STROKE CARE MAPPING:

A STUDY OF THE DEVELOPMENT AND APPLICATION OF THE DEMENTIA CARE MAPPING TOOL IN STROKE CARE

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SECTION C: CASEWORK

A CASE STUDY EVALUATION OF MOBILE PHONES AS A NEW EXTERNAL MEMORY AID

An evaluation of a new external memory aid using mobile telephones

1.0 Introduction

The role of memory functioning is one of the pervasive aspects of our mental life; it allows us to reflect on our experience of the past, adapt ourselves to the present and look towards the future. It is a primary cognitive process that is critical for successful functioning in even the most basic aspects of daily living and often represents one of the most common neuropsychological deficits found in brain injury (Kapur 1994). In Great Britain, for example, about 1000 people suffer severe head injuries each year from which they will not recover sufficiently to return to work, and about one third of whom will have significant and permanent memory impairment (Schacter and Crovitz 1977). In addition, some 93,000 people in Great Britain are disabled as a result of a stroke (Weddell and Beresford 1970), many of whom may experience difficulties in memory functioning, not to mention those who may be affected in a similar fashion as a result of a tumour, degenerative disease, toxic disorder, temporal lobe epilepsy, HIV disease, multiple sclerosis or anoxia.

Decreased memory functioning can have a devastating effect on a person's educational or vocational goals as well as on quality of life, and unfortunately there is no known way that lost memory functioning can be restored in patients with organic impairment once the period of natural recovery is over. This places a great burden upon health services and other agencies attempting to care for them, but perhaps the greatest burden is on immediate family members. Owing to lack of resources, and sometimes lack

of knowledge and understanding on the part of professional staff, large numbers of these patients often receive less than adequate services to assist in reducing the effect of their handicap on their everyday functioning (Wilson 1995). Many professional staff working with these individuals who present with memory difficulties are often so influenced by the organic nature of the cause of the memory problems that they regard them as untreatable (Wilson 1987) and therefore do not seek to assist in finding ways of coping with the affects. However, despite this common belief, the lives of brain-injured people can be made more tolerable, for example, by teaching them, to bypass certain problems or compensate for them, or to use their residual skills more efficiently.

Where a rehabilitation approach is considered for people with memory impairments there are two broad approaches to treatment: restoration and compensation (Sohlberg and Mateer 1989). 'Restoration' has the goal of rebuilding memory through exercises involving repetitive practice and drills. However, studies have repeatedly documented the failures of such an approach to impact functional memory in everyday situations (Godrey and Knight 1985; Prigatano et al 1984; Schacter, Rich and Stampp 1985). Despite the lack of evidence that this approach has any generalisable effects on memory enhancement, repetitive drilling is the approach taken in almost all of the published computer programs for 'memory training'.

The 'compensation' approach involves the training of strategies or techniques for memory compensation and aims to circumvent any difficulties that arise as a result of memory impairment. There are two traditional types of training techniques: one is the teaching of internal memory aids and the

other is training in the use of external memory aids. The former involves internal mnemonic strategies (Patten 1990, McGlynn 1990) which may focus on enhancing organisation of information to be recalled, rehearsing information to be remembered, or training specific mnemonic devices such as peg words or visual imagery (Cermak 1975; Crovitz 1979; Gianutsos and Gianutsos 1979; Gasparrine and Staz 1979; Wilson 1981,1982). There has been some limited success using mnemonic systems (Yates 1966, Wilson 1987, Moffat 1992), probably because these techniques encourage a deeper level of processing (Craik and Lockhart 1972), allow previously isolated items to be integrated with one another (Bower 1972), and provide in-built retrieval cues in the form of initial letters, locations or pegs. However, this approach is only likely to be successful with people whose memory is not severely impaired (Wilson 1995) because of the demands mnemonics place on concentration and learning skills, so if these skills are impaired to any significant degree the approach has limited value (Schacter et al 1985; Baddeley 1982).

The other training technique which involves the use of external memory aids, attempts to help people to remember by using systems to access or record information. Unfortunately these aids have received far less attention in the literature to date, with few systematic studies as to their value, despite their enormous potential (Kapur 1995). There are two major types of external memory aid (Harris 1992). The first method enables the user to access internally stored information, such as a cue sound as a reminder to switch off an appliance, but this is not very helpful if the user cannot remember what they should be remembering to do. The second type are those that record information externally. They include diaries, notebooks, lists, wall charts and

calendars. There are often difficulties arising when using external aids with memory-impaired people as the aids often involve the learning of new techniques for their efficient use, and using even the simplest of external memory aids involves a number of cognitive processes (Intons-Peterson and Newsome 1992). Individuals with a memory impairment may forget to use the aid, or be unable to programme it, or may use it in an unsystematic way or be embarrassed by it.

A recent development that looks promising for large number of memory impaired people is the NeuroPage (Hersh and Treadgold, 1994), which is a simple and portable paging system with a screen that can be attached to a belt. The system utilises a software program linked to a conventional computer memory and, by telephone, to a paging company. The scheduling of reminders for each individual is entered into the computer and from then on no further human interfacing is needed. At the arranged time and date the reminder is transmitted to the pager. The user is alerted to the incoming message by a flashing light and an audible cue. Once the message appears, users are requested to telephone a person or an answer service to confirm the message. Without this confirmation, the message is repeated. NeuroPage has the benefits of being easy to use, not requiring a great deal of learning to be used effectively, and being highly portable. The benefits of the Neuropage system have been demonstrated by Wilson et al (in press) for 15 neurologically impaired individuals with whom they found a significant improvement between baseline and the treatment phase for each subject. However one of the criticisms of using the pager system is one of ecological validity as it separates those individuals who use them from the 'normal' population as a whole, and therefore embarrassment may prevent a number

of individuals using such a system which they could find of considerable benefit. It was felt that if individuals could use equipment which was part and parcel of everyday life and was not obviously a memory aid any such embarrassment would be avoided or minimised and so the aid would be more likely to be used effectively. It was therefore decided to evaluate the use of mobile telephone rather than dedicated NeuroPagers, but to retain the computer-activate messages.

1.1 Benefits of using mobile phones as an external memory aid

One of the most appealing reasons for examining the use of mobile phones to provide memory prompts for individuals with brain injury is that they represent the fastest growing market in communication technology. In just 8 years the number of cellular subscribers in the United Kingdom has grown from one million to thirteen million (Financial Times Business Ltd 1998). This rate of this growth is expected to continue and it is predicted that between 70-75% of all UK voice traffic will be carried to some extent on cellular networks by 2007 (ABN Amro Investment Bank).

A mobile phone service would also have number of advantages over the paging system for a number of individuals:

- Individuals with visual impairments or perceptual difficulties often find it difficult to read the small screen of a pager, which often has poor message/background contrast, and using a verbal message eliminates such a problem.

- The mobile phone system gives a verbal message, meaning it can be used by people with poor reading abilities or acquired dyslexia.

- Young people may be embarrassed about using a memory aid, and as the majority of traumatic head injuries occur in young males a mobile phone seems more socially acceptable and so more likely to succeed as an effective memory aid.

- As well as being used as a memory aid for individuals with brain injury, a mobile phone also has another advantage in that if a person is known to wander off or become lost the mobile phone can be used directly by family members as a two way means of communication.

To assess whether it was possible to deliver messages via mobile phones, a computer software company was approached to help develop a computerised system to send reminder messages to mobile telephones. The system that was subsequently developed, named 'Synatel', incorporated a number of additional features to help ensure messages were received, to keep information on its use, and to make it user-friendly. Such features are outlined below:

1. The spoken message can use the user's own voice, their caregiver's, a computerised voice, or an anonymous human voice, whichever is most appropriate. This was thought to be important because it would introduce the element of choice to the person receiving the service and occasionally the identity of the voice may be important to ensure whether a person does something; for example, if a person disliked being told what to do, if they

received a message with their own voice and so be more likely to respond to it then they may see this as less threatening.

2. The message is voice-activated by the recipient, ensuring that no part of the message is missed between the time of pressing the answer button to placing the telephone near the ear. This helps to normalise the process of answering the mobile phone in an everyday context.

3. Each message is preceded by the explanation that it is a recorded message, to avoid confusion as to the source of the call. This will inform the receiver straight away that this is a memory prompt rather than a telephone call from a friend or relative.

4. Messages can be as long as required, meaning messages can be tailored to the individual, and users can be talked through subtasks. This would enable the person to carry out the task with the mobile phone if a sequence of events was required to complete the memory task.

5. When encountering an engaged tone the computer will continue trying to send the message until it gets through. This ensures that the message is always delivered and enables the person to use the phone normally without the worry of blocking up the line for memory prompts.

6. If a message is not answered the computer will repeat trying at regular intervals. This is another mechanism to ensure that the message is received if the person decided for whatever reason to switch off the mobile phone.

7. Messages can be specified as 'high priority' in which case unanswered calls can be transferred to the caregiver, alerting them that the message has not been received. In this way, caregivers can be assured that they will know messages are being received. This provides a failsafe mechanism to carers who may otherwise worry about messages being received.

8. Users can be asked for confirmation of completing tasks by simply keying their personalised number into the phone (e.g. confirmation of taking medication). This may be needed if a person may tend to forget the message after it is received.

9. The central computer records user information, such as the time taken to answer, which calls were missed, and which calls were transferred to the caregiver. This provides useful information as to how the telephone is being used.

To evaluate the newly devised system it was decided to carry out a small pilot study using a number of cases to assess the effectiveness of this memory aid.

2.0 Design and Overview

2.1 Participants

Five individuals with brain injury which resulted in a memory impairment were selected from the referrals made to the States of Jersey Health and

Social Services Psychology Department from June to December 1998. The five individuals were asked if they would consider being involved in a study to evaluate the effectiveness of using mobile phones as a memory aid. All five, three males and two females, ranging in age from 18 to 51 years, agreed to take part.

Functionally, all the participants demonstrated memory impairments in everyday living following a brain injury and were chosen as a result of their need to carry out activities independently. The length of time post head injury ranged from one to fifteen years. Only one of the participants was in paid employment, and all participants lived with a member of their family. All participants were part of an experimental group and the aim of the project was to see if the mobile phone was an effective memory aid, was user friendly, and had the potential to be used by a wider number of individuals in Jersey. All potential participants were visited at home and told about the mobile phone project in detail, they received an information sheet and if they agreed to take part in the trial they were asked to sign a consent form (Appendix 4). All participants were informed that they would have the option of continuing to use the service if the memory aid was of demonstrable benefit. Mobile phones were provided (on loan free of charge from Jersey Telecoms) to the three of the five participants in the project.

2.2 Baseline measurements

It was explained that the initial focus of using the mobile phone as a memory prompt would be to identify four or five target areas where a reminder would

be beneficial. A diary was constructed for the user (and/or caregiver) to record how frequently the identified targets were remembered independently before the introduction of the phones. For example, a caregiver may have recorded daily whether they had to remind the participant to take their medication. The diaries were kept for six weeks prior to the commencement of the trial (See appendix 5 for an example of the diary).

Participants were also assessed neuropsychologically using a number of standardised, reliable, and valid assessments. The tests employed were:

- Wechsler Adult Intelligence Scale - Revised version (W.A.I.S.-R) (Wechsler 1981) which is one of the most commonly used tests of overall intellectual functioning and provides an intelligence quotient (IQ) score.

- National Adult Reading Test (N.A.R.T.) (Nelson 1982) which is a well established test of pre-morbid intellectual functioning.

- Rivermead Behavioural Memory Test (Wilson et al. 1985) is a widely used memory test developed to detect impairments of everyday memory functioning and to monitor change following treatment.

- Behavioural Assessment of Dysexecutive Syndrome (B.A.D.S) (Wilson et al 1996) which is a test of executive functioning skills.

2.3 Mobile phone trial

Once the baseline measurements had been established for each participant the relevant messages were recorded into the computer and the mobile telephones were introduced. For this project messages were recorded using an anonymous male voice. After 12 weeks with the phones, the diaries were given back to the caregivers to measure the change in performance for those targets.

3.0 Results

The following case histories aim to evaluate the effectiveness of using mobile phones as memory aids. Each of the participants are presented individually with background information, neuropsychological assessment, and experience of the mobile phone trial.

3.1 Case 1- EF (male; 51 years old)

3.1.1 Background information

EF had a stroke in February 1997 for which he received in-patient rehabilitation. After approximately six months he was discharged to the community and returned home to live with his wife and teenage daughters. This participant has not sought employment following his stroke and does not intend to work again.

3.1.2 Neuropsychological Assessment

The CT scan for EF showed a 8mm lesion to the right internal capsule and an infarct from a previous head injury located in the right frontal lobe infarct. He presented with a right hemiplegia, language difficulties and some memory problems. To examine the extent of this participant's cognitive difficulties a neuropsychological assessment was carried out. In this assessment EF was well orientated to time, place and person. To provide a pre-morbid estimate of intellectual functioning the National Adult Reading Test (N.A.R.T) was conducted. This test provided an estimated pre-morbid Intelligence Quotient (IQ) of 103 points. To assess overall cognitive functioning following the stroke, a Weschler Adult Intelligence Scale (W.A.I.S-R) was carried out and on this a full scale IQ score of 83 points was obtained. This overall score is divided into a verbal IQ of 78 and a performance IQ of 89. The verbal sub-tests of the W.A.I.S-R proved the most difficult, in that the Comprehension sub-test had to be abandoned because of the expressive problems experienced, and on the Similarities sub-test this participant found difficulty in abstract thinking. On performance IQ the W.A.I.S-R scores were higher, although the sub-tests of Object Assembly and Block Design showed a decline in speed of thinking, and on the Digit Span sub-test a low attention level was demonstrated.

To explore language difficulties in more detail, the Speech and Language Therapist concluded that this participant had good receptive language skills, but found that spontaneous output was characterised by sentence production which contained a predominance of content words such as nouns and verbs

but few adjectives. He had a slight impairment in articulation in that he occasionally could not find the word to express his thoughts, but was capable of conveying his meaning to most conversational partners.

To examine executive functioning in more detail a Behavioural Assessment of the Dysexecutive Syndrome (B.A.D.S) was carried out. On this assessment a score in the low average range was obtained. One test of note in the B.A.D.S was the modified version of the six elements test where this individual did not stick to the rules given in the instructions and failed to make the most effective use of his time on the different elements.

A Rivermead Behavioural Memory Test was carried out to assess memory functioning. This participant attained a profile score of 12 which is indicative of a moderate impairment in memory. The greatest difficulty was found in immediate and delayed verbal memory, although this score may also have been exacerbated by language difficulties as English, the language of the test, is not EF's native tongue. Low scores were also achieved other items, namely belonging and appointment and on both of these items the participant remembered to ask about each but had forgotten the detailed information necessary to be awarded full marks.

3.1.3 Mobile Phone Trial

Given these difficulties in memory functioning it was suggested to this participant that he take part in a mobile phone memory project to assist with his memory. He was keen to try this, and following a conversation with his

wife, information was obtained on what was being forgotten on a day to day basis. Three targets were identified which included: forgetting to take his medication each day, remembering to get ready to attend the Stroke Club luncheon on a Tuesday and going for a walk each day. Baseline measurements were taken by asking his wife to record daily whether these items had been remembered over 6 weeks. It was found that these items were consecutively forgotten and so the mobile phone system was introduced. Following the introduction of these memory prompts this person achieved 100% success on all of these items independently at the end of 12 weeks. Indeed, the person reported that his memory had improved with the phone and he had learnt the contents of each message. Therefore, at the end of the trial it was decided that the mobile phone was no longer necessary because this participant was now doing the tasks independently.

3.2 Case 2 - GH (male; 21 years old)

3.2.1 Background Information

GH suffered a head injury in 1996 and was an in-patient of a rehabilitation unit for approximately one year. He was discharged home and now lives with his father at home. He is presenting carrying out a course at the local college in general studies which has been specifically designed for individuals who have cognitive impairment.

3.2.2 Neuropsychological Assessment

The CT scan of GH showed haemorrhagic contusions to both frontal lobes and blood in the left ventricle. This individual was having problems with memory and organisation of his day. To assess cognitive functioning in more detail a range of tests were employed. To estimate the level of intellectual functioning which might have been expected prior to the head injury a N.A.R.T test was carried out and on this test a score of 90 points was obtained which represents an average level of ability. To assess overall cognitive ability following his accident a W.A.I.S.-R test was administered and an IQ of 62 points was obtained, which represents a significant overall decline. Within this score there was a discrepancy between the Verbal IQ, which was 74 points, and the Performance IQ of some 49 points. In the latter a number of the sub-tests were abandoned because of visuo-spatial problems, and in those which were completed he showed a slowness in speed of information processing. To assess visuo-spatial abilities further the Chessington OT Neurological Assessment Battery (CONTAB) was carried out. This test indicated that this gentleman was severely impaired on a test of manual dexterity with both of his hands. He had problems with constructional ability and scored poorly on tests of spatial awareness along with some problems in sequencing ability.

To examine executive functioning in more detail, a B.A.D.S was carried out and on this test he attained a score of 11 points, which is in the borderline range of ability. Difficulties were demonstrated in the problem solving independently without prompts and structure.

A Rivermead Memory Test was administered to assess memory functioning. He attained a score in the moderately impaired range with a screening score of 12 points. He showed difficulty in the retention of verbal material on the immediate and delayed items of the test. He was unable to remember the name of a person he had been asked to recall but did ask for a belonging to be returned at the end of the test and spontaneously asked the correct question when the timer alarm sounded.

