedback to enhance performance, and the game promoted more enthusiasm and increased attention span…many subjects continued playing Simon after they had completed 10 repetitions". [61]

Malec's study (1984) showed no improvement in performance on measures of sustained attention for patients using a games machine, compared with those not receiving treatment. However:

> Subjects in the study appeared to enjoy and to be engaged by the video games. The subjects actively participated in video game sessions even

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[58] Sietsema J. et al., "The use of a game to promote arm reach in persons with traumatic brain injury", American Journal of Occupational Therapy, 47/1, Jan 1993 pp. 19-24; Malec J., et al, op. cit; Glisky E., op. cit; Purdy M.& Neri L., op. cit, 34-38.

[59] Batt R. and Lounsbury P., "Teaching the patient with cognitive deficits to use a computer" American Journal of Occupational Therapy 44/4 Apr 1990 364-367.

[60] Sietsma op. cit, p. 19

[61] ibid, p. 23

> though many were highly uncooperative and distractible in other rehabilitation activities.[62]

Stern (1999) commented: "Although not clinically researched, it appears that many patients regain some self-esteem through using the computers".[63] Kirsch (1991) noted that computers "can increase a patient's self-esteem and life-satisfaction".[64] Johnson's study (1994) using TEACHware software observed "Both the subjects and the normal students reported that the TEACHware program was motivating and fun to use".[65] The full results of the study made a similar affirmation: "Computers provide… a motivating, interactive learning environment." [66]

Purdy's study (1988) concluded that patients "showed an increase in attention and motivation as well as improvement in skills specifically addressed by the program".[67] Skinner (1985) found that "we have noted with all patients the increase in motivation was greater with this program than with more conventional treatment modalities".[68] McGuire (1990)noted that "This feeling of control of the situation by the patient can lead to increased motivation and feelings of self-worth". [69] Bergman (1991) observed "Computer-enhanced self-sufficiency in the performance of routine activities improves self-esteem and emotional adjustment". Further, "Successful implementation of a cognitive prosthesis… can lead to task mastery, enhanced self-esteem, and better overall use of resources".[70]

The remarkable consistency of these comments across a wide variety of studies suggest that the motivational capabilities of computers for people

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62 Malec op. cit, p. 22
63 Stern 1999 op. cit, p. 552
64 Kirsch N. et al, 'Focus on clinical research' Journal of Head Trauma Rehabilitation 6: 35-45 (1991)
65 Johnson P. et al., "Development of a Computer-Based Program for the Remediation of Cognitive-Communication Skills in Young People with Head Injuries", The Journal of Cognitive Rehabilitation, Jul/Aug 1994 pp. 10-15
66 Thomas-Stonell op. cit., p. 26
67 Purdy & Neri op. cit, p.34
68 Skinner A., op. cit p. 472
69 McGuire op. cit p. 304

with TBI should be taken seriously. The importance of a technique that elevates a patient's motivation and self esteem is significant, given the acknowledged negative impact of deficits in attention for people with brain injury. Gray, for example, notes how attention deficits "can compromise rehabilitation in other spheres". [71] Malec had earlier noted the importance of attention in rehabilitation:

> Because of the close association between learning and the ability to sustain attention to the learning task, improving sustained attention following craniocerebral trauma may be critical to enhance other types of learning in other rehabilitation therapies.[72]

So what appears to be a side-issue to the main debates of the period may be more important than at first realised. Motivation, confidence and self-esteem can be precious commodities for a person with brain injury. Gains in these areas may improve the person's prospects for cognitive rehabilitation in general.

Computers and Recreation

It is time in this review to focus our attention on our main concern, the recreational benefits of computers for people with brain injury. Not surprisingly, this has not been a major theme in the literature.

The matter was addressed in an early study by Purdy and Neri in 1988.[73] They saw computers being useful in the home setting, especially in cases where motivation continued to be high. They noted a number of advantages, but mainly in the area of therapy rather than recreation *per se*:

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[70] Bergman op. cit p. 103

[71] Gray J. et al., "Microcomputer-based Attentional Retraining after Brain Damage: A Randomised Group Controlled Trial" Neuropsychological Rehabilitation 2(2) 1992 p. 97.

[72] Malec op. cit, p. 18

[73] Purdy M. and Neri L., op. cit.

?? It can be used to supplement a formal therapy program.

?? It can be used to improve or maintain the current level of cognitive functioning once formal treatment has been discontinued.

?? It provides the person with something productive to do in his or her spare time.

?? It develops skills that could be used outside the therapeutic environment, such as at school or at work.

?? It provides for unlimited practice and repetition.