3.2.3 Mobile Phone Trial

Given these memory difficulties the mobile phone was suggested as an aid in day to day living. The participant was willing to try and 6 targets were decided upon for the project which included prompts to: wake up in the morning with information on the day and date, take medication, shower, apply deodorant, clean teeth in the morning and evening, to shop each day and to make a packed lunch for college. A baseline diary was kept for six weeks by his father and it was found that this gentleman forgot to take medication 68% of the time, he cleaned his teeth in the morning 92% of the time but this reduced to 65% in the evenings. With regard to showering this participant forgot only 8% of the time, he forgot to put on his deodorant some 25% of the time. He only remembered to pack his lunch 50% of the time but he managed on 80% of occasions to remember to shop for his evening meal. Following the introduction of the mobile phone there was initial success with this gentleman achieving 100% on all of these items. However, after a few weeks there were a number of problems which developed this gentleman found that he could not stop himself from using the

phone to make calls, despite having made an agreement that it would only be used for incoming calls. He expressed concern that he could run up an excessive phone bill that he would be unable to pay. The mobile phone aid was therefore discontinued in his case.

3.3 Case 3 - AT (male; 36 years old)

3.3.1 Background Information

AT suffered a severe head injury 15 years ago. He is married with three young sons under 5 years of age and a grown up step son and daughter. He worked for 11 years after the accident but eventually had he had to give up his job and is no longer seeking further employment.

3.3.2 Neuropsychological Assessment

A CT scan showed global atrophy with no focal lesions. This participant was having significant memory difficulties on a day to day basis, particularly after an epileptic fit. A W.A.I.S-R was selected in order to assess his overall cognitive functioning. The results of this was that he obtained an IQ of 96 points, which is identical to his pre-morbid IQ estimated by the N.A.R.T. Memory abilities on the Rivermead Behavioural Memory scale show a moderately impaired range of ability with a profile score of some 16 points. On this assessment the most notable difficulties were in verbal recall and prospective memory. The B.A.D.S test of executive functioning placed this

person in the impaired range with an age corrected standardised score of 59. Difficulties were encountered with regard to the sequencing of activities and planning a course of action.

3.3.3 Mobile Phone Project

The idea of the mobile phone project was met with some enthusiasm and it was decided that the prompts would be aimed solely at medication in the first instance. Prior to the telephone's introduction this gentleman remembered his medication without a reminder 48% of the time. When the effect of having the phone was evaluated 3 months later he was independently taking his medication 92% of the time. In addition to being a memory aid, the phone has served to increase this participant's independence; when out his wife could contact him at all times, and the home telephone number was programmed into the phone in case of emergencies. When evaluating the phone service the user and his wife found it had many benefits in terms of independence. The main difficulty was the phone being left behind. They were both keen to continue to use the service and increase the range of memory prompts.

3.4 Case 4 - BJ (female; 48 years old)

3.4.1 Background Information

BJ suffered a sub-arachnoid haemorrhage in 1997, which has meant she has given up her job and spends most of the day alone at home. She lives with her husband who works full-time.

3.4.2 Neuropsychological Assessment

A CT scan revealed that BJ had damage to the left middle cerebral artery following a sub-arachnoid haemorrhage. There was also a faint low attenuation area in the left post parietal region from a clipped aneurysm. The haemorrhage and ensuing operations have left BJ with some language difficulties along with memory and executive problems. Difficulties occur in planning and organising the day and in carrying out tasks at appropriate times; for example, dinner is regularly prepared at 2pm when it was not needed until 6pm. BJ would also leave the house without having showered or brushed her hair and her husband stated that occasional comments from friends in respect of this caused her some embarrassment when she was out. Formal cognitive assessment revealed a W.A.I.S-R of 63 points, which may have been a conservative score because of a cultural bias given that this participant is from Portugal. A pre-morbid estimate could not be effectively made because English was not this person's first language. Results of the Rivermead Memory Battery showed moderate impairment with a profile score of some 13 points. Particular difficulties were noted with prospective

memory and verbal recall. The B.A.D.S test also showed an impaired score with a age-corrected standardised score of 38 points. The test illustrated difficulties deciding the appropriate course of action and an inability to pick out relevant information. This slowed decision-making affected performance considerably on this test.

3.4.3 Mobile Phone Trial

This participant agreed to take part in the mobile phone project and the targets chosen were designed to help bring structure to her day. There were reminders to: shower, brush hair, have lunch, do some reading and writing, to begin getting dinner ready and to take medication. There were also targets to help increase organisation by reminding this lady to place her glasses and wallet in a particular place each evening, ready for the morning. The baseline diaries showed that, although tasks were frequently carried out, some 87% of the time, the timing was variable and sometimes inappropriate. Lunch was frequently missed.

The mobile phone was introduced with these targets and this participant has used the telephone effectively. On a re-evaluation of the diary the phone can be shown to have helped organise her day, with tasks being carried out at appropriate times 100% of the time. When evaluating the telephone system this lady and her husband rated it highly, seeing it as easy to use and understand and feeling that the targets are being carried out more effectively through using the phone. They were both keen to continue with the service.

3.5 Case 5 - MR (male; 18 years old)

3.5.1 Background Information

MR suffered a severe head injury in a road traffic accident approximately 10 years ago. He lives with his parents and sister and has recently started a part-time job on a farm.

3.5.2 Neuropsychological Assessment

A CT scan revealed multiple white matter contusions showing a diffuse head injury. MR has great difficulties with attention and concentration. Problems are experienced in planning and memory functioning, such that appointments are frequently missed, he regularly misses the bus to and from home, and forgets to take his medication. His family were having to remind him to carry out these tasks throughout the day, and were understandably concerned when he was out alone as they had no means of contacting him.

Formal cognitive assessment with the W.A.I.S-R placed this participant in the severely impaired IQ range of some 70 points. On the Rivermead Behavioural Memory Scale a profile score of 7 was obtained which is also in the severe range of ability. His performance on this test showed difficulties with prospective memory, verbal and non verbal recall of information and orientation, although he showed good recognition for faces and objects. In terms of executive functioning, the B.A.D.S score was in the impaired range with a standardised score of some 65 points. In addition, his reading skills

were very poor. He had impaired phonological awareness, being unable to rhyme words or split words into their constituent sounds effectively.

3.5.3 Mobile Phone Trial

The mobile phone was accepted as a good way of tackling memory problems and the targets chosen were aimed at increasing his independence by giving him reminders of appointments and bus times. Reminders for the last bus home were given daily to help prevent him getting stuck away from home. Reminders were also given for taking medication. Baseline measurements indicate that this participant was not carrying any of the targets without a reminder. With the introduction of the telephone this participant was carrying out targets 82% of the time. When evaluating the telephone, the usefulness of this method was noted but the participant occasionally left it behind. His family were keen to continue with the service.

4.0 Discussion and Conclusions

The experience of these five participants demonstrates that the system of using the mobile phone as a memory aid was effective for four of them. All of those who took part in the trial found an improvement in the target items from baseline measurements. The participant EF found that the mobile phone improved his memory for the target areas so much that he no longer needed to be reminded but this is possibly because a limited number of items were used repeatedly over the course of a number of weeks and this repetition

enabled certain information to be entered into long term memory storage. The participant BJ found the mobile phone very useful and reached 100% of her targets. With regard to the case of AT, the mobile phone was only used to a limited extent, but now that its success has been established with this one target item it is possible to increase the number of areas and therefore increase the value of the mobile phone as a memory aid. There were a number of occasions when he left the mobile phone at home by mistake and we discussed the possibility of using a belt on which to secure the phone as a desirable option for the future. Only one participant (GH) dropped out, because he felt he was tempted to over-use the mobile phone and was worried about running up a large bill. One possible way round this problem it to suggest the use of pre-paid charge cards which have recently been introduced for users of mobile phones and which only allow the caller to make calls up to the limit of the card before needing to buy another card. This helps the caller to budget and also to avoid running up an enormous bill. Unfortunately, at the time of the trial there was no awareness of this new development, which may have enabled GH to continue with the project.

Although modest in terms of design and number of participants the above trial indicates that mobile phones are not only of benefit for everyday memory problems but can also assists individuals who have problems with planning and organisation. This finding was also noted by Evans et al (1998) who noted the benefit of the Neuropage as an external cueing system in the rehabilitation of a 50 year old woman. A number of individuals in the trial not only had memory problems but also some executive difficulties and for those individuals the use of the mobile phone is of benefit as a memory aid to help organise their day to day routine. For example, the participant BJ found

it of great benefit to receive a reminder to prepare the evening meal at the correct time. Prior to the introduction of the mobile phone she was beginning to prepare it many hours before her husband returned from work and so it was often wasted, but when the mobile phone was introduced she was able to plan her day more effectively because she knew she would be reminded at the correct time to carry out this task.

The mobile phone as a memory and organisational prompt has a potential to enhance independence and therefore it may also have the potential to reduce stress and frustration amongst carers. In the trial one carer noted that after the introduction of the mobile phone it was a very pleasant change not to remind her husband (MR) to take his tablets. Another carer of GH also stated although his son did forget to take his mobile phone on occasions he found it comforting to know that in the majority of occasions he would be able to contact his son through the mobile phone in case he were to get lost.

It is interesting to note that the participant BJ who found the mobile phone of most benefit already had a mobile phone. This suggests that this was a familiar aid for this person who could simply add on messages to a system she was already using. This may be an important consideration for the future when making a decision with the person who has memory problems about which memory aid will be the most efficacious and given that mobile phone use is on the increase it is likely its use as a memory aid will become increasingly popular in the future because people will be familiar with it, as distinct from a dedicated memory aid such as a NeuroPage.

For the other participants who were not familiar with mobile phones there are a number of specific factors which will need further consideration in the future. Firstly, prior to embarking on the mobile phone trial it will be important to consider whether the person can be trained to use the memory aid. Learning how to receive calls and charge up the device are all factors which may need to be taught. Kapur (1995) suggests that a specific training programme should be designed for the use of memory aids and recommends that these training tasks are broken down into steps with the use of principles such as spaced rehearsal, graded reduction of support/vanishing cues and error-free learning (Wilson et al 1994). With the mobile phone project it would have been useful to have devised such a training programme prior to the commencement of the project and to have involved the carer in that training if appropriate.

In future studies it is also important that the mobile phone has validity for the user. With the case of the participant MR the mobile phone was only used to receive messages and it may be for this reason that the phone was left at home on occasions because it did not have enough value as a communication aid as well as a prompting system for the young person. In this particular case it may have been more beneficial if a system had been devised whereby those individuals working with the person and carers were encouraged to contact the participant on a regular basis thereby increasing the meaning and validity for him of the mobile phone.

This pilot study was carried out in order to assess whether mobile phones have a benefit to individuals as an external memory aid. The results of the pilot do suggest that a larger trial would be worth considering, particularly to

incorporate a number of points raised in the discussion. There are some amendments which require some immediate attention such as the introduction of a training package for those who are unfamiliar with how to use a mobile phone prior to the introduction of messages. Secondly, it may be possible to overcome potential problems of remembering to charge the mobile phone by incorporating this into the memory prompts. In addition, another recorded message could remind a participant to strap their mobile phone to the belt or place it in a handbag prior to going out and this may reduce the likelihood of leaving the phone behind. There are also some changes to the software which need further consideration such as developing a system whereby the administrator of the system can easily obtain information on the frequency with which the person is answering the memory prompts. Another consideration is to see whether a system could be devised so that a person or carer could be encouraged to enter their own memory prompts on their own computer and thereby increase flexibility of the system. It is more difficult to see how a person can be encouraged not to overuse the mobile phone except through the introduction of the pre-paid card system. This difficulty will be more of a problem if the person has limited budgeting skills and therefore a careful assessment will need to be carried out prior to recommending this memory aid. However, this does not detract from the conclusion to be drawn from the pilot study that the mobile phone has potential value as a memory aid, not only for user, but also for their carers.

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SECTION D: LITERATURE REVIEW

A REVIEW OF THE ASSESSMENT AND TREATMENT OF EXECUTIVE FUNCTION IMPAIRMENTS

A Review of the assessment and treatment of executive function impairments

1.0 Introduction

Every waking second of our lives we are using information and making decisions to anticipate, to plan, to determine an appropriate course of action, and to adjust our plans if necessary. These abilities are absolutely vital in making us effective as human beings and damage to these 'executive' areas of the brain can, more than any other cognitive process determine, the extent of social or vocational recovery. Damage to the frontal areas of the brain, which are responsible for the successful operation of 'executive' functions, can occur as a result of a variety of diseases or traumatic head injuries and the effect often produces subtle yet profound difficulties with day to day living. These changes may show themselves in altered social behaviour, which may lead to continual problems within relationships, or at work where a person finds a reduced ability to perform the functional tasks of a job. Although these difficulties can have a devastating effect on a person's life, executive dysfunction as a possible cause of such problems is often overlooked, not only by general practitioners but also by psychologists and other professionals. When there is a recognition of the problems faced by sufferers of executive function impairments, efforts at remediation have also been fairly minimal (Sohlberg and Mateer 1989).

The purpose of this review is to examine and analyse the research that has been carried out to date to establish the present state of knowledge, and to then seek to identify from that analysis the areas and techniques which require further investigation for there to be progress to improve the quality of life of sufferers to the greatest extent possible. It begins by providing a brief historical background of the development of our knowledge in relation to the workings of the frontal lobes, which are the part of the brain in which executive functioning is centred. This is followed by an examination of the neuroanatomy pertinent to this area of the brain along with the clinical presentation of impairments to these regions of the frontal lobes which will be linked to neuropsychological assessment. The use of the umbrella term 'executive functioning' is explained in more detail and the various models which have been applied to this area will be examined. The second part of this review considers the rehabilitation of those experiencing 'executive' function impairments, and involves a review of the management and treatment of those with cognitive difficulties followed by a synopsis of the emotional and psychosocial sequelae that can often result from this problem. The conclusion looks critically at the present state of knowledge and identifies the areas where the greatest emphasis is needed.

2.1 The frontal lobes

The frontal lobes are very large structures which make up about one third of the mass of the cerebral hemispheres and are unique to human beings. This region of the cerebral cortex is the most recently developed part of the brain in an evolutionary sense, and the relatively massive growth of the prefrontal cortex is considered to be a major contribution to the superior mental capacity of human beings. This region has numerous connections to other parts of the brain, and the functions it carries out are products of information collected from widespread locations in the CNS.

Damage to the frontal lobes can occur for a variety of reasons, though the most common is a head injury, which can occur with or without skull fracture. Lesions of the frontal lobes tend not to disrupt cognitive functions as obviously as do postcentral lesions; rather, frontal lobe damage may be conceptualised as disrupting reciprocal relationships between the major functional systems which have been characterised as "derangement of behavioural programming" (Nauta 1971). Attention has been drawn to a breakdown in the temporal organisation of information with frontal lobe lesions and therefore behaviour becomes less effective, resulting both in deficient integration of immediate past experience (situational context) with ongoing activity and in defective planning (Fuster 1989). For behaviour to be effective it requires an anticipatory relationship to the goal in the form of planning, along with the ability to monitor ongoing actions so as to

effect change should deviations from the plan occur, and the effectiveness of action must finally be checked against the anticipated outcome and any necessary adjustments made. Behaviour which fulfils these requirements can be thought of as adaptive behaviour, and it is the frontal lobes which are so crucial in this process.

Historically, the frontal lobes have long been recognised for their important role in motor planning and activation. However, the recognition of the behavioural difficulties that result from damage to this cerebral region has been more difficult. Such impairments were first formally recognised by the classical case of Phineas Gage, described by Harlow (1868), which provides a compelling example of the subtle personality changes that can occur following frontal damage. Harlow reported that this man suffered:

> *" ..... a severe frontal injury when an iron tamping bar was blown upward into his brain region while he was working on a railroad construction crew. Although, he appeared to make a complete recovery, his emotional behaviour and personality were greatly changed. Following his accident, he was described as fitful and irreverent, indulging at times in the grossest profanity (which was not previously his custom) manifesting but little deference for his fellows, impatient of restraint or advice when it conflicts with his desires ..... " (page 390)*

These changes occurred without any notable change in language, reasoning skills, perceptual, motor and sensory abilities. The

observations in the Phineas Gage case sowed the seed for the development of the notion of 'the frontal lobe syndrome'. However, this theory did not blossom until the first half of the twentieth century. During the 1940's there were two opposing viewpoints as the effect of frontal lobe damage: Goldstein and Scheerer (1941) held the view that damage to the frontal lobes resulted in a loss of abstract attitude, and Hebb (1942) reported that there was little or no reduction in measured IQ following frontal leucotomy and concluded that there was a disorganisation of cerebral function caused by a lesion and that removal of the impaired tissue led to a restoration of function.

During the 1940's and 1950's the growing popularity of psychosurgery coupled with the large number of war wounded from the Second World War provided case studies of frontal brain damage and it became clear that the ability to perform many cognitive functions may be disrupted by frontal lobe damage. A more cautious approach emerged in the 1960's due to controversy about the effectiveness and objective evaluation of frontal leucotomy, combined with a growing appreciation of the complex yet subtle functions of the frontal lobes. During this time, the role of the frontal lobes as executor of the brain and mediator of specific cognitive processes was established. Although knowledge of this area of the brain was developing rapidly, there was still a widely held view that "the frontal lobes" were an integral structure and entity in their own right. However, this perspective was shortly to be challenged with the development of non-invasive methods of assessment such as MRI, PET and SPECT which revolutionised the dominant modes of scientific inquiry.