Other studies have made brief mention of benefits relating to the use of computers at home. Gianutsos (1992) mentioned the point that computers "made it possible for people to pursue the restoration of cognitive function as long and as intensely as they could possibly desire".[74] The study by Glisky (1992) also identified benefits available in domestic computer use, in this case as a memory aid: "Computers can also play a significant role in the home. Various kinds of information relevant to everyday activities — listings of addresses and phone numbers, schedule of daily activities, information about home finances or budget, instructions for carrying out household chores, medication regimes, special dates and so forth — can be stored in a computer database and retrieved when necessary."[75]

The study by Batt and Lounsbury (1990) is one of the few to focus on recreational benefits of computers used at home. Their study highlighted the social and recreational benefits of computer activity for the patient concerned, who reported that "his social life and family life are more interesting and

[74] Gianutsos R., op. cit.
[75] Glisky E., op cit

entertaining now because he can share his computer skills and play computer games with his family and friends".[76]

One major Australian study has made a useful contribution to this area. It was a study undertaken on behalf of Headway Victoria.[77] It outlines ways in which computers are being used "to assist with communication, memory, organization, planning and learning new skills".[78] Significant gains in independence, personal organization and self esteem are noted among the 20 participants in the study.[79]

Overall we can observe that recreational benefits of computer activity have been noted in the literature, but few studies have pursued this issue with any vigour.

Conclusion

Some general observations are possible from this survey of the literature in this relatively new field. Computer technology has had an impact here, as in just about all other fields.

We have seen how earlier enthusiasm gave way to suspicion and defensiveness. It was not until the 1990s that a re-assessment of the proper role of computers in cognitive rehabilitation took place. Some have pursued the restorative approach, seeking to use computer technology to achieve measurable gains in cognitive functioning. Greater rigour in the selection of software and participants has been called for. One suspects the problem of individual differences in spontaneous recovery, as well as the problem of

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[76] Batt R. and Lounsbury P., "Teaching the Patient with Cognitive deficits to Use a Computer", American Journal of Occupational Therapy, 44/4 1990 . p.366 .

[77] McNamara C. et al., Personal Support and Technology for People with Cognitive Disability., MGM Consultants/HeadWay Victoria, Melbourne, 1996.

[78] ibid, p. 22

[79] ibid., pp. 22-26

generalising gains to real-life situations, will continue to thwart the persuasiveness of these types of studies.

The majority of studies have looked at the alternative, a compensatory strategy. Here there has been more success. Computers have an established role in assisting people with TBI to cope with real-life situations. Recent technologies such as virtual reality may strengthen this role.

Other issues have been mentioned. Computers offer benefits as a therapist's tool. They allow patients to pursue remediation of function for as long as they desire.   Computer access issues for people with brain injury have been given some attention, as has the importance of user-friendly, age-appropriate software.

We have noted consistent mention of the computer as a device that increases motivation, self esteem and confidence of people with brain injury. This surely invites further research as a topic on its own right.

Finally, we have noted that recreational uses of computers have been mentioned in the literature, but only in a small number of studies. This is in spite of research that suggests loss of leisure options is one of the major sequelae of traumatic brain injury.

3. METHODOLOGY

This pilot study was undertaken at the Brain Injury Unit, Royal Rehabilitation Centre, Sydney. The steps involved in conducting the research are described below.

Selection of Software

Before the research commenced, the staff at Ability evaluated a range of software to have available for the project. Alternative interfaces, word processing, drawing, personal organization, reference and recreational software were examined for their possible usefulness for people with brain injury. This meant that we were able to accommodate the specific interests of all participants as they arose.

Selection of Participants

Staff at the Brain Injury Unit, Royal Rehabilitation Centre, Sydney, distributed an information sheet to patients at the Unit. This sheet described the research and gave undertakings regarding confidentiality and the right to withdraw from the project at any time. Meetings were then held with interested patients and members of their families. Those who decided to accept the invitation to be involved signed (or had their guardian sign) an Agreement to Participate form. A total of six patients were involved (five males and one female), each for a period of four weeks. The research was undertaken in two separate periods (in 1998 and 2000) due to staff changes both at the Brain Injury Unit and at Ability.

Computer Access and Training

An occupational therapist from Ability Research Centre assessed each participant to determine their computer access requirements. Appropriate equipment was then organised and installed on the computer. Training was provided. The specific needs of each person are discussed in the next chapter.

Monitoring Computer Usage

It was initially planned that participants would have access to the computer as part of their recreational activities at the Unit. Each patient's use of the computer would be recorded in a Log Book. Another researcher from Ability would then visit each participant weekly to monitor their feelings and progress.