2.2 Neuroanatomy and assessment of the frontal lobes

Clear structures within the frontal lobes have been identified which are anatomically and functionally very distinct. These divisions have been referred to as the precentral (or primary motor) cortex; the premotor cortex; and the prefrontal cortex. The precentral cortex is the primary motor cortex which mediates movement and as such has important connections with the cerebellum, the basal ganglia, and the motor divisions of the thalamus. Lesions here result in weakness or paralysis of the corresponding body parts. The premotor cortex is the area where the integration of motor skills and learned action sequences takes place. Lesions here disrupt the integration of the motor components of complex actions, producing discontinuous or uncoordinated movements and impaired motor skills. Lesions may also affect limb strength. This supplementary motor area appears to mediate preparatory arousal to action at a preconscious stage in the generation of movement, and thus lesions in this area may disrupt initiation of other kinds of movement as well. The prefrontal cortex is the site of interconnections and feedback loops between the major sensory and major motor systems, linking and integrating all components of behaviour at the highest level. This area of the cortex attends, integrates, formulates, executes, monitors, modifies and judges all nervous system activities (Stuss and Benson 1987). The various divisions of the prefrontal cortex, which incorporates the dorsolateral cortex (which is concerned with the preparation and

execution of action), the medial frontal cortex (which mediates self-initiated action and sustains behaviour at an appropriate level) and the basal or orbital cortex (which appears to be related to the flexible control of excitation and inhibition and the emotional control of behaviour).

2.2.1 Dorsolateral frontal cortex

The dorsolateral region encompasses a large area of the prefrontal cortex, including the frontal pole, and mediates higher cognitive processes that are to some degree lateralized to the left and right regions. The cognitive and behavioural systems operating in this region are multimodal and the region is strongly interconnected with posterior cortical association regions, including the interior parietal lobule and superior temporal gyrus, that provide highly processed visual, auditory and somatosensory information along with strong subcortical links. The characteristic impairments associated with damage to this region include poor integration and synthesis of information which means a person cannot learn from errors and learning capability is therefore affected. Such patients appear to show an uncritical attitude to their actions, especially their own errors. This may arise from an inadequate evaluation of the patient's own action rather than from a failure to appreciate or fully comprehend the nature of the instructions (Luria I969). Typically patients recognise errors

and those of others but nevertheless remain unable to utilise this information to modify a subsequent course of action (Konow and Pribram 1970).

The connection between error recognition and error utilisation is a crucial part of the learning process, which is why these patients provide the frontal lobe paradox of a person who has a seemingly preserved or restored intelligence but who fails to cope with his/her occupation. These errors are particularly difficult for employers to understand because the person can verbalise what he or she should do but cannot translate that into the correct action. This inability to alter behaviour to take proper account of recognised errors has been described as 'a curious dissociation between knowing and doing' (Teuber 1964). In terms of neuropsychological assessment, problems in the completion of the Porteus maze (Porteus 1959) are commonly seen.

The prevailing view is that simple registration and recall of both visual and verbal material is largely unaffected by frontal lesions. However, evidence seems to suggest that frontal lesions suppress the programs which govern the execution of the mental strategies that bring recall and memorisation into play during the operation of any new task, whether it be the resolution of a problem or the learning of a piece of poetry. The difficulty arises when the patient is confronted by novel material, particularly when it is lengthy and complex (Barbizet 1970) and results from the intellectual organisation of the material for the

process of committing it to memory rather than as an amnesic difficulty. These difficulties with learning have also been shown on formal tests of learning, where patients have demonstrated little improvement and even when a person reaches success on a particular test they often make errors on subsequent attempts at the same test. This has been coined '*imperfect learning*' (Walsh 1991). This type of behaviour is often exhibited when people return to work after rehabilitation and make apparently inexplicable errors. Errors do not occur in situations where old well established routines or practices will suffice, but only become apparent in learning new information or in adapting old 'programmed' behaviour to new situations.

Difficulties in terms of intellectual organisation of visual material and subsequent inability to recall can be seen by performance on the visual memory subtest of the Adult Information Processing Battery devised by Coughlan and Hollows (1985). In this subtest the person is instructed to copy a complex figure. What can be noted is that the figure copy is poor and therefore it becomes hard to remember. In addition, in another subtest of this battery which assesses verbal learning by instructing a person to recall a list of words, an unsystematic order of recall from trial to trial with loss of primacy and recency effects and a plateau of learning only 1 or 2 units above the immediate memory span will be evident.

Another characteristic of impairment in the dorsolateral frontal region is cognitive rigidity with concrete-literal thinking and a tendency to

perserveration. To test for perseveration a variety of tests can be useful, with particular emphasis on tests involving impaired response modalities; for example, the patient can be asked to copy and maintain alternating letters or patterns or repetitive sequential patterns of hand movements. Individuals were often unable to inhibit customary modes of responding (Milner 1963). The person can also become 'stimulus bound', which means the person has problems shifting from a conscious and volitional mode of behaviour based on abstract thought processes to a concrete determination of behaviour by aspects of the present situation. In turn, this seems related to the tendency of the patient to show little concern with the past and future, an alteration which has been construed as a 'personality' change.

Difficulties in this area can be assessed using the Weigl test (Goldstein and Scheerer 1941), in which patients are asked to sort the test material which consists of three different shapes and colours. The person is asked to arrange the test material so that 'those which are alike go together', and then to try and think of another way of grouping the test material. Patients often demonstrate an inability to shift from one sorting criteria to another, to 'shift set'. Another test which can examine initiation of thought and action and examine mental inflexibility is the Controlled Oral Word Association (Benton and Hamsher 1976), which has become more commonly known as the "FAS test" because the patient is asked to generate within one minute as many words as possible with the letters 'F', 'A', and 'S'. Frontal lesions tend to depress fluency scores (Merceli 1981). This test is

quick and easy to score, and although it has an educational bias there is a correction factor which can be used to take this into account.

The Wisconsin Card Sorting Test (WCST) (Berg 1948) is another widely used test devised to study 'abstract behaviour' and ascertain the degree to which an individual can 'shift set'. Patients with frontal lesions are prone to perseverate on the WCST. However, there have been some criticisms of this test. Firstly, the instructions of this test are quite hard to understand and a poor score it itself may occur because of other language problems or simply because a person finds the test difficult without brain injury. Recently, the Brixton test from the Hayley and Brixton (1998) test of executive functioning has been devised, which is similar to the WCST but is more 'user friendly', being both quicker for the subject to perform and easier for the examiner to score. Another test of abstract thinking which has been used extensively is the Similarities subtest of the WAIS (Wechsler Adult Intelligence Scale, 1955, 1981), which asks in what way two objects are alike. Patients who have difficulty with this subtest often simply say that the objects are not alike and cannot find a link to associate them together.

The dorsolateral cortex is among the many structures involved in attention. Significant frontal activation takes place during selective attention activities in intact subjects, which suggests that the dorsolateral cortex mediates the capacity to make and control shifts in attention (Mirsky 1978). This region is thought to "participate decisively in the higher forms of attention", for example in "raising the

level of vigilance" in selectivity and in maintaining a set (Luria 1973). Patients who suffer an impairment in this area are therefore likely to be sluggish in reacting to stimuli, unable to maintain an attentional focus, or highly susceptible to distractions. The test of everyday attention (Robertson et al. 1994) can be a very useful tool to examine this area in further detail. It has 8 different subtests which involve an everyday activity such as elevator counting and map search. It examines selective attention, of which divided attention and attentional switching are part. There are also a number of subtests which examine sustained attention by assessing the ability of the patient to pick out relevant information from a background.

In addition, a patient can show significant difficulties with problem solving and integrating information, which can lead to a disorganisation in thinking and behaviour. Problem solving skills also rely on the ability to look ahead to work out the solution to a problem. The Tower of London test has been used to look at this type of planning disorder in more detail, in which to arrive at the best (most direct, fewest moves) solution the subject must look ahead to determine the order of moves necessary to rearrange three coloured rings or beads from their initial position on two or three upright sticks to a new set of predetermined positions on one or more of the sticks (Shallice 1982).

Frontal problem solving difficulties are also readily demonstrated by visuo-constructive tasks such as the block design subtest from the

WAIS. This has been described as the 2-4-6-8 problem (Walsh 1991), and is based on his observation that patients may have more difficulty completing the designs which are numbered 2, 4, 6, and 8 because an analysis has to be made due to the fact that the design elements are not obvious. However, on the others, numbered 1,3, and 5, the designs may be copied readily by matching one obviously perceptual unit with one face of the block. Patients who show an analytical or integration difficulty on block design copying may also demonstrate deficiency in problem solving in other areas such as mathematics. The problem in not a loss of arithmetical operations but of the logical analysis and reintegration necessary to arrive at the solution. Fasotti (1992) illustrates with the following example: if there are 18 books, with twice as many on one shelf as the other, how many books are there on each shelf. Patients answer 9 because they cannot analyse the question and yet, if asked, they would find no difficulty dividing 18 by 3 and multiplying by 2. Another example of difficulty with integration is the picture arrangement subtest from the WAIS. The frontal patient often tends to describe each picture as separate rather than as an integrated series, and may on occasion be quite satisfied to leave the cards in the presented random order.

Assessment of the dorsolateral frontal cortex requires use of a whole range of neuropsychological tests which can make identification problematical. The most important ingredient to identifying problems in this area appears to rely not so much on the score achieved in the test but the way the test has been completed. This obviously requires skill in assessment, and the psychologist has to know what types of errors are typically made with an individual presenting with difficulties

which suggest dorsolateral involvement.

2.2.2 Mesial frontal cortex

This area can be divided up into the superior and inferior frontal region. The superior mesial region for someone with bilateral injury can cause profound akinesia and mutism with complete or near-complete absence of responsiveness and spontaneity. In most instances, patients are not confused or even aphasic, and may briefly speak or otherwise respond normally. This has been termed adynamia, and the problem is one of self regulation of arousal or motivation since patients respond appropriately to external stimulation, especially if this is repeated, but lapse back into inactivity when the external stimulus is removed.

Unilateral lesions cause lesser forms of impairment including apraxias, as well as reductions in spontaneity, initiation and range of emotional expression. Damage to the inferior region, which refers to structures of the basal forebrain, commonly include amnesia, particularly for temporal-spatial aspects of recent memory. In some cases utilisation behaviour can be affected. This has been noted by Lhermitte (1983) who found that when an object (eg glass of water) was put in front of a patient they will use it even if they are instructed not to. Lhermitte suggested two possible explanations for this behaviour, one phenomenolgical and the other neuroanatomical. The

phenomenolgical would suggest that the visual stimuli imply to the patient an order to grasp the object presented and use it. This may result from an imbalance between the activities of the frontal and parietal lobes. The grasp reflex (DeRenzi and Barbieri 1992) provides another example in which the patient is unable to inhibit a response. The examiner puts two fingers on the palm of the subject at the level of the wrist and moves them distally to the level of the thumb/index finger. The examiner instructs the subject not to grasp but the patient cannot inhibit. This difficulty was found to be apparent in patients with damage to the mesial area.

A breakdown in programming, regulation and verification of activity has been coined *action disorganisation* (Schwartz and Reed 1991). The patient has difficulty with selecting which actions are to be carried out at which time. This can best be assessed by watching someone eat breakfast, when the patient will often carry out actions with the wrong objects; for example, pouring the milk into the orange juice instead of into the coffee. These errors have been described as place and object substitutions (Schwartz and Reed 1991).

The assessment of damage to the mesial region relies more on observation than on formal neuropsychological assessment. Again the examiner is looking for quite specific behavioural manifestations of the problem. There is no simple checklist for psychologists to carry out; a trawl of neuropsychological texts is required to identify these tests, let alone what responses are expected. In addition, the work of assessment may not be completed by simply seeing the individual in

isolation, and therefore in any examination it would be essential to talk to care staff or carers to establish what type of behaviour occurs during the course of a day.

2.2.3 Orbital frontal region

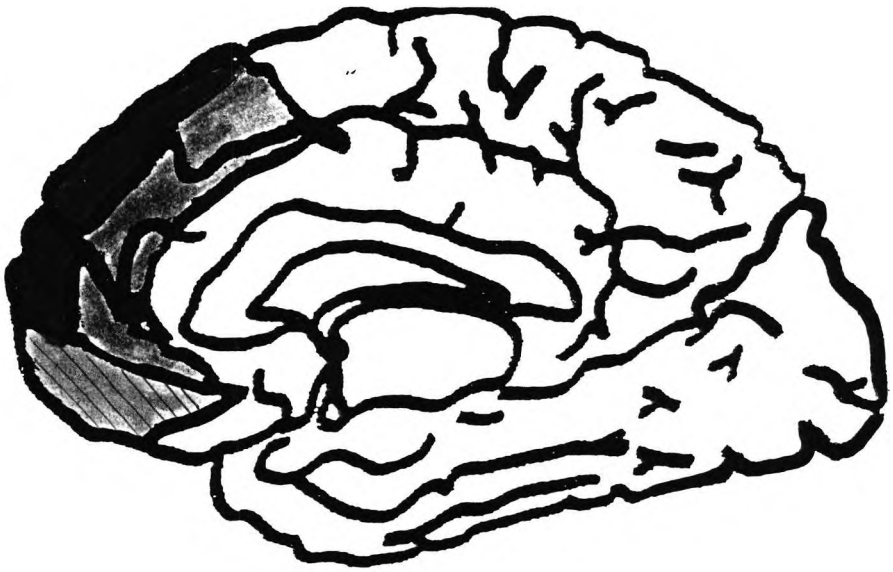
This region is very different from the mesial and dorsolateral regions of the frontal lobe in connectivity and clinical characteristics. Orbital frontal lobe damage without involvement of the basal forebrain region has been associated with significant change in personality and social behaviour as well as impulsive actions with reduced empathy (Stuss and Benson 1986). Individuals with damage to this area show marked difficulties in adjustment and adaptation out of proportion to any degree of cognitive or neurological disability. A good indicator of such basal damage is the presence of anosmia (loss of smell) due to damage to the olfactory bulb and tract which lie on the inferior surface of the frontal lobe. The hallmark of orbital frontal damage is the loss of control of inhibition. This pattern of behaviour, even to a minor degree, results in a major psychosocial deficit.

An adequate control of inhibition is a basic requirement of intellectual processes requiring selectivity - where a decision has to be made between competing hypotheses or response tendencies. Such patients have difficulty on tests such as the Trail Making Test. This test originally formed part of the Army Individual Test Battery (1944). The test has two parts; in part A the person has to draw lines to connect consecutively numbered circles, and in part B the person has

to connect the same number of consecutively numbered and lettered circles on another worksheet by alternating between the two sequences. In part B patients who have problems inhibiting a response tendency will demonstrate the most difficulty. However, it is important to point out that to do this test it is necessary to know the alphabet and performance has been found to be very sensitive to the effects of medication. However, the great advantage of this test is that it has been completed on a huge sample size and has found to be very sensitive to damage. The Hayley Test from the Hayley and Brixton test (1998) of executive functioning also provides a response suppression task which requires a subject to inhibit or suppress an automatic response.

Figure 1 on the next page provides a diagrammatic outline of the structures discussed above:

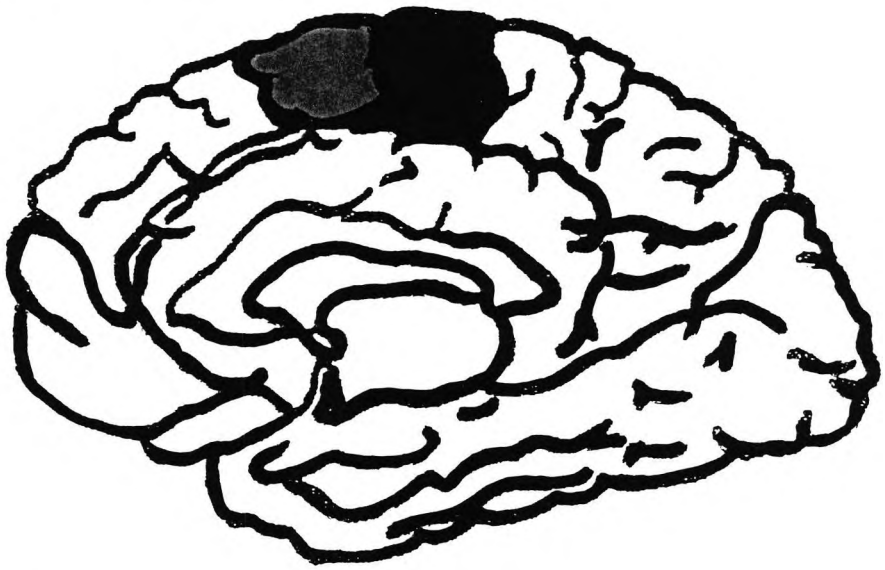
Figure 1: Medial views of the brain showing the sub-divisions of the frontal cortex



DORSOLATERAL

MESIAL

ORBITAL



PRECENTRAL CORTEX

PREMOTOR CORTEX

2.3 Critique of established methods of neuropsychological assessments

Although this review has attempted to identify the most appropriate neuropsychological tests for the subdivisions of the frontal cortex it must be emphasised that this approach is not standard. The majority of text books present the tests in isolation and can often refer to them as tests of frontal lobe functioning. This approach appears to stem from the failure to see the diverse nature of the frontal lobes even though our knowledge base has moved on considerably from the 1960's. This widespread assumption about the functioning of the frontal lobes has been perpetuated by the use of the term 'the frontal lobe syndrome'. The use of this term has been heavily criticised for not only does it fail to incorporate the diversity of the anatomical structures of the frontal lobes but also the complexity of their influence, which spans over a number of domains and includes behavioural, physiological emotional and cognitive functioning. However, this term is still used to this day and some aspects of neuropsychological assessment have helped to perpetuate its use. Simple standardised tests cannot measure the complexity of deficits that a person can exhibit or their effects: they are unable to measure whether or not a person can return to work or has the capacity to make decisions.

In addition, to some of the criticisms of standardised and validated tests of brain function do not merely relate to their technical merits.

The main criticism has been one of ecological validity. It is vitally important that tests are not used in isolation and do not usurp the clinical importance of collecting a full clinical history. Firstly, assessment of a person requires a thorough knowledge of what the person was like prior to the onset of their difficulties to look for changes in personality and social behaviour. Secondly, although the diversity and variability of difficulties in frontal lobe functioning are its hallmark, neuropsychological assessment has as its emphasis the reliability of findings. Thirdly, it is dangerous to make too many generalisations from the tests to real life situations. Implicit in this is the fact that during an assessment a person is in optimum conditions whereas our cognitive functioning in an everyday context has many distractions and interruptions. An example of the problem of drawing conclusions from neuropsychological tests to the everyday context has been well illustrated by the work of Shallice and Burgess (1991) who described in some detail three people who performed satisfactorily on tests thought to be sensitive to frontal lobe lesions yet were unable to act effectively on their own initiative. Finally, another aspect worthy of mention is the tendency to focus on the score obtained and not enough emphasis is placed on the way in which the responses are given and what this in itself may reveal. When examining frontal areas of the brain and performance it is often 'how' a person responds and their approach to a test which is often the discriminating factor in an assessment (Lezak 1995).

2.4 Emergence of the role of executive functions

Given the criticisms of 'the frontal lobes' which has been mentioned previously and the growing awareness of the diversity of frontal lobe functioning which contains cognitive, behavioural and emotional factors many psychologists now refer to the operations of the frontal lobe as 'executive functions'. The 'executive functions' operate as an umbrella function that comes into play within all realms of cognitive processing and when executive functions are impaired, all other cognitive systems are potentially affected, even though they remain individually intact. Executive functions may be considered a composite of the following activities related to goal completion: anticipation, goal selection, planning, initiation of activity, self regulation or self monitoring and utilising feedback.

Increased popularity in the use of the term 'executive functions' has led to the use of the term 'dysexecutive syndrome' to describe damage to these areas, the manifestations of which include: disturbed attention, increased distractibility, difficulty in grasping the whole of a complicated state of affairs, well able to work along routine lines but unable to master new types of task, and at a loss in new situations (Baddeley and Wilson 1988).

The cognitive processes which are damaged in such patients are called 'executive processes' because they are part of a system that acts in a supervisory capacity (Shallice 1988) in the overall hierarchy of brain

processing. Patients with damage to these cognitive processes often experience one or more of a wide range of difficulties in everyday life. However, not all patients with dysexecutive problems show the same range of problems. Thus the dysexecutive syndrome is hardly a 'syndrome' in the proper sense but more a constellation of problems which may occur in various combinations in any one patient. We do not currently know the limits of these combinations, but it seems likely that the executive system is composed of a number of different processes or systems which can be impaired singly or in combination in any one patient (Burgess 1996). Generally speaking, patients with dysexecutive syndrome (DES) are likely to be impulsive, distractible, have problems utilising feedback, and to behave inappropriately in social situations (Alderman and Ward 1991).

To overcome the problem of ecological validity described previously mentioned the "six elements test" was developed (Shallice and Burgess 1991), which requires subjects to organise their activities in order to carry out six tasks in a limited period and without breaking certain rules. It was found that this test was sensitive to everyday dysexecutive problems experienced by patients with frontal lobe damage, which led to the realisation of the need for a test of a more pragmatic nature, illustrating the importance of obtaining realistic behavioural observations from a naturalistic setting in order to create some meaning of how the patient's experience of these problems affects day to day living, rather than relying only on test results.

Another test which attempts to cover a number of areas of frontal functioning and with some ecological validity is the Behavioural Assessment of the Dysexecutive Syndrome (BADS) (Wilson et al 1996). The test has six subtests, one of which is a version of the "six elements test" mentioned earlier. The standardised score is obtained with an overall classification structure which ranges from impaired to very superior. The test also has a self rating questionnaire, which can be very useful to assess an individual's awareness of the problems they are experiencing. Another questionnaire is also filled out by someone who knows the patient well, which can provide useful information as to how problems are manifested for that person in everyday life situations. This test has helped enormously in popularising the problems individuals with frontal lobe damage experience. It is easy to use and is employed by a variety of professionals, and helps to overcome the requirement for the multiplicity of tests described earlier when examining different brain regions. However although it has made a significant contribution, there is a slight problem in massing together an individual's problem in one global phrase. When used by a variety of professionals it is also not uncommon to hear opinions that the patient has '*dysexecutive syndrome*' without any statement of precisely what difficulties the person is experiencing, so the label can be one that can stick but without giving any precise details. Such global imprecise labelling may hinder our attempts at rehabilitation of a person because the assessment is not specific enough to identify areas that rehabilitation needs to target.

Other tests which are trying a new approach include the work of Goel (1997) which has as its emphasis the direct observation of behaviour on a financial planning test. Other researchers are developing the use of self rating scales further (Coolidge and Griego 1995). However, the value of these new approaches are yet to be demonstrated. Another approach is presently being developed by the Brain Injury Rehabilitation Trust in England by Andrew Worthington (1998). This approach which has been coined SAFES (Structured Assessment of Functional Executive Skills).

2.5 Models of executive functioning

In an attempt to provide a model of the workings of the 'executive' functioning a computational information processing approach has been developed (Norman and Shallice 1980). This model proposes that control over the sequencing and integration of the components required for complex but well-established patterns of behaviour is mediated by hierarchically organised 'schemas' or memory representations, which suggests that under many conditions we can function on 'auto pilot', selecting and integrating cognitive or behavioural skills on the basis of established schemata. Once a schema has been triggered it competes for dominance and control of action by a process of stopping other schemas which would be likely to conflict with it; this process is called "contention scheduling". However, when flexibility or planning for novel solutions is needed the selection of schemas becomes modulated

by the supervisory attentional system. Shallice (1982) states that many frontal lobe lesions lead to a deficit at the level of the supervisory attentional system. This can explain both the phenomena of impaired sustained attention (distractibility) and perseveration. This model will undoubtedly require elaboration in the future because there is no differentiation of function of the 'supervisory' system (Shallice 1988). However the approach is promising because it provides pointers towards a multicomponent 'executive' system.

The work by Stuss (1991) develops the model proposed by Norman and Shallice (1980) by proposing a conceptual framework for understanding the executive control system, via a three component model. Input to the first component corresponds to sensory and perceptual or knowledge based information; these automatic processes form the daily routine of behaviour. The second component of the hierarchy is associated with the executive control or supervisory function of the frontal lobes; this adjusts and directs the ongoing automatic behaviours of the lower modules. These first two components of the hierarchy of information processing are discussed by Norman and Shallice (1982). However the Stuss model raises a third component which incorporates the concept of self reflectiveness or self awareness; this meta cognitive capacity appears to be dependent on the prefrontal region (McGlynn and Schacter 1989).

A further model which attempts to explain some of the emotional and behavioural disorders which can result from lesions to the frontal lobes

is proposed by Eslinger et al. (1995). They introduce the concept of the 'social executor', and argue that the role of the 'executor' in organising and directing components is well established and therefore it is plausible that adaptive social behaviour may be viewed as a complex functional system for which the frontal lobe operates as executor. When the frontal lobe is intact, personality and social behaviour systems operate in a unique and organised pattern for each person. However, after damage has occurred to the frontal lobes, personality and social behaviour may become fragmented, disorganised and unregulated, resulting in behaviour which is inappropriate to the context or emotional state of the individual. Social executors may be distinguished from other emotional interpersonal and reactive processes (for example, anxiety and depression) by virtue of their close relationship with higher cognitive and executive control processes (Eslinger, in press). They propose a social executive system which can be evaluated through a taxonomy that includes four specific aspects of social and interpersonal behaviour; "Social self regulation" refers to the patient's ability to manage the initiation, rate, intensity and duration of their interaction with others. Difficulties range from apathy to disinhibition. "Social self awareness" refers to a specialised form of knowledge and insight about one's self in social situations; these individuals often under or overestimate their social and emotional effectiveness. "Social sensitivity" refers to the ability to understand another person's perspective, point of view or emotional state. Finally, "Social salience" includes a variety of cognitive autonomic and visceral processes that regulate somatic and emotional states; the orbital frontal region may play a prominent role in such processes.

These four aspects require further studies to confirm knowledge of these social impairments.

3.0 Rehabilitation of executive functions

The effects of executive function impairments are numerous and present a challenge to the individual, their family and the rehabilitation team, not least because frontal lobe damage frequently alters a person's ability to understand and conceptualise, and therefore their ability to participate in a rehabilitation programme, by virtue of its effects on the executive control networks of the brain. The primary focus of management and treatment must be to address the consequences of deficits in self-regulation and the executive control of cognition and social behaviour (Eslinger 1995).

Cognitive rehabilitation has been described as an 'assortment of procedures to improve or restore a diverse collection of abilities and skills' (Wood 1990). The assortment of procedures may be classified into two main approaches, the first reflects the rationale of theories of restoration of function and attempts to restore the specific impairments that may underlie a range of problems. The second considers the functional adaptation to cognitive difficulties and involves environmental modification, behavioural compensation and behavioural techniques. It is based on theories of behavioural

compensation or functional adaptation, and targets the problem at the level of the disability, attempting to teach the individual strategies and skills to reduce the impact of the impairment as manifested in everyday settings.

3.1 Restoration of cognitive impairment by retraining

This broad category of therapy has often been referred to as the 'process-specific approach' (Sohlberg and Mateer 1989) and encompasses attention training, prospective memory training and planning and organisation training. Treatment is orientated towards targeted remediation of specific cognitive areas, and it assumes that these specific areas can be treated individually. Following assessment to identify the target problems, a person is retrained and remediated in those areas. The essential strategy of this approach is the repeated administration of hierarchically organised treatment tasks that target distinct, theoretically motivated components of a cognitive process. Data is gathered on each performance of the task. When set criterion levels are reached, remediation of another cognitive process or an additional component of the current process is initiated.

A few words of caution are necessary before proceeding with a more detailed examination of this area. It should be noted that this approach is excessively task orientated and even if a person is shown to improve on the performance of certain tasks it is difficult to see what

conclusions can be drawn from this improvement. The question remains as to what extent these laboratory tasks can be reminiscent of real world activities. So, therefore, the question of generalisation must pose a major problem. There is also concern regarding the lack of empirical data to support the efficacy of process orientated executive functioning exercises and to date the benefits have yet to be demonstrated. Another major difficulty with regard to the fundamental principles of this approach hinges around its expectation that in addition to a skill there would be a corresponding improvement in the supporting cognitive process; however, as yet there is no evidence to support this.

3.1.1 Attention training

Many patients with frontal pathology have preserved general knowledge, intact language processing and no primary auditory or visual impairments. The difficulty these individuals may encounter is with more complex attentional processing such as the ability to maintain attention, switch focus, divide attention or select out target information (Stuss et al. 1989). Several studies have suggested that individuals can benefit from exercise and retraining of attentional processes (Ben Yishay et al. 1987). However, few studies have controlled to allow adequately for spontaneous recovery, the effects of practice and concurrent therapy. In addition, few studies have assessed the degree to which training generalises to an everyday situation. One study which did meet all these criteria was not able to demonstrate significant gains (Wood and Fussey 1987). Another study failed to demonstrate significant responses to computer-mediated attention training programmes (Malec et al 1984). However, Gray et al. (1982) found that their experimental group did show more improvement than a control group on a variety of neuropsychological tests and that this effect was stronger six months later, although it could be suggested that this effect may have been due to increased proficiency in the use of strategies. In summary, no studies have demonstrated conclusively that this form of training has had an impact on the everyday lives of individuals with executive problems which involve attention.

3.1.2 Prospective memory training

Another type of cognitive remediation is prospective memory training, which requires that a person perform a particular action at a specified time in the future based on a self initiated and internally generated plan of action, such as paying a bill or returning a telephone call. Lack of this capability is another way in which difficulties might be manifest at the action program level as seen in patients who suffer executive dyscontrol. It has been suggested that prospective memory capacity can be improved by such training (Sohlberg and Mateer 1986); however, whilst there was an increase in the span of prospective memory within the experimental paradigm, evidence of generalisation to naturalistic settings was unclear and the subjects were also receiving other forms of therapy concurrently, so the results are not reliable.

3.1.3 Remediation of planning and organisation training

In this area it is proposed that patients may benefit from structured exercises that provide multiple opportunities for initiation, planning, and performing goal directed activities. A variety of computer programs targeting these functions could be included in this category; for example, ALGERNON is a program in which the user plans a route through various mazes in order to assist a mouse in obtaining some cheese. Such a program might be useful in targeting planning skills, but the problem of generalisation is again of paramount importance.

The Executive Function Route Finding Task (EFRT) developed by Boyd et al. (1987) offers another type of exercise that might be used to stimulate planning and organisational processes. Route finding is highly dependent on the integration of information and the selection and execution of cognitive plans. Patients were asked to locate a target in an unfamiliar destination. Task performance is scored according to the following parameters: task understanding, incorporation of information, seeking and retaining directions, error detection, error correction, and task behaviour. The EFRT utilises a unique cueing system that might be applied to any task that tests executive functions. The cueing is divided into non-specific and specific cues which provide a hierarchy for training. This task may serve as an excellent therapeutic task, but it has yet to be standardised and undergo efficacy studies.

3.2 Functional adaptation of cognitive difficulties

3.2.1 Environmental modification

Some patients are best served by examination of their physical environment to evaluate how it can be organised to enable them to take on the functions previously carried out without difficulty. This approach may be well utilised during the acute recovery phase as it is not usually possible to diagnose and treat all of the patient's frontal

lobe related cognitive and behavioural impairments. Although this approach is common in clinical practice, very little experimental evaluation has been described in the literature. Also, training has often been given on artificial tasks in settings which bear little resemblance to those encountered in everyday life. Ideally one would identify the specific environment for each individual person with brain injury, find out where deficits in executive control are interfering in daily functioning, and then recommend an appropriate environmental manipulation to compensate for the deficits in executive functioning. For example, the elimination of clutter or external distractions serve as potential strategies profitable for select patients (Sohlberg et al. 1989), or in the workplace it may be possible to alter duties so that they minimise demands on memory or initiative, or the worker may be placed in a quieter environment to avoid distraction. Other examples include posting cues such as labelling cupboard contents or writing prompts to carry out specific actions and organising the physical space such as using key holders etc. Training the person to attend to the environmental cue or change must be accomplished if a person is to make maximum use of the environmental cues.

Cueing systems may be established that allow patients suffering executive dyscontrol to plan, organise, and follow through with multiple-step tasks. This is thought to be useful for individuals who exhibit difficulties at the second component of the executive control model proposed earlier by Stuss (1991). Examples of such systems include the case described by Kirsch et al. (1987) of the successful application of a computer-mediated cueing system to improve the

performance on a biscuit making task. Other examples include training patients to use a watch with an alarm or a calendar system. The use of a neuropage, designed to bleep at prearranged times of day and provide instructions or reminders on activities and recently used for individuals with memory problems, has also been shown to be useful with executive difficulties. Neuropagers can also have some benefit for a person who has problems organising and planning their day, and can help a person who may have difficulties initiating activities (Hersh and Treadgold 1994).

Some promising work has been carried out using a comprehensive, three-phase behavioural approach to training involving the use of a memory or organisation book in an individual with severe amnesia and executive dyscontrol (Sohlberg and Mateer 1989). Initially, the training focuses on increasing the patient's knowledge. This is followed by regular practice using the system, and the last phase addresses use in real world contexts. However, as yet there have been no trials with a number of individuals to validate this approach.

3.2.2 Behavioural approaches

There are a variety of skills training techniques that concentrate on a behavioural management component. Behavioural programmes that minimise the amount of stimulation present, provide consistent and immediate feedback on inappropriate behaviours, and identify very specific and concrete goals for patients to focus on are useful. It is often not possible for an individual to learn, conceptualise and remember the various sequences of steps and activities that are required to improve their self care and other functional activities, so training prescribed sequences of behaviour for highly functional activities by repetitive practice can be useful for such individuals (Craine 1982). This approach would be utilised most effectively for those individuals who are at the first component of the executive control system framework as discussed by Stuss et al. (1991). Routines which are task specific such as getting dressed etc. can be written in a step by step format. Following regular practice with patients, progressively less cueing can be provided until the sequence can be followed with maximum independence. Verbal prompts have been used successfully which were gradually faded to train individuals on washing and dressing tasks (Giles and Clark-Wilson 1988).