We had hoped to monitor user keyboard presses and mouse movements/clicks over the period of the study, thus giving some indication of variations in fluency and activity over the period. Various programs were evaluated before we decided to use *Ergo Sentry*, a specialised application that monitors computer activity for ergonomic purposes. (When a user passes a set number of key presses or mouse movements/clicks, they are advised to take a rest or undertake various stretching exercises.)

However staff shortages at the Brain Injury Unit meant the Unit was unable to arrange computer activities as part of the patients' recreational program. A different approach had to be devised. An Ability trainer sat with each participant for two sessions per week during the four week period. The participants did not use the computer independently during the study period; indeed, our impression was that they were unable to do this at this time (although some had the potential to do this is the future).

This approach meant that any measurement of computer activity was pointless. It was not possible, from the figures obtained, to distinguish computer activities performed by the trainer from those performed by the participant.

However there were benefits with the approach adopted. It gave us more detailed information about user problems, obstacles and preferences, as we were on hand to witness these. Running changes to software and settings were able to be made. The dangers of user frustration and possible abandonment were also overcome.

4. RESULTS

The following notes outline the experience of each participant in the study. They are organised in terms of the study's original aims:

?? Computer Access

?? Appropriate software

?? Identification of benefits

The names of participants have been changed.

1. WILLIAM	
Computer Access Issues	William has used a Macintosh computer previously at home. He is non verbal. He communicates via a LightTalker device. He has minimal use of his right upper limb. His spelling and literacy are good. His motivation was good. William has a good sense of humour. He learnt to use a Microspeed PC-TRAC trackball fluently with his left hand during the period of the project. He also found a compact keyboard (Cherry) of assistance, as it enabled him to position the trackball next to the keyboard on his tray. William's independence increased during the study.
Appropriate Software	William enjoyed exploring Encarta encyclopedia. He had previous interests in photography and Jewish history that he was able to explore through Encarta. He enjoyed the challenge of the Encarta quiz. He also liked the Hangman game.
Benefits	William enjoyed the computer sessions very much and his motivation remained high throughout the study. Social benefits were evident when he shared computer activities with another patient during some shared sessions. William was keen to pursue photographic imaging through using a computer.

2. PAMELA	
Computer Access Issues	Pamela had used a computer previously in her work. She remembered the location of keys on the keyboard. She had impairments in initiation and problem-solving. She also needed to move her eyes very close to the keyboard. She was confused at times between the two sets of arrows on a standard keyboard. KidDesk was helpful in providing an alternative interface. BigKeys large coloured keyboard very helpful. She was able to use standard mouse with her right hand. Pamela required repetition of instructions.
Appropriate Software	Pamela enjoyed Paint program. She reached the stage of independently choosing colours and paint tools. She really enjoyed a poker machine simulation game. She loved the sensation of winning. Other software she enjoyed included Encarta, Hangman, Bulldozer and Card Match.
Benefits	Pamela was able to concentrate on computer activities. She gained a lot of enjoyment in using a computer. Social benefits were evident during shared sessions with William. She was very proud of her painting work, which was printed for her.

3. SHAUN	
Computer Access Issues	Shaun had very little prior computer experience. He was able to read text on the screen. A large cursor helped him to locate the cursor on the screen and to track its movements. A high contrast screen colour scheme was helpful. A modified interface with large icons was set up through the Compaq User Desktop. He had problems using the standard PC-TRAC trackball. He had cognitive difficulties distinguishing left and right buttons. The version of the trackball with coloured buttons (Kid-TRAC) would have been helpful. The double-click function was slowed down. Shaun had a desire to press buttons on the screen. A touch screen may have helped. He was able to use a joystick and found this easier than a trackball for mouse functions. However the software developed faults. Shaun found it difficult to distinguish the letters on a standard keyboard. Larger keys and labels would have been helpful.
Appropriate Software	Shaun was unable to access the buttons in Encarta as they were too small and were not customisable. He enjoyed CART Precision Racing but not Ski Racing, as he had no familiarity with skiing. The Crossword game was too difficult for him. His favourite game was an interactive game called Monkey Island. He preferred games with humour and interactive dialogue rather than action games. He enjoyed music CDs. He had difficulty using Outlook Express – a simpler program would be required for e-mail. We have since had some success with EeZee Mail.

Benefits	Shaun was able to demonstrate a sense of humour in computer activities. His laughing was appropriate, not random. No behavioural problems were evident during the study (unlike in some other activities in which he participated). The computer provides text in a more readable / adaptable format for reading / vocational activities. There was some indication that there were improvements in his hand-eye coordination during the study. Shaun enjoyed computer activities. His interest was aroused.