3.2.3 Behavioural compensation

This approach targets the problem at the level of disability, attempting to teach the brain injured patient strategies and skills to reduce the impact of the impairment as it is manifested in everyday settings. At the most cognitively demanding level are attempts to train the person to use self-instructional or self-monitoring strategies in a variety of situations, for example, training a sequence of steps to be followed in different problem-solving situations. This approach has been used in the domain of executive function (Cicerone and Wood 1987) where a self-instructional approach for a person with impaired planning ability and poor self control was applied, with the patient being required to verbalise a plan of behaviour before and during the execution of a training task which was a modified version of the Tower of London test. Overt vocalisation was gradually faded. Generalisation training in applying planning and problem-solving strategies in real-life situations was conducted over 12 one-hour weekly sessions after completion of the self instructional training. There was an improvement on the Tower of London task which was re-administered four months after training. More significantly, there was evidence of transfer of gains regarding planning behaviour on some other neuropsychological measures. There were also significant increases in self-control ratings made by an independent therapist during the generalisation training. Similar findings were made by other research using the Tower of London puzzle as a training task (Cicerone and Giacino 1992), who report positive results across six patients utilising a self instructional technique. A similar self reminding procedure has been used by

Lawson and Rice (1992) termed WSTC (**W**hat am I suppose to be doing? **S**elect a strategy. **T**ry the strategy. **C**heck a strategy) to successfully increase verbal memory in a brain injured individual, but there is little to support the efficacy of this approach.

Problem solving approaches to psychological difficulties have been used with some success by Von Cramon et al. (1991) who used a framework previously utilised by D'Zurilla and Goldfried (1971). This approach emphasised the following stages: problem orientation; problem definition and formulation: generating potential alternatives to solutions; solution implementation; and solution verification. Using this approach Von Cramon believed this technique would enable an individual to "reduce the complexity of a multi-stage problem by breaking it down into more manageable portions. A slowed down, controlled and stepwise processing of a given problem should replace the unsystematic often rash approach these patients spontaneously prefer". He utilised a problem solving therapy which is based on groupwork over a period of about 6 weeks with an average of 25 sessions. Suitable patients included those who were impaired on neuropsychological testing, who often frequently acted rashly and without prior consideration, and who ignored or did not recognise information relevant to problem solving in everyday activities. They often showed difficulty in responding appropriately to feedback and hardly considered alternative solutions when the chosen course of action was unsuccessful. However, for inclusion in the problem solving therapy, individuals needed to be able to concentrate for more

than 20 minutes and a willingness to make an effort and have at least a vague concept that their thinking has been impaired. It is important that the person does not have severe perceptual or language deficits and retains some learning capacity with some ability to think in abstract terms. The general aims of the therapy are to enhance the conscious control of thought and action and to encourage the self motivated active participation in rehabilitation. Results from a trial carried out by Von Cramon et al. (1991) showed that patients tended to show improvements in intelligence test on issues involving 'inductive reasoning', 'categorising' and 'similarities'. Patients who had received the therapy also showed improvements on the Tower of Hanoi test. However, the control group who received memory therapy showed none of these changes. Nevertheless, they also found that some patients in the problem solving group were worse after therapy. Von Cramon suggests this may be due to an increased awareness of the complexity of problems leading to confusion, in contrast to their pre-treatment propensity towards premature and ill considered actions. Von Cramon et al. are uncertain whether patients from the group would be able make use of their newly acquired skills in everyday life and evidence from cognitive literature suggests that generalisation is problematical. This has an implication for rehabilitation and suggests that like any treatment approach generalisation must be an integral part of the programme.

In a more recent case, Von Cramon and Matthes-Von Cramon (1994) were able to demonstrate a significant impact of their training

approach on the work performance of a medical doctor who was exhibiting executive problems nine years post injury. Intensive training was conducted over a 12 month period. Problem solving strategies were applied directly to his work related difficulties using self instructional techniques initially with external guidance from the therapist, which was gradually withdrawn over time. After the training period the doctor was able to utilise problem solving strategies in his everyday work.

Other methods to help individuals to solve problems have made use of self initiation checklists for two patients who were showing difficulty with completing vocational tasks (Burke et al. 1991) by doing things in the wrong order along with problems in planning as well as memory loss. The advantage of the checklist was that it could be withdrawn after 12 days, thereby reducing the need for external assistance such as job coaches.

3.2.4 Critique of rehabilitation approaches

In comparing the two main approaches of restoration versus functional adaptation it is the second approach which is the most practical, and has a face validity for all who are working in the area. One of the main problems of the restoration approach is that it appears to assume that damage to the brain is like a muscle and the more your exercise and

practise it the better and stronger it will become. Unfortunately, this is rarely the case with damage to the brain. Many rehabilitation units use the vast array of computer programmes which have now been devised which span the whole array of cognitive functioning. The implication from the advertisements of these computer software companies is that practise on the programme will enhance skill and restore any deficit. Many of these programmes are taken at face value by some of the professionals working on rehabilitation units and it is not unusual to see a member of the rehabilitation team, such as an Occupational Therapist, using a computer programme with a patient on this basis. For example, a programme may involve practising completing a maze. There are many executive tasks that are involved in this task but if the professional does not use the programme to look at strategies for problem solving all that will happen is that the patient may hopefully improve his/her performance on this particular programme without any extension to the real world.

In addition, the restoration approach continues to lack experimental evidence evaluating treatment efficacy. A particular area of weakness is the lack of ability to extrapolate strategies from abstract tasks to the real world. In addition, our theoretical knowledge of many of the impairments underlying cognitive difficulties resulting from brain damage remains very limited which means that there is no sound basis for the design of restorative treatment programmes. There may be a place for impairment orientated restorative therapy for some individuals in the early stages of the rehabilitation process, but the

research so far indicates that this is unlikely to result in a significant reduction in the injured person's disability and handicap. On balance the functional approach has the greater merit and there is a weight of evidence to suggest that functional adaptation should be the focus of rehabilitation (Ponsford et al. 1995).

3.3 Emotional and psychosocial considerations

Frontal lobe mechanisms are crucial for personality and social behaviour, and this obviously has a strong impact upon the outcome of the rehabilitation. It is the social disability which often produces the greater barrier to rehabilitation and functional recovery than other neurological and cognitive deficits (Grattan and Eslinger 1991). The complexity of the problem is acknowledged by Lezak (1983) who states that "for the most part the personality changes, emotional distress and behaviour problems of a brain damaged patient are the product of extremely complex interactions, involving his neurological disabilities, present social demands, previously established behaviour patterns and his ongoing reactions to all of these".

3.3.1 The remediation of social and interpersonal impairments

Various social intervention strategies have been proposed by Eslinger et al. (1995) based on the heuristic model for social processes discussed earlier. They note the usefulness of external cueing systems and verbal mediation for social self regulation. If an individual is withdrawn or apathetic, structured interactions may prove useful. Periods for social exchanges should be time limited, focussed, and start with low levels of stimulation. Interpersonal cues can be provided through questions and comments. For the person that is most disinhibited, the external cues need to revolve around helping them to inhibit their impulsive behaviours. For social sensitivity the goal of intervention is to help patients extricate themselves from a set position and consider alternative perspectives in a social situation. Elsinger et al. (1995) propose exercises that advance the patient's ability for alternative solution thinking; consequential and means/end thinking are essential. Once those are mastered, increasing the number of references to others and the accuracy of person perception can be addressed, and at the advanced stage improving the patient's accuracy in communicating empathic understanding is important. With regard to social salience they acknowledge that effective means of treatment are limited, but they have noted that with some patients it is useful to make cognitively explicit that which the patient cannot appreciate at an effective level - to encourage them to cognitively process who is most important to them and what emotion is usually associated with certain circumstances. This information may be then used to guide some of

their interpersonal behaviour. These approaches are in the embryonic stage of development and much work is needed to develop them further.

Another approach to improving social impairments is found in the work of Hopewell et al. (1987) who proposed "social competence training" which was used with some success for survivors of traumatic brain injury in a residential setting. In this approach, actual conflicts were stimulated and alternative responses were practised. Flashcards were used to provide a cueing procedure that prompted the patient to review an alternative response repertoire. Cues for self control were also utilised. Overall they found that the training had a good effect on behaviour and that these effects were maintained well beyond the training period.

3.3.2 Developing self awareness

A lack of insight commonly reduces motivation for rehabilitative therapy, and results in unrealistic decisions regarding work or study, which can cause conflict with family members (Prigatano and Fordyce 1986). According to Ezrachi et al. (1991), the development of realistic self appraisal is essential if the individual is to return successfully to a productive lifestyle. Recent studies evaluating the effectiveness of specific cognitive interventions have also identified self awareness as an essential ingredient to their success (Kovacs et al. 1993).

To assist in the development of self awareness, information regarding the causes and nature of the changes resulting from the injury needs to be conveyed to the individual from the time of admission (Ponsford et al. 1995). However, it is important that such feedback regarding performances is given in clear and simple terms, and therapists should also be at pains to demonstrate strengths and positive attributes. Families should also become involved in supportive feedback. Sensitivity is imperative in order to minimise the loss of self esteem. One of the ways of tackling this issue is to help an individual by teaching them about their problems using exposure and re-education and providing feedback immediately before and after doing a task (Judd 1986). He suggests that the family should be trained in this technique and the patient encouraged to constantly check their judgement with others. This view is reinforced by the work of Sohlberg and Mateer (1989) who suggest that a person is most likely to work through impaired awareness of deficits via group work as this environment gives opportunities for the patients both to observe the problems that others have and to get feedback on their own performance. They do not suggest that denial or lack of awareness changes quickly or easily, but that it is more likely to change in an accepting, trusting environment which provides many opportunities for the demonstration or experience of problems in a therapeutic fashion. They are also at pains to emphasise that although these problems have an organic basis, they are likely to be exacerbated or influenced by complex interactions taking into account the person's pre-existing personality along with their reactive responses to their particular situation.

The formation of "circles of support" is another method of enhancing self awareness (Willer et al. 1993). A "circle of support" is a semi-structured approach by the establishment and operation of a small circle of friends who have experienced brain injury and have disabilities who meet on a regular basis with an individual who has returned to the community and who has also experienced brain injury and has disability and who has attained a level of awareness which they have not yet achieved. The objective of such a group is for the individual to help the other members of the group to develop similar awareness.

However, for individuals who have attentional problems and very limited behavioural control, such as is often seen in the dysexecutive syndrome, individual or group therapy is unlikely to be successful. However, ongoing feedback and experience might lead to change over time (Ponsford et al. 1995) and it appears that there is no substitute for time in that it is frequently not until an individual has returned to the community and had more direct experiences of change in their capabilities that they may gain some awareness.

3.3.3 Behavioural Treatments

A behavioural approach has been helpful for some of the behaviour and personality changes that occur post injury such as low frustration tolerance, verbally threatening or physically aggressive behaviour, and self-centredness leading to attention seeking and/or manipulative

behaviour. These behaviour problems can be severe and potentially result in danger to rehabilitation staff and families. If used for the right reasons, the application of appropriate behaviour management techniques can be an important part of the rehabilitation process.

The most popular methods have relied mainly on the principles of positive reinforcement, together with those of extinction, particularly time out (Wood and Eames 1981, Wood 1984, 1987). However, it has been noted that these methods are generally ineffective when used with patients whose performance on tests of frontal lobe and memory functioning is grossly impaired (Alderman and Burgess 1990). In many cases it would appear that poor performance on tests of memory is partially attributable to difficulties with attentional control due to deficits in frontal lobe functioning which, alongside the types of behaviour deficit observed, can be seen as part of a dysexecutive syndrome.

A number of behavioural techniques, for example "response cost" and "cognitive overlearning", can be particularly valid for the treatment of behaviour disordered patients presenting with a dysexecutive syndrome (Alderman and Ward 1991). "Response cost" is based on the principle of negative punishment, that is the removal of something of value every time a defined target behaviour occurs. "Cognitive overlearning" (Wood 1987) involves a form of negative practice. Alderman and Ward suggest that response cost programmes appear to facilitate learning because the way in which they are utilised avoids

some of the obstacles to conditioning imposed by dysexecutive syndrome. Increased distractibility as a product of this syndrome will impede conditioning due to difficulties in using feedback from the environment. Response cost uses the approach that helps this difficulty, in that, every time a target behaviour occurs, the programme compensates for poor executive functioning by focusing attention and selecting the relevant information from the environment necessary to facilitate learning on the patient's behalf. In relation to cognitive overlearning, the enhancement of verbal feedback appears to lead to internalisation of this information and changes cognition in a way that influences behaviour. The mechanism involved gives support for the information processing model put forward by Norman and Shallice (1980).

These behavioural treatments have shown some success, but it is important to note that the majority of them occur in specialist units for individuals with brain injury. Therefore the transference of these techniques into the home settings on a rehabilitation ward often depend on a number of factors outside of the techniques themselves such as the consistency of the responses of carers, which is essential if a behavioural treatment is to be successful. This consistency depends on all staff, some of whom may not themselves be trained in behavioural techniques, adopting the same method, and this may be even more problematical for parents or loved ones who may bend the rules on a few occasions.

3.3.4 Approaches to psychological therapy for people with executive function impairments

In many ways the psychological and emotional consequences for the individual who has executive function impairments are similar to those who have sustained a brain injury and represent a complex interplay of changes in cognition, behaviour and personality resulting directly from the brain injury and reactive problems. For many individuals with frontal lobe damage many aspects of one's life changes; for example, there is likely to be a decline in vocational status, family or marital relationships, and social or leisure pursuits (Oddy 1984, Lezak 1987). The psychological and emotional consequences of such devastation can include reduced self esteem, loneliness and depression (Tyerman and Humphrey 1984). The mental changes that contribute to this reduced working capacity usually consist of impaired initiative, inability to plan or sustain activity, lack of emotional control and low frustration tolerance (Thomsen 1984) and these are some of the factors associated with the dysexecutive syndrome. These changes invariably place a heavy burden upon family members and can lead to social isolation (Gianotti 1993). The process of isolation has been described by Kozloff (1987) who found that with increasing time after injury the patient's social network undergoes two major modifications; firstly, there is a reduction in size as the number of people interacting with the patient decreases progressively, and secondly, there is an increase in its intensity, due to the fact that the only persons remaining in contact with

the patient are those who are committed to a lasting relationship. Being unable to resume a satisfactory job and to maintain intimate relationships (Weddel, et al. 1980), these individuals often become lonely and depressed (Oddy and Humphrey 1980). However, despite these findings there is relatively little documentation of the emotional and social consequences from the point of view of the person, partly because there is a perception that such individuals are either less aware of their responses than others and so less able to reliably report inner experiences, or by virtue of cognitive dysfunction simply do not experience a significant emotional response to the injury. These issues are described as being of the utmost importance by Prigatano et al (1988) who have outlined the premises, goals and components of a holistically orientated rehabilitation of brain damaged patients. Even patients with severe brain damage can often return to a productive life-style if given the opportunity to deal with the affective issues that are raised by an attempt to return to productive work (Ben Yishay and Prigatano 1990).

Many individuals with cognitive difficulties may not benefit from traditional psychotherapy which is heavily reliant on verbal interaction and a capacity to remember the content of that interaction from one session to the next. However, cognitive behavioural techniques acknowledge these difficulties, are well structured, focus on concrete behaviour or thoughts, allow for the use of written aids, and can also allow another member of the family to be included. A close family member can be the co-therapist and may be able to act as the

individual's 'frontal lobes', providing concrete feedback in situations and prompting more adaptive responses. However, as Mckinlay and Hickox (1988) point out, the therapist should be sensitive to family dynamics which may prove to be counterproductive if the relatives deny or have difficulty in accepting the presence of changes in behaviour.

Depression is a relatively common experience for a number of individuals following brain injury, and has been found to be a significant problem for 57% of patients in a survey five years after injury (Brooks et al. 1986). It is thought that the incidence of depression increases with the development of a more realistic self-awareness (Fordyce et al. 1983), which is why it is vital that individuals should be given the right to express their emotional responses to the losses which have occurred. Cognitive-behavioural techniques may also be a useful means of helping to gain a sense of control and perspective.

Anxiety is also another problem that can emerge following injury. Although this does not usually occur at the acute stages of recovery, it has been found to be most common 6 months after injury (Lezak 1987). Relaxation, distraction and cognitive restructuring may be useful to help in the management of anxiety. Another approach which may help with memory problems is the use of cue cards to implement self talk strategies.

Problems in controlling anger are also commonly experienced by many people with a dysexecutive syndrome. Such difficulties may persist

over many years after injury, and can contribute to problems in establishing and/or sustaining employment, personal relationships, and social or leisure pursuits (Jacobs 1988). For some individuals who have developed an awareness of their problem and are motivated, cognitive behavioural approaches to anger management, such as that outlined by Novaco (1975), can be successful.

Marital and relationship problems have also been frequently noted (Tyerman et al. 1994). Couples often need support with the changes imposed on both individuals following a brain injury, both at couple and individual level. The issues of dependency and role change are likely to be a particularly significant source of stress and conflict for many couples Willer et al. (1991). Marital therapy can prove useful in these situations, with a particular focus on giving each other positive feedback rather than focusing always on negative changes.