4. NATHAN	
<u>Computer Access Issues</u>	Nathan had some previous work experience with computers. He typed with one finger on a standard keyboard. His spelling was poor, as was his ability to edit what he has typed. He was able to use a PC-TRAC trackball effectively. We had to slow down the double-click function. Nathan also had trouble with drag/lock functions. He also wanted to touch the icons on the screen. Nathan required a list of tasks for each session - he liked to keep the sessions 'business-like', not like an experiment. We modified the Compaq User Desktop to develop an alternative to the standard Windows interface. Large icons were used. The manner and language of the trainer was very important in his case. The trainer had to be mature, be able to handle Nathan's behaviour and show patience. He could not be condescending. Nathan was able to sustain attention for over 20 minutes.
<u>Appropriate Software</u>	Nathan did not like Write:Out Loud (text reader). He used Word with the buttons and font size increased significantly. This was his favourite program and the one he used most of the time. He enjoyed some of the musical aspects of Encarta. He was able to use Outlook Express. Nathan enjoyed programs with photos – he enjoyed viewing pictures. However he did not like games. Age appropriateness of software was very important to him.

Benefits	Nathan told staff using the computer was his most enjoyable activity. His enjoyment was evident during the project. There were no behavioural problems during the activities, unlike in other activities. Nathan required the most attention by the trainer. The computer provided Nathan with an enjoyable way of communicating, using MS Word and Outlook Express. It was a good outlet for personal expression. He enjoyed writing but his spelling was poor. The computer provided a good way for him to listen to music. Overall the computer was a source of motivation for him.

5. ALAN	
Computer Access Issues	Alan was familiar with computers before his injury. He was able to read the text on the screen. He had good literacy and spelling, and good reading skills. He also desired to press buttons on the screen - a touch screen may have helped. Alan found the BigKeys (BW Qwerty) keyboard useful. However he needed to access some of the keys not found on this model of BigKeys, such as Page Down. (Note: Later version of BigKeys – the LX – has a full set of keys). He wasn't able to manage a mouse. He was able to use a PC-TRAC trackball (although occasionally he tried to roll the trackball!). He was able to use a joystick for mouse functions; however the Joystick-to-Mouse software was faulty.
Appropriate Software	Alan loved the skiing game – skiing was a previous interest. His performance in the game increased during the study. He had travelled before and was interested in boats. He used Encarta encyclopedia to look up 'Boat Building' and 'India'. He seemed to enjoy these connections with his past. Used Outlook Express, Tennis - Pong (we had to had to re-arrange the buttons), and Eager Echo. He used Microsoft Word a lot for communication and expression, to answer questions and interact.
Benefits	In areas of interest he demonstrated good concentration. He enjoyed computer activities very much. The use of a computer would provide communication benefits.

6. BRENNAN	
Computer Access Issues	Brennan functioned at a higher cognitive level. He was very keen to go home and was discharged after only 3 weeks in the project. He desired to press the buttons on the screen - a touch screen may have helped. He suffers vision impairment. A larger screen would have helped. We did change the desktop settings to give High Contrast with Extra Large layout. Brennan found the BigKeys large keyboard helpful. He also found the PC-TRAC trackball easier to use than a mouse.
Appropriate Software	It was a challenge to find recreational software of interest to Brennan. The Golf game caused him frustration because it was hard for him to see the detail. He enjoyed CART Precision Racing but found his eyes got tired after a while. Overall he enjoyed communication programs (like Outlook Express) rather than games. He had a strong desire to send his brother e-mails.
Benefits	Email useful for communication in Brennan's case, with perhaps some perhaps vocational. His strong preference was for communication and vocational programs/activities, rather than recreational software.

5. CONCLUSIONS

The conclusions of this pilot study relate to the study's aims, as outlined in the Introduction. They are discussed below.

1. Identification of Benefits of Recreational Computer Activity

The six participants all secured benefits through their computer activities. They all enjoyed using the computer and seemed to be motivated by these activities. Staff reported that using the computer was the favourite activity for several of the participants.

Simple proficiencies gained or revived (such as writing or drawing) increased participants' self esteem and confidence.

For many of the participants the computer enabled a connection with their former lives. Previous interests, such as photography, skiing and boat building were all able to be replicated through the computer. Participants seemed to find this connection helpful.

For some participants, the computer provided a means of communication and self expression. In one there was some indication that hand-eye coordination was improved through computer activity. Attention span was longer for most participants than in other activities. For one pair of participants, social benefits were evident as they shared computer activities together.