3.3.5 Critique of the treatment of emotional and social difficulties

The whole area has received a lack of emphasis which has meant that many individuals receive no assistance in dealing with emotional or relationship problems throughout their rehabilitation McSweeny (1990). It is widely accepted that psychological therapy is unlikely to be successful (Kinsella et al. 1988). Although this may true for the acute stages of recovery or where impairment is severe, but the availability of a close confiding relationship has been found to be significantly associated with a more positive emotional disposition in those with brain injury.

The limited amount of work carried out in the domain of emotional difficulties has been hampered by the inherent methodological difficulties, such as gaining an adequate sample size to conduct 'scientific research'. Furthermore, the work of psychologists in this area has been hampered by an overemphasis on scientific neuropsychological assessment which has at its roots standardisation and validation to name a few of the phrases routinely used in scientific studies. The nature of this work is much more qualitative and therefore has received less emphasis, although there is a hint that the tide may be turning. Another difficulty in this area is the complexity and vast array of problems that can be experienced by an individual with executive function damage. In this respect, it is encouraging to see the growth of the single case study in this area which is beginning

to become more widely acceptable as a way of moving our knowledge forward in this complex area.

4.0 Conclusion

This review has considered a wide variety of approaches to the assessment, and treatment of individuals with executive function impairments. On the subject of assessment much has changed in recent years and we now have a range of tools which have been standardised and validated to compare the performance of an individual with brain injury on a range of neuropsychological assessments with what we would expect from an individual without such difficulties. This review has attempted to link neuroanatomy with test performance so that given the location of damage we can predict reasonably well where the person may experience problems in relation to certain tests or vice versa. The attempt to look at test results linked to the dorsolateral, medial frontal and orbital cortex remains undeveloped but has potential in terms of its predictive value and detailed explanation of difficulties.

The neuropsychologist needs to proceed with caution in this area because the tests come from a variety of different sources and have some inherent difficulties which have been discussed. One way forward is to use a selection of the standardised tests as a screen or a hint of whether or not a problem exists and, if so, progress to more complex tests. It has recently been suggested that a screen could include the FAS test and the Trail Making Test at the very least with the possible inclusion of the Winsconsin Card Sorting Test (Powell 1998). In addition, observational skills are essential to observe 'how' a person performs on the range of other tests which comprise a neuropsychological assessment which have been mentioned earlier. If a person is showing some difficulties in these areas then a more detailed assessment could follow which might include the BADS (Behavioural Assessment of the Dysexecutive Syndrome) which is ecologically sound, along with direct behavioural observation and interviews with either friends or relatives. Any assessment must also include some measurement of mood and mental health status because this is well known to have a marked effect on test outcome and rehabilitation. This approach takes time and must not be done in a quick fix session if the results are to be useful. The purpose of the assessment is not for a diagnosis but rather to lead to some pointers as to rehabilitation needs of the person.

Caution also needs to be applied to the use of the term 'dysexecutive syndrome' which may merely replace the already criticised 'frontal lobe syndrome'. The most sensible approach would seem to be to use the term but only with some qualification as to what it refers to and

how this manifests itself in behaviour. There is also some concern for the potential mis-use of such tests as the BADS. It can be carried out by a whole variety of professionals such as Occupational Therapists, Speech Therapists and Nurses, some of whom may have very little experience of neuropsychology and who may well provide a person with a label without really knowing the detailed nature of their difficulties and how this may affect them in everyday situations. One of the major problems of global labels it that once they emerge into the medical notes every type of behaviour the person exhibits can be so easily explained away using this term even when a person's actions may at times be totally reasonable and it is the professional who is at fault.

Once a person has received a detailed assessment of the nature and extent of 'executive' difficulties there is a whole myriad of types of rehabilitation intervention. Most of the research supports the functional adaptation to cognitive difficulties, rather than the restoration. The latter has been somewhat hampered by some inherent difficulties. One of the major criticisms of work in this area refers to the methodological problem of having a number of concurrent therapies occurring at the same time so it becomes impossible to decipher which therapy is having what effect. In addition, there seems to be a problem of generalisation in that not many studies look to see if the intervention has a positive benefit for the individual outside of the experimental setting and whether, if there are any effects, this is long lasting. The latter two criticisms can also be levelled at the behavioural compensation interventions referred to in

terms of functional adaptation. To put these criticisms in their context, most of the therapies in this area are somewhat experimental and, require diagnostic trials with careful measurement to determine if the approach is effective. An encouraging development for the future is the attempt to provide frameworks which direct a clinician to a set of treatment options that correspond to the components of their proposed model that may be disrupted (Stuss 1991, Eslinger et al. 1995). This approach is still at an embryonic stage and needs much further work, but the results so far suggest that this could prove to be very effective.

One of the areas which has received little attention in terms of treatment of executive function impairments is the treatment of people other than the sufferer but who are indirectly affected and/or involved in the care of the patient; for example, little appears to have been done to ensure a comprehensive process of education for the carers, potential employers, friends, lovers, general practitioners and ward staff etc. The list is endless, but there is surely a duty to begin to make such people aware of the devastation of such a 'hidden disability'. Because it is not visible many people, including professionals, assume that the person suffering from executive dysfunction is simply being difficult or unhelpful: for example, it might be that the person is unable to help themselves in their own rehabilitation, and this can mean they can sometimes be their own worst enemy, resulting in rejection from many quarters. The charity 'Headway' does much to educate the public as to the problems that can be experienced, but there is also a duty for professionals to do the same within their own service and out in the community. There is often the need to communicate with all

those involved in the life of a person with executive function impairments and if professionals see education of those close to the sufferer in particular, and also the general public as one of their key roles the greater awareness could provide a very powerful force in rehabilitation and may contribute to much more successful social re-integration following a head injury. Better education and understanding would also enhance the detection of individuals with executive function impairments and ensure they do not 'slip through the net' but receive the treatment and rehabilitation they require.

Another area which seems to have been neglected is that of emotional or interpersonal problems. There is a dearth of literature which explores the persons subjective experience of how they are coping and what difficulties they face. Insight, or the lack of insight, has been identified as one of the biggest challenges of executive function impairments, but this does not mean that the person should not be consulted on a regular basis as to their opinion of how they are coping and what they are experiencing. One of the prevailing attitudes is that the professional knows best because the person is not able to reliably report inner experiences. Further research is desperately needed in this area. However, in my experience if a trusting and valuable relationship is established with a professional much work can be done in this field which can also help to mitigate against the feelings of isolation and low self esteem. This need not necessarily be with a psychologist but with a trusted adult. It is encouraging to note that in the case of head injuries, there is a proliferation of brain injury case managers whose job it is to help a person to access the services they

need and achieve the highest degree of quality of life. They have often been referred to as advocates on behalf of the person and in this respect a long term view is taken spanning years rather than a short burst of rehabilitation which has been traditionally offered. Indeed, the concept of rehabilitation as being a finite resource with a beginning and an end is probably short sighted given that many people with executive function difficulties are likely to experience problems for the rest of their lives. Because of the long term nature of potential problems for the person, 'flexibility' seems to be the most helpful key in terms of helping the clinician to structure rehabilitation and look at possible helpful interventions. This approach allows for change and provides the optimum assistance to an individual whose ultimate goal is to live a life which is as full as is possible given the constraints of executive impairments.

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APPENDICES: FOR SECTION B AND C

Appendix 1

Section B -Stroke care mapping: A study of the development and application of the dementia tool in stroke care

Letter Sent To Participants

Clinical Psychology Department
Overdale, Westmount Road
St Helier, Jersey, JE 1 31JH
Tel: (01534) 622003

8 September 1997

Dear

Re: **Research Project**

1 am a Clinical Psychologist doing a research project on the environment of the rehabilitation ward. We are constantly looking towards improving the quality of the service which we provide, and with this is mind I would like to find out what the experience of rehabilitation is like for the patient.

I am writing to invite you to take part in my research project. This will involve a researcher observing what is going on for you on a day to day basis in rehabilitation. This will be done as unobtrusively as possible. Your privacy will be respected at all times. Therefore an observer will not be present for personal procedures.

Please read the enclosed information sheet and attached consent form before making your decision. Your participation will be voluntary and you can decide not to proceed without giving a reason. If you require further information please do not hesitate to give me a call. My telephone number is 622033.

Yours sincerely

Tracy Wade
Chartered Clinical Psychologist

Appendix 1 (contd)

INFORMATION SHEET

I am carrying out a study to examine the Samares ward environment which has been approved your Consultant Physician, Dr Gibson. In this study I shall be collecting information on how a patient spends their day on the ward by observation and occasionally taping conversations which occur with professional staff. The observations will be carried out between 9.00am and 4.00pm and during this time your dignity and privacy will be respected at all times and therefore the observer will not be present for personal procedures. The observer will sit in a corner of the room to carry out observations so as to merge into the background and minimise any disturbance. Throughout the time that the observer is present you have the right to ask them to withdraw and the tape recorder will also be stopped at your request.

The results of the observation will be noted down on a series of charts and you if you wish the results of the observation can be shared with you. A code will be assigned to each participant taking part so that your name will not appear on any documentation. All documentation will remain under lock and key until it is analysed and it will be destroyed following the end of the research period.

Your decision to participate is a voluntary one and you have the right to change your decision without giving any reason.

If you think of any further questions that come to mind before making your decision please do not hesitate to get in touch on telephone number 622003. Thank you for considering giving your consent to this study.

Appendix 1 (contd)

CONSENT FORM

Please can you circle your response to the following questions:

Have you read the information sheet?.....Yes/No

Have you had an opportunity to ask questions and
discuss the study?.....Yes/No

Are you satisfied with the answers to any questions?.....Yes/No

Do you understand you are free to withdraw from the
study at any time without giving **any** reason?.....Yes/No

Do you understand that you are free to withdraw from
the study without affecting any future care?.....Yes/No

Do you agree to take part in the study?.....Yes/No

Signed:.....

Print Name.....

Date.....

Appendix 2

Results for Participant 2

Basic information for P2

Participant:P2.
Age:85
Admission to Rehabilitation Ward:4.1.97
Length of time on Rehabilitation Ward prior to SCM: 2 days.
Reason for admission: CVA.

Results of Map 1

SCM 1 was carried out on 6.1.98

Individual Profile of P2 for SCM 1

Main Behaviour Categories	Time	%	Care Value
(A) Articulation	1hr 5mins	25%	3.0
(B) Socially involved, passively	50mins	20%	1.6
(F) Eating and drinking	45mins	17%	1.7
(N) Sleeping and dozing	40mins	17%	1.0
(PHYp) Physiotherapy practice	30mins	11%	3.0
(K) Walking and Moving	15mins	6%	3.0
(P) Personal Care	10mins	4%	3.0

Individual Care Score: 2.3

Personal detractions

None

Results of Map 2

This lady was discharged before a second map could be carried out.

Results for Participant 3

Basic information for P3

Participant: P3
Age: 82
Admission to Rehabilitation Ward 10.12.97
Length of time on Rehabilitation Ward prior to SCM: 29 days
Reason for Admission:
CT Scan: There is extensive infarction in the Right posterior cerebral artery territory.
Left Hemiplegia, left hemianopia

Results of SCM 1

SCM 1 took place on 8.1.98

Individual Profile of P3 for SCM 1

Main Behaviour Categories	Time	%	Care Value
(B) Socially involved, passively	1hr 40mins	32%	1.0
(A) Articulation	1hr 5mins	21%	2.7
(OTp) Occupational Therapy practice	45mins	14%	3.2
(F) Eating and drinking	30mins	9%	1.6
(M) Engaged with the media	30mins	9%	1.0
(Z) Opthalmologist	20mins	6%	3.0
(O) Own Care	10mins	3%	3.0
(P) Personal Care	5mins	2%	3.0
(K) Walking and Moving	10mins	3%	3.0

Individual Care Score: 2.3

Personal Detractions

A:8 Slightly disparaging remark or put down - "You've got verbal diarrhoea"

Results of Map 2

SCM 2 was carried out on 12.2 98 on 'B' side.

Individual Profile of P3 for SCM 2

Main Behaviour Categories	Time	%	Care Value
(A) Articulation	2hrs 20mins	4 1%	3.7
(PHYp)Physiotherapy practice	1hr 5mins	19%	3.3
(F) Eating and Drinking	30mins	9%	3.0
(I)Using intellectual abilities	35mins	10%	3.0
(N)Sleeping and dozing	25mins	7%	1.0
(OTp) Occupational Therapy practice	15mins	4%	3.0
(K) Walking and Moving	10mins	3%	2.0
(E) Expressive Activity	5mins	1%	3.0
(O) Own Care	5mins	1%	1.0

Individual Care Score: 2.4

Personal Detractions

None

Comparison of SCM 1 and SCM 2

In comparing this lady's results it can be noted that she moved from A side to B side as she began to improve. In the first mapping session this person was having some difficulty in interacting with others due to her severe visual neglect, so conversations in a group setting could be disjointed because she could not trace the source of some of the conversational partners. By the time of SCM 2 there were many improvements in her visual neglect, and this, combined with an increased empathic response from others, may account for some of the increase in the number and quality of her interactions with people. It is interesting to note that the category of being socially involved but only passively reduced

dramatically from 32% on map 1 to 3% on map 2. This may be due to a number of factors, including a change in environment in that on B side she was on the ward rather than in a room on her own. In addition, on SCM 2 she attended a group and spent 23% of the day having therapy on a one-to-one basis.

Results for Participant 4

Basic Information for P4

Participant: P4
Age: 79
Admission to Rehabilitation Ward 2.11.97
Length of time on Rehabilitation Ward prior to SCM: 5 days
Reason for Admission:
Low density in the right internal capsule region in keeping with an infarct.

Results of SCM 1

SCM 1 took place on 7.11.97.

Individual Profile of P4 for SCM 1

Main Behaviour Categories	Time	%	Care Value
(B)Socially involved, passively	1hr 25mins	28%	1.0
(A) Articulation	1hr 5mins	22%	2.5
(M)Engaging with the media	20mins	7%	1.0
(F) Eating and drinking	50mins	17%	1.8
(N) Sleeping and dozing	40mins	13%	1.0
(PHYp) Physiotherapy practice	20mins	7%	3.0
(P) Personal Care	15mins	5%	1.7
(K) Walking and Moving	5mins	2%	1.0

Individual Care Score: 1.6

Personal detractions

B:15 Disregarding personal dignity - Patient is lying on bed and nurse wolf whistles at her and says "she didn't want her black knickers on today - I wonder why! She'd rather have these grey ones with no elastic. Up to her boobs and down to her knees" (laughter)

Results of Map 2

SCM 2 took place on 6.2 98 on B side.

Individual Profile of P4 for SCM 2

Main Behaviour Categories	Time	%	Care Value
(A) Articulation	1hr 20mins	27%	3.0
(F) Eating and drinking	1hr	20%	2.0
(PSY) Psychology	55mins	19%	-
(I)Using intellectual abilities	50mins	17%	3.0
(PHYp) Physiotherapy practice	20mins	7%	3.0
(B) Socially involved passively	15mins	5%	1.0
(K) Walking and moving	10mins	3%	3.0
(MC) Medical care	5mins	2%	3.0

Individual Care Score: 2.6

Personal Detractions

None

Comparison of SCM 1 and SCM 2

P4's individual care score has increased by 1.6 from map 1 to map 2. This represents a move from "good" to "very good". In the second map P4 did not spend any time in the socially involved but passive category, as compared to 28% of her day in map 1. The major changes seem to be in

the areas of participating in a group. This group appeared to rekindle an interest in crosswords and P4 then proceeded to spend some 50 minutes continuing with this activity in the afternoon on her own.

Results for Participant 5

Basic Information of P5

Participant: P5
Age: 66
Admission to Rehabilitation Ward 16.09.97
Length of time on Rehabilitation Ward prior to SCM: 20 days
Reason for Admission:
Loss of grey/white matter on the right side.

Results of Map 1

SCM 1 took place on 5.11.97.

Individual Profile of P5 for SCM 1

Main Behaviour Categories	Time	%	Care Value
(B) Socially involved passively	1hr 35mins	30%	1.2
(F) Eating and drinking	40mins	13%	1.0
(A) Articulation	40mins	13%	3.0
(M) Engaged with the media	35mins	11%	3.0
(OTp) Occupational Therapy practice	35mins	11%	2.1
(PHYp) Physiotherapy practice	35mins	11%	3.3
(K) Walking and Moving	30mins	10%	2.3
(MC) Medical Care	5mins	2%	3.0

Individual Care Score: 2.4

Personal detractions

None

Results of Map 2

SCM 2 tool place on 9.2.98 A side.

Individual Profile of P5 for SCM 2

Main Behaviour Categories	Time	%	Care Value
(B) Socially involved passively	1hr 10mins	23%	1.8
(A) Articulation	1 hr	20%	2.9
(OTp)Occupational Therapy practice	55mins	18%	2.6
(M)Engaged with the media	45mins	15%	3.0
(PHYp) Physiotherapy practice	40mins	13%	3.5
(F) Eating and drinking	20mins	7%	2.0
(K)Walking and Moving	15mins	5%	3.0

Individual Care Score: 2.7

Personal Detractions

None

Comparison of SCM 1 and SCM 2

The overall care value for this person has increased by 0.3 and he remains in the very good category. He spent the same amount of time in the socially involved but passive state but his care value for this Behaviour Category Code has increased. This increase might be explained by the fact that P5 was no longer alone on the ward. P5's interactions increased in amount by the second map as did the amount of occupational therapy that he received. His care value for occupational therapy increased by .5, although it was noted from the data sheets that he was again having great

difficulty with a computer task, without any constructive instructions being given.

Results for Participant 6

Basic Information for P6

Participant: P6
Age: 70
Admission to Rehabilitation Ward 27.10.07
Length of time on Rehabilitation Ward prior to SCM: 17 days
Reason for Admission: subarachoid haemorrhage, right sided weakness

Results of Map 1

SCM 1 took place on 12.11.97.

Individual Profile of P6 for SCM 1

Main Behaviour Categories	Time	%	Care Value
(B) Socially involved passively	2hrs 55mins	49%	1.1
(A) Articulation	1hr 10mins	19%	3.1
(F) Eating and drinking	35mins	10%	2.1
(K) Walking and moving	35mins	10%	2.1
(OTp) Occupational Therapy practice	25mins	7%	3.0
(PHYp) Physiotherapy practice	10mins	3%	0
(D) Distress	5mins	1%	1.0

Individual Care Score:1.8

Personal Detractions

B:21 disparaging remark - " none of that kind of messing around okay"

B:14 Imposing a high demand to perform correctly "Maria stand up straight alright" (in severe tone)

C:28 Using threats "If you hurt one of our girls by messing around, I'll be so annoyed, I can't even tell you

C:28 Using threats " You don't wanna make me angry now"

C:21 Extremely Disparaging Remark " Don't hurt none of our girls backs when they have little children to go home to".

C:30 Major invalidation " Why can't you speak without crying. You just have to say can you give me my slippers please".

C:30 Major Invalidation "We don't need all the tears that go with it".

C:28 Using threats "I'm really annoyed with you ..... You don't want me to be annoyed with you" (shouted at patient - another nurse looking on in act of compliance).

Results of Map 2

The patient was discharged before a second map could take place.

Results for Participant 7

Basic information for P7

Participant: P7
Age:73
Admission to Rehabilitation Ward 4.12.97
Length of time on Rehabilitation Ward prior to SCM: 34 days
Reason for Admission:
Left CVA with right dense hemiplegia

Results of Map 1

SCM 1 took place on 7.1.98.

Individual Profile of P7 for SCM 1

Main Behaviour Categories	Time	%	Care Value
(B) passive involvement	1hr 25 mins	25%	2.0
SLT(p)Speech Therapy practice	55mins	16%	3.1
(A) Articulation	50mins	15%	3.0
(F) Eating and drinking	45mins	13%	2.0
(K) Walking and moving	35mins	10%	2.5
(M)Engaging with the media	20mins	6%	3.0
(O) Own care	15mins	4%	3.0
(PHYp)Physiotherapy practice	15mins	4%	3.0
(OTp)OccupationalTherapy	15mins	4%	3.0

Individual Care Score:2.7

Personal Detractions

B.16 The television was switched off without consulting any patients

Results of Map 2

SCM 2 took place on 5.2.98.

Individual Profile of P7 for SCM 2

Main Behaviour Categories	Time	%	Care Value
(F)Eating and drinking	55mins	17%	2.3
(B)Socially involved passively	45mins	14%	1.6
(PHYp) Physiotherapy practice	45mins	14%	3.0
(M) Engaging with media	40mins	13%	1.5
(N) Sleeping and dozing	35mins	11%	1.0
(SLT) Speech and language Therapy practice	35mins	11%	3.0
(K) Walking and Moving	25mins	8%	2.6
(O) Own care	15mins	5%	1.0
(P) Personal care	10mins	3%	3.0

Individual Care Score:2.1

Personal Detractions

None.

Comparison of SCM 1 and SCM 2

This lady's care score has decreased by 0.6 from the "very good" category to the "good" category. It can be noted that the category of interacting with others was not observed at all on the second map; this is possibly because the conversation was subsumed by the activities that were taking place. On the second map P7 received the same amount of therapy, which took up almost one quarter of her day. However it is important to note that she did not have Occupational Therapy on the second map, which had previously given a care value of 3.0. In the second map it can also be seen that P7 had a sleep of 35 minutes which only carries a care value of 1.0, and the Behaviour Category Code of her own Personal Care declined from 3.0 to 1.0.

Results for Participant 8

Basic information for P8

Participant P8
Age: 77
Admission to Rehabilitation Ward 22.5.97
Length of time on Rehabilitation Ward prior to SCM:168 days
Reason for Admission: Dense right hemiparesis

Results of Map 1

SCM took place on 6.11.97

Individual Profile of P8 for SCM 1

Main Behaviour Categories	Time	%	Care Value
(A) Articulation	1hr 15mins	24%	2.7
(M)Engaging with the media	45mins	14%	1.7
(OTp) Occupational Therapy practice	35mins	11%	1.0
(SLTp) Speech and Language Therapy practice	35mins	11%	3.0
(B) Socially involved passively	30mins	9%	1.4
(F)Eating and drinking	30mins	9%	1.0
(PHYp) Physiotherapy practice	30mins	9%	1.0
(K) Walking and Moving	30mins	9%	2.0
(P)Personal care	10mins	3%	3.0
(P)Own care	5mins	2%	1.0

Individual Care Score:1.8

Personal Detractions

C:23 Mistreating participant as an object - patient was moved to table without being spoken to and was obviously afraid

A:5 Infantilisation without malice - "Gosh you're a hungry boy today"

Results of Map 2

SCM 2 took place on 10.2.98.

Individual Profile of P8 for SCM 2

Main Behaviour Categories	Time	%	Care Value
(M) Engaging with media	1hr 25mins	26%	2.2
(PHYp) Physiotherapy practice	1hr 15mins	23%	3.0
(F) Eating and drinking	1hr	19%	2.3
(B) Socially involved passively	35mins	11%	1.0

(N) Sleeping and dozing	20mins	6%	1.0
(O) Own care	15mins	5%	3.0
(K) Walking and Moving	10mins	3%	3.0
(A) Articulation	10mins	3%	3.0
(OTp) Occupational Therapy practice	10mins	3%	3.0

Individual Care Score:2.4

Personal Detractions

None

Comparison of SCM 1 and SCM 2

This person's score has increased by 0.6 and he has moved category from "good" to "very good". From both maps it is clear that this person enjoys reading books and the time spent doing this has increased. It is also interesting to note that during physiotherapy on the second map P8 engaged in more independent activity, with limited supervision from the Physiotherapy Assistant.

Appendix 3

Section B - Stroke Care Mapping: A study of the development and application of the Dementia Care Mapping tool in stroke care

STROKE CARE MAPPING MANUAL

EVALUATING THE EXPERIENCE OF STROKE CARE

An adaptation of
the Dementia Care Mapping Manual
devised by Kitwood and Bredin (1994)

N.B. This manual has a separate page numbering system to Volume 2 because it is a document in its own right

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INTRODUCTION

Stroke Care Mapping ("SCM") has its evolutionary roots in the method of Dementia Care Mapping ("DCM") (Kitwood and Bredin 1994), which attempts to observe and evaluate the quality of care given to people with dementia moment by moment. It was designed to make a more detailed objective appraisal of the care given to individuals with dementia by trying to record care received from the perspective of the dementia sufferer. DCM is essentially a very simple tool which, with a little training, provides a wealth of information about daily experiences of the patient in a care environment from their perspective. It was felt that this tool could be successfully adapted for individuals who have suffered a stroke and are on a stroke rehabilitation unit. As with DCM, the emphasis of SCM is on the process of care and the experience of stroke rehabilitation from the patient's perspective.

Traditionally stroke care has focused on enhancing physical recovery of the patient, with little attention paid to the effect of the psycho-social environment of the ward on rehabilitation outcome; indeed the majority of traditional outcome measures examine aspects of the service rather than looking at the process of rehabilitation and the patients' experience of treatment. SCM has been developed to fill this gap by looking more thoroughly at the process of care from the patients' point of view. This can be used not only to examine current practice but also to potentially influence the outcome of rehabilitation for the individual patient.

Underlying principles of SCM

The psycho-social environment of the stroke patient is of crucial importance in rehabilitation. Everyone's experience of coming to terms with a disability will be different. However, for some this will engender a whole range of feelings from anxiety, sadness, apprehension and powerlessness. The way a person with a disability is treated may play a crucial part in their overall rehabilitation. It is therefore essential that staff create an environment which deals with the emotional and psychological needs of the patient as much as their physical or practical needs. Rehabilitation in the full sense involves so much more than restoring functional ability. Personhood", one of the underlying principles of DCM, is also one of the focal points when looking at the quality of stroke care. Respecting "personhood" involves valuing each person's unique history, abilities, tastes, preferences, vulnerabilities, strengths, needs and so on. It seeks to maintain and enhance individual emotional and psychological well-being, which may influence a person's receptiveness to rehabilitation. Although individual characteristics have a significant role to play in determining a person's motivation and willingness to take part, "well-being" refers to a sense of being valued, a feeling of uniqueness, a sense of agency (being able to make things happen), a sense of belonging and of hope.

The 'Malignant Social Psychology'

This refers to a social psychology of care which is malignant, even when care staff are kind and well-intentioned. This social psychology engenders a sense of ill-being which can damage "personhood", manifesting itself in comments or interactions with patients which involve processes such as infantilisation, outpacing, invalidation and stigmatisation. These interactions are often very short lived and unconscious on the part of the staff, but their influence may often be far more damaging

than their duration and affect how a person thinks and feels about themselves. As for DCM, Stroke Care Mapping records these small episodes as Personal Detraction Coding (see pages 44-50).

Uses of SCM

SCM is a flexible tool which can be employed in a variety of ways to suit the particular objectives of the ward. Its potential applications are described below:

- SCM can provide a "snap shot" of one patient's experience throughout the day. This can be used to look at how patients spend their day, to structure further rehabilitation, or to assist in overcoming challenges or difficulties that may arise in terms of a patient's behaviour.

- SCM can be used to map several patients over the same period and the results can be collated to provide information for the whole unit. This can be used to examine quality of the service or to provide insight into the ward environment. This type of evaluation can be used to provide evidence related to care practice which can be used to evolve an action plan for the purpose of improvement.

- SCM can be used to examine particular sessions or specific times of day to obtain detailed information, such as to evaluate group work or to look more closely patient's experience at breakfast time.

- SCM is designed to enable a particular aspect to be extracted for closer scrutiny such as focusing on specific behaviour category codes and experience values for a number of patients or examining the whole process of activity related to goals

- SCM can be carried out as a "before and after" measure to examine the effects of training sessions on patient's experiences of the care provided in stroke rehabilitation.

- SCM can be used to look at the nature of interaction between staff and patients in more detail.

INTRODUCTION TO THE METHDO

During an evaluation the mapper is situated with the relevant forms near to the person that is being mapped, but unobtrusive. In SCM it is possible to either follow one person throughout the course of the day or to map a context whereby a number of patients are being observed at any one time. The maximum for each observer is generally five individuals at any one time.

Coding

Data recording is based on five minute periods. There are three recording frames:

(1) Behaviour Category Coding (BCC) combined with Experience Values (EV).

(2) Personal Detraction Coding (PD's)

(3) Goal Activity Coding (GAC)

Behaviour Category Coding involves coding the behaviour of a person with a stroke which has occurred during a 5 minute period. A letter is used and a mapper chooses from 22 different categories (see page 9 for a list). Rules are used to assist the mapper in making decisions when coding behaviour (see page 13), which helps to increase the level of reliability and objectivity in SCM. When coding behaviour interactions with other people, such as staff members or visitors etc. are also noted and the abbreviations for this are provided on page 10.

Experience Values are assigned during the same five minute period. This involves making a judgement about the value of the experience for the person. The scores range from -5, -3 , -1 to +1, +3, +5 depending the level of well-being or ill-being experienced by the person.

Personal Detraction Coding represents an attempt to keep a record of comments and actions which are thought to contribute to the 'malignant social psychology'. There are 46 Personal Detraction categories with five degrees of severity (list A: mild detractions; list B: moderate detractions; list C: severe detractions; list D: very severe detractions; list E: extreme detraction). For further information see pages 44-50.

Goal Coding involves eliciting goals that have been set for each patient. These goals are written down and numbered as a reference point for the mapper. Each time a goal occurs the mapper records which goal has been attempted.

Behaviour Category Codes

The following list contains the code letter and general description for each category and corresponding cue word:

Code	memory cue	description of category	page
A	Articulation	Interaction with others verbally or otherwise	18
B	Borderline	Being socially involved, but passively	19
C	Cool	Being socially involved but withdrawn	20
D	Distress	Expressing distress	21
E	Expression	Engaging in expressive or creative activity	22
F	Food	Eating and drinking	23
G	Games	Participating in a game	24
I	Intellectual	Using intellectual abilities	25
J	Joints	Participating in active exercise with the joints while stationery	27
K	Kuming (coming together)	Participating in a meeting to review progress	28
Lw -walking **Ls** - standing **Lwh** - in a wheelchair	Locomotion	Walking, standing, or moving	29
M	Media	Engaging in media	31
N	Nod, land of	Sleeping , dozing	32
O	Own Personal care	Engaging in activity of a personal nature such as washing, dressing, taking tablets.	33
P	Practical care	Receiving practical physical or personal care	34
R	Religion	Participating in a religious activity	36
S	Senses	Activities related to direct engagement of the senses	37
T	Transfers	The movement of transfers from the standing to sitting or vice versa	38
U	Unresponded to	Communicating without receiving a response	40
W	Work	Performing all types of work including housework	41
Y	Yo-yo	Self stimulation of a repetitive nature	42
Z	Zero Option	Behaviours fit no category	43

Interactions with others - Abbreviations

The following abbreviations are used for staff members:

Nurses = nu
Physiotherapy staff = pt
Occupational Therapy staff = ot
Speech and Language Therapy staff = st
Medical staff (doctor) = dr
Clinical Psychology staff = cp
Carer= c
Visitor= v
Patient= p
Other = oth

Considerations when using SCM method

- **Observer effect**

It is possible that when people know they are being observed they may change their behaviour, which could have an effect on the results of mapping. However, the experience of mapping suggests that after an initial burst of interest the ward are much too busy for there to be any lasting effects.

- **Maintaining privacy**

During mapping it is essential that the privacy and dignity of the patient are observed at all times, so therefore certain aspects of caring such as dressing etc. are not included.

- **Qualitative data**

To attempt to capture a person's experience SCM relies on qualitative data, which is not scientific in the true sense of the word because it depends on the judgement of the mapper. However, the method nevertheless enables an insight and a wealth of information to be gained for the practical purposes of improvement of the rehabilitation experience.

General guidelines for recording behaviour

1.BCC

Select the most appropriate BCC for the patient from the list of the 22 behaviour category codes during each five minute period and record under the appropriate time frame. Apply the Rules on page 13 to determine which BCC is most applicable. It is important to record what you feel the patient is experiencing as opposed to what the member of staff intended.

2. Abbreviations For Interactions With Others

Use the appropriate abbreviation after the BCC where there is staff involvement with a patient.

3. Goals

Prior to mapping the goals for the patient need to be elicited from the multi-disciplinary team and added to the mapping form so that each goal has a specific number. When activity towards a goal is observed note down the assigned number/s during the specific time frame in which that activity occurred.

4. V

This code is used when the patient cannot be visibly observed by the mapper. It may be useful to make additional information on the 'notes' section.

5. /

This is used when the mapper is interrupted or leaves the area for a period of time, and also when the mapper has become involved in the interaction and therefore has influenced the behaviour being observed.

6. Z

This is used if no BCC adequately describes what has occurred; observations can be made under 'notes.'

Guidelines for recording Experience Values

Well-being and Ill-being

Determine experience values which best describe the nature of the experience of the activity or inactivity as judged from the participant's viewpoint and record it. This value varies within negative (-5,-3,or -1) or positive (+1,+3,or +5). To guide your decision when assigning a value attempt to look for evidence of well-being or ill-being as follows:

Signs of well-being include:

active engagement with surroundings
assertiveness
bodily relaxation
expressing a range of emotions
humour
demonstrating pleasure
helpfulness
initiating social contact and affection

Signs of ill-being include:

unattended distress
intense or sustained anger
anxiety
fear
boredom
cultural alienation
apathy and withdrawal
despair
imposition of physical or psychological power.

Rules for determining Behaviour Categories

Rule 1

The order of precedence when assigning behaviour category codes is:

1. Type 1 (E,F,G,I,J,K,L(w,s,wh),M,O,P,R,S,T,W,X)
2. Type 11 categories (A,B,C,D,U,Y)
3. N

Example:

i) a subject is sleeping (N) during most of the five minute time frame, but wakes and looks at his watch (B) before nodding off again (N). This would be coded as B.

ii) if during the next five minutes the subject look passively into space (B) and in the latter part of the time frame starts to comb their hair(O) this would be coded as O.

Rule 2

When two or more Type 1 behaviours are occurring within the same five minute period, record the category engaged which is concerned with the achievement of a goal. If this is not relevant to the time frame choose the behaviour engaged in most of the time.

Example:

i) a subject is receiving physical care from a nurse (Pnu) for about 4 minutes of a time frame, and is watching television (M) for about 1 minute. The category coding would be Pnu.

ii) if the subject was standing with the physiotherapist (Lspt) and then began to walk across the room (Lwpt) the correct code would be Lwpt if the walking activity was related to a goal, but if the walking was not related to a goal then the correct code would be that for the activity which took up the greater part of the period.