We believe these benefits were significant in the lives of these participants.

2. Facilitation of Computer Access

All participants were able to access the computer, but all required some modification and customisation to enable this to happen. Some useful adaptations were:

- Use of an alternative, simpler desktop interface than that available under Windows. We used *KidDesk* and also the customised desktop available with the Compaq computer.

KidDesk

- In several cases the colour scheme / contrast level / icon size of the display had to be altered to facilitate access.
- Use of a trackball certainly was more intuitive for these participants than a standard mouse. Sometimes mouse functions such as double-click had to be slowed down.

Microspeed PC-TRAC trackball

- In some cases a smaller keyboard improved the efficiency of keyboard input, while in other cases a larger keyboard achieved the same result.

Cherry Compact keyboard

Big Keys Plus

- ✍ A large cursor also assisted several participants, making it easier for them to track cursor movements on the screen.
- ✍ Almost all participants had an urge to touch the buttons showing on the display. We were not able to determine whether a touch screen would be a useful mouse input alternative, or whether participants should be ushered past this impulse to more standard devices. In our study we had no alternative to the latter course, as a touch screen was not available for the project. However the fact that all participants adapted to the trackball in a short period perhaps suggests that this would be a preferred course of action. Still, there may be a role for a touch screen in the early stages of rehabilitation for some clients.
- ✍ The same comments applied to the use of a joystick as an alternative mouse device. From our experience this is more intuitive to use than a trackball. However the Joystick-to-Mouse software used in the study caused problems with other programs, to the extent that we were

unable to use it for long. So the question of the role of a joystick mouse device could not be addressed in this study. We note that a device such as the *Penny & Giles Joystick Plus* has been used successfully by Ability with other clients with brain injury.

Penny & Giles Joystick Plus

We conclude that it is most unlikely that people such as those in this study would be able to use a standard computer to achieve the benefits mentioned earlier. Customisations such as those listed above were required to increase participants' independence in using the computer and to give them confidence. However each person's needs were unique – there is no formula that could be applied to meet the needs of all.

3. Identification of Appropriate Software

There was a wide variation in the software that participants in this study found enjoyable. Simple games and puzzles were popular with some, whereas others preferred writing and more serious activities. Some enjoyed Encarta. One enjoyed a Paint program. For some, standard programs such as

Outlook Express were fine, whereas others would require simpler programs to achieve similar ends. Our study confirmed that age appropriateness is a key issue when choosing games for adults with TBI.

Sometimes the settings in the games had to be adjusted to meet the needs of participants. *CART Precision Racing* is an example of a game where customisation can reduce the skill required to achieve a satisfying result. In this game many of the processes, such as gear-changing, can be automated. Skids can be moderated and the car even be made to follow a good line through the corners, without sacrificing realism. The net result is that the person merely has to move the joystick forward to accelerate, and gesture slightly to left or right to negotiate a corner, without diminishing the thrill and self esteem benefits that come from winning.

We conclude that some care is required in the selection of appropriate software for people with TBI. We believe mainstream software is the most appropriate for adults with TBI, but great care is required in its selection. A comprehensive study of suitable software would be a great resource for all who work with people with TBI – in its absence, considerable trial and error will be required.

Wider Issues

As a pilot study, this research has achieved its moderate aims. While the conclusions are limited, they do permit the raising of some wider issues and questions.

As the literature review has shown, the 1990s has witnessed a variety of trends in the use of computers for people with TBI. There are those who seek more rigour in the pursuit of restoration of cognitive function, through more detailed assessment procedures and software that targets specific areas of cognitive functioning. Alternatively there are those who see the role of computers in developing compensatory techniques, ways of improving the quality of life and independence of people with TBI.

Our study fits more into the second category. It raises the tantalizing possibility that quality of life outcomes for TBI patients may be better achieved through the carefully guided use of mainstream computer programs, rather than through the use of specialised cognitive rehabilitation software. Could it be that the motivation and self esteem benefits arising from productive computer activity could kick start new interests and directions, as people with TBI rebuild their lives? Some new research beckons.

In this study one of our staff sat with the person throughout each session. None of the participants reached the stage of being able to use a computer completely independently, although this appeared to be a realistic goal in the case of some. They would require some form of direct support, as was available in our study, in their use of computers at home. Sometimes they reach obstacles they cannot get around on their own. Telephone support or else appropriately trained family members/carers would be indicated.

A follow-up study would look at patients once they return home, and would operate in conjunction with family members and therapists. Over a longer period it may be possible to see more clearly the outcomes tentatively observed in the current research.

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