Rule 3

When two or more Type 1 behaviours are engaged in roughly the same amount of time, record the category that relates to goal directed behaviour; if there is no goal directed behaviour, record the category that has the more extreme experience value.

Example:

i) if in the first few minutes the person is trying to eat (F) using a fork in the right hand which had been recorded as a goal, then in the latter few minutes they started to read the newspaper (M), the frame would be coded as F.

ii) if in the first few minutes a patient is eating (F) and appears to be in a state of severe ill-being (-5), then in the latter few minutes the person is leafing through a newspaper (M) with minimal interest (+1), the frame would be coded as F-5.

Rule 4

When a person is engaging in two or more Type 1 behaviours, neither of which had any relevance for goal directed behaviour, for roughly the same amount of time and which score the same experience value, record the behaviour which occurred in the latter part of the five minute period.

Example:

i) if a subject is engaging in an expressive activity (E+1) for the first half of the period and eating (F+1) for the remainder, this would be coded as F+1.

Rule 5
When two Type 11 behaviours are occurring within one time frame the order of precedence of D U B C Y is used; the length of time and experience value are not taken into account.

Example:
i) if a subject is sitting in a passive state(B) for 3 minutes and then makes desperate attempts to get the attention of a nurse without success (U), the correct coding would be U.

Rule 6
The 'degeneration rule' applies to Type 11 behaviour categories C,D,U,Y. It states that if a person has experienced ill-being for an extended period of time, the experience value becomes increasingly negative, even if the behaviour itself has not changed. Any positive experience value, apart from sleeping (N), stops the degeneration process,. (The BCC's of B and N 'degenerate' in a specific way see pages 19,32).

Rule 7
The 'combination rule' states that the degeneration rule applies to any combination of categories C, D, U and Y.

Example:
i) a subject has been coded as U-1 for ten minutes, then C-1 for ten minutes and then D-1 for ten minutes. If the behaviour of the subject in the next mapping time period is properly coded in any of these categories it should be recorded as -3.

Rule 8

All behaviour category codes involving interaction with other/s are denoted by coding the person with whom the subject is involved if observed. If two staff are involved in a particular activity then the professional who plays the lead role is coded. If the BCC records a meeting (K) then the professional who is leading the meeting is noted down.

Example:

i) if the subject was talking to another patient this would be coded as Ap.

ii) if the subject was taking part in computer rehabilitation with the Clinical Psychologist (and this was part of a goal) then this would be coded as Icp.

Rule 9

Any significant information lost in applying these Rules should be described under Notes.

Example:

i) if the behaviour of a subject is coded as Iota which involved working on a goal related to computer practice, and the mapper feels the behaviour should be explained in more detail, the additional information should be added under "Notes".

Completing Raw Data Sheets

Example:
You are to map Mrs Lever from 09.00 for one hour. Mrs Lever spent the first 20 minutes engaged in her own personal care (O), of which 10 minutes is involved fulfilling one of her goals of putting on her own stockings while dressing. Once dressed she then started her breakfast. While she was eating breakfast (F) Mrs Lever had a conversation with another patient (p) for 15 minutes. She spent a further 10 minutes eating (F) in silence, and the remainder of the hour gazing around the ward being passively interested in her surroundings (B). Whilst she was engaged in her own care and also whilst conversing with another patient she was deriving some considerable satisfaction (+3). Later in the time frame the subject was not involved so much in her surroundings and therefore had a lower experience value (+1).

The sample raw data sheet shown below illustrates how this information is recorded:

Participants name: Mrs Lever	Date: 22.9.98	Time Period: 09.00-09.59	Observer: HG
Place: Rehabilitation Ward			

Time	09.00	09.05	09.10	09.15	09.20	09.25	09.30	09.35	09.40	09.45	09.50	09.55
BCC	O	O	O	O	Fp	Fp	Fp	F	F	B	B	B
Goal	1	1										
EV	+3	+3	+3	+3	+3	+3	+3	+1	+1	+1	+1	+1

Notes
None

Personal detractions
None

Goals

1. To put on her own stockings while dressing
2. To carry out stretching activities with a nurse every day on the ward
3. To carry out two tasks each day which require fine motor movement of her left hand

A. INTERACTING WITH OTHERS, VERBALLY OR OTHERWISE

+5 highly meaningful verbal or gestural exchange
example: talking about their feelings connected with their stroke or making a disclosure of information which is highly personal.

+3 demonstrating a moderate level of well being in a verbal or gestural exchange
example: talking about their day's activities for a few minutes or their likes and dislikes.

+1 a minimum level of verbal or non-verbal exchange
example: greeting a person or giving them some brief information.

-1 in a state of slight ill-being while interacting with others
example: feelings of discomfort or disinterest during the conversation.

-3 showing evidence of ill-being while interacting with others
example: starting a conversation about feelings with no attention being taken of the person's level of feeling.

-5 showing evidence of severe ill-being while interacting with others
example: a conversation lasting a few minutes in which the person is responded to in a belittling or demeaning way.

B. BEING SOCIALLY INVOLVED, BUT PASSIVELY

+3 showing a great deal of interest in others or the surroundings without taking an active part
example: being acutely involved in surroundings while only observing what is going on, looking around with a great deal of interest.

+1 showing a limited interest in others or the surroundings without taking an active part
example: being present but not particularly involved in what is going on around the ward.

C. BEING SOCIALLY UNINVOLVED, WITHDRAWN

-1 uninvolved and displaying no interest in other people or what is going on

example: not watching any activity, staring at nothing in particular; sitting silent, slumped, and motionless.

-3 after 30 minutes of being withdrawn

-5 after 60 minutes of being withdrawn

Note 1.

The 'combination rule' and 'degeneration rule' apply to C. However with the latter, as many older people get tired in the evenings, being less involved for a longer time period may not be an indication of ill-being. With this in mind, after 19.00 hrs do not apply the degeneration rule. In addition, in the early stages of a stroke a person may become very physically tired and therefore an extended period of sleep may be appropriate.

D. EXPRESSING DISTRESS

+5 displaying distress and receiving a great deal of comfort, shaking with anxiety and having a person being calming yet reassuring.
example: crying and receiving a great deal of comfort, shaking with anxiety and having a person being calming yet reassuring

+3 showing distress and being given a reasonable level of response
example: responding to a person's distress by physical contact without some sensitivity

+1 showing slight distress and receiving an appropriate response
example: receiving the company of the staff member with a great deal of reassurance following an episode of tearfulness.

-1 unattended minimal distress
example: struggling at the table to cut up food with one hand and showing some signs of difficulty while the others have nearly finished eating.

-3 unattended moderate distress (or after 30 continuous minutes in a state of minimal unattended distress)
example: desperately trying to get out of bed and crying without being comforted

-5 unattended severe distress (or after 60 continuous minutes in a state of minimal unattended distress)
example: displaying extreme anxiety, wanting to leave immediately, being left unattended after vomiting.

Note 1. The 'combination' and 'degeneration' rules apply here.

E. ENGAGING IN AN EXPRESSIVE OR CREATIVE ACTIVITY

+5 displaying a great deal of involvement in an expressive activity
example: singing an old favourite song with a great deal of reminiscence and enjoyment

+3 displaying a moderate degree of involvement in an expressive activity
example: singing along with others and showing enjoyment

+1 being minimally involved in an expressive activity
example: tapping fingers intermittently while a song is being heard.

-1 in a state of slight ill-being while engaging in an expressive activity
example: looking rather anxious while a song is being played

-3 in a state of moderate ill-being while engaging in an expressive activity
example: singing but showing signs of sadness or discomfort.

-5 in a state of severe ill-being while engaging in an expressive activity
example: being told to be quiet while singing a song which brings back many memories and responding by being upset.

Note 1. Singing, humming, whistling, playing an instrument, making rhythms (clapping, tapping, etc.), dancing, creative movement and certain kinds of artwork (which are more expressive or creative, such as art therapy) are all kinds of expression.

F. EATING, DRINKING

+5 being helped to eat a meal with a great deal of sensitivity, eating with great sociability, or pleasure
example; helping a person to eat their meal in a sensitive manner when they have left half of their plate full of food due to visual neglect, eating a delicious meal with a great deal of social interaction.

+3 eating a meal with some pleasure or some empowering assistance, eating with obvious enjoyment in the company of
others
example: eating a biscuit while have a chat to another patient, enjoying a good meal with signs of pleasure alone.

+1 eating a small snack, sweet or drink with minimal enjoyment
example: drinking a cup of coffee alone, quietly eating a biscuit.

-1 eating or drinking in a slight state of ill-being
example: miserably sipping a cup of tea, alone.

-3 eating or drinking in a moderate state of ill-being
example: being excluded from the dining room because of eating habits, being fed by a member of staff at too fast a pace.

-5 eating or drinking in a severely state of ill-being
example: having food shovelled in by a member of staff who is talking to a colleague.

G. PARTICIPATING IN A GAME

+5 taking an active part in a game
example: having a game of dominoes and being helped to participate in a most sensitive manner.

+3 taking a moderate part in a game
example: playing a game of cards with some enjoyment.

+1 taking a minimal part in a game
example: playing along with a game of bingo but only taking a passive role.

-1 in a state of slight ill-being while participating in a game
example: being encouraged to take part in a game of cards despite displaying reluctance.

-3 in a state of moderate ill-being while taking part in a game
example: being teased for not playing a game correctly according to the rules or being laughed at while dropping a pack of cards onto the floor by accident.

-5 in a state of severe ill-being while participating in a game
example: being coerced to play a game and displaying some anxiety and tension as a result.

Note 1. Board games, card games, bingo, pool, snooker and darts are all examples of games, however, if the game has an intellectual emphasis (such as quiz games) then use category I.

I. USING INTELLECTUAL ABILITES

+5 taking a very active part in an intellectual activity
example: participating in a cognitive assessment with a great deal of enjoyment or an being intensely involved in the task; having feelings validated when concerns are expressed about performance of cognitive test; carrying out some cognitive rehabilitation for visual neglect with the occupational therapist with obvious pleasure and achievement; receiving a high degree of encouragement or praise for success or for effort.

+3 being moderately involved in an intellectual activity
example: with some signs of interest or enjoyment during a computer session with the occupational therapy assistant, spasmodic, but successful, involvement in a quiz game.

+1 being minimally involved in an intellectual activity
example: showing a minimal level of participation in a quiz game, occasionally taking part in a naming of objects game; minimal interest shown in a cognitive assessment.

-1 in a state of slight ill-being while participating in an intellectual activity
example: being allowed to make mistakes on the computer without assistance as to how to rectify their errors with an accompanying sense of frustration; being coerced into carrying out a cognitive assessment when the person is obviously tired or unwilling.

-3 in a state of moderate ill-being while participating in an intellectual activity
example: being under some demand to perform correctly in a quiz and clearly not enjoying it; carrying on a cognitive assessment with obvious signs of distress about their performance with no feedback from the psychologist

I. USING INTELLECTUAL ABILITES (contd.)

-5 in a state of severe ill-being while participating in an intellectual activity

example: being under high demand to perform correctly in a name game, and being told off when answers are 'incorrect" with signs of embarrassment, frustration and anger; being told off for not using a strategy while carrying out a computer session when they obviously are unclear about what is expected and are highly distressed.

Note 1. An activity is regarded as 'intellectual' if its prime focus is on the use of memory, reasoning and judgement, without physical activity. Typical examples would be cognitive rehabilitation, quizzes, general reminiscence exercises, naming of objects, etc.

J. PARTICIPATING IN ACTIVE EXERCISE WITH THE JOINTS WHILE STATIONARY

+5 Participating in moving joints with a great deal of achievement and /or support
example: a person is attempting to move an arm up and they are finding the exercise difficult but manage with very supportive and sensitive assistance.

+3 Participating in moving joints with some achievement and/or support
example: a person is working on leg movements in the wheelchair with the Physiotherapy Assistant and is feeling a sense of achievement at gaining some movement, or receiving a great deal of support from the member of staff.

+1 Participating in moving joints with some interest
example: being guided through a range of movements with limited encouragement.

-1 Moving joints in a slight state of ill-being
example: a person is reluctantly moving their arm around with a Physiotherapist and those feelings being ignored.

-3 Moving joints in a moderate state of ill-being
example: a person is feeling distressed by the exercise and is trying to make contact with the nurse who remains pre-occupied with active exercise.

-5 Moving joints in a severe state of ill-being
example: a Physiotherapist laughs at a person's attempts to move their arm.

Note 1: on occasions a session with a member of the multi-disciplinary team will be difficult for the person and at times her/she may experience pain but what it important when mapping this behaviour is the way it is handled by the member of staff.

K. COMING TOGETHER IN A MEETING

+5 receiving great therapeutic benefit during a meeting
example: A person is fully included in a progress or discharge planning meeting and his/her opinions are listened to and validated. Time is taken to explain the meeting and to consider the needs of the other person.

+3 receiving some benefit during a meeting
example: A person is involved most of the time in the meeting and staff are seen to listen to the opinions voiced by the person.

+1 receiving intermittent benefit during a meeting
example: a person is minimally involved in the meeting and at times staff talk as if the person is not there.

-1 receiving no benefit during a meeting

example: a person is not paid attention to during the meeting and the other participants ignore the person's potential input.

-3 receiving negative benefit from a meeting

example: a person is criticised or put down during a meeting to his/her obvious distress.

-5 receiving very negative benefit from a meeting
example: a person is ignored, and put down on many occasions throughout the meeting and is in a state of severe ill-being.

L. LOCOMOTION

+5 standing walking or moving in a wheelchair with another

example: being walked with a physiotherapist with a great deal of achievement or encouragement; standing in a pulpit whilst chatting animatedly with other patients or the physiotherapy assistant; being moved in a wheelchair and having a meaningful talk about feelings with a member of the nursing staff

+3 standing walking or moving in a wheelchair with someone or alone with great interest

example: being helped to walk or standing with a member of staff and engaged in an enjoyable conversation; taking care and being aware of the difficulties a person is experiencing in trying to walk

+1 standing walking or moving in a wheelchair without signs of ill being

example: engaged in a physiotherapy session with a minimal degree of achievement, satisfaction, participation or encouragement

-1 standing walking and moving in a wheelchair in a state of ill-being

example: moving in a wheelchair with a nurse and making comments which are not acknowledged by the member of staff, practising standing exercises in a moderate degree of discomfort without encouragement from the physiotherapist

L. LOCOMOTION (contd.)

-3 standing walking and moving in a wheelchair in a state of moderate ill being
example: standing walking or moving around in a withdrawn manner; attempting to make contact with a physiotherapy assistant whilst distressed in a pulpit

-5 standing walking and moving in a wheelchair in a state of severe ill being
example: being moved in a wheelchair crying and extremely anxious and receiving a 'put down' from the member of staff

Note 1: if a person has discomfort during locomotion this does not necessarily denote a negative experience value if the person feelings are validated and constantly monitored.

Note 2: **LW** is used when a person is walking, **LS** is used when a person is moving while standing up and **LWh** is used when a person is moving in a wheelchair.

M. ENGAGING WITH MEDIA

+5 displaying a very active interest in some form of media

example: joining with others in cheering when a football team scores a goal on the television, looking through a newspaper with a member of staff and talking with a great deal of enjoyment about its content.

+3 showing moderate interest in some form of the media.

example: reading a magazine together with a member of staff and commenting on an article for a few moments, talking about what happened on a television programme the night before.

+1 showing minimal interest in some form of the media

example: watching the television or reading a magazine in a solitary fashion, flicking through a magazine without a great deal of interest in the content.

-1 displaying a state of slight ill-being with some form of media

example: looking at a television programme and showing evident signs of boredom.

-3 displaying moderate ill-being in some form of media.

example: Struggling to read a newspaper with one hand and having obvious signs of difficulty.

-5 displaying severe ill-being in some form of media.

example: Watching a television film and being very distressed but not being able to remove oneself from the room in the wheelchair despite making every effort to do so, with an accompanying rise in anxiety.

Note 1. If the television is on in the day room and it is merely background noise and the person is not involved with this activity this is not coded as **M.**

N. SLEEPING, DOZING

+1 an appropriate level of sleep depending on the time of day (any sleeping after 7pm).

-1 sleeping for longer than an appropriate level of sleep for up to 30 minutes

-3 sleeping more than a total of thirty minutes after the period of appropriate sleep

-5 sleeping more than sixty minutes after the period of appropriate sleep

Note 1. The appropriate period of sleep is sometimes difficult to measure and this will often depend on the period of time since a person has experienced a stroke. As a rule of thumb, sleep which is under 1 hour is thought to be an appropriate level. However, if a person has had a particularly exerting morning in the physiotherapy or occupational therapy department then the sleeping period may be extended

0. INDEPENDENTLY ENGAGING IN SELF-CARE

+5 carrying out practical or physical self care with a great deal of achievement
example: doing up buttons very slowly and with some difficulty but feeling a great sense of achievement, washing hands for lunch independently with a great deal of deal of satisfaction.

+3 carrying out a practical or physical self care with a moderate level of achievement
example: combing hair or putting on lipstick with signs of satisfaction at the result.

+1 carrying out a practical or physical self care with a minimum level of achievement
example: carrying out a small routine task such as taking tablets, or powdering one's nose.

-1 carrying out a practical or physical self care with a signs of slight ill being
example: *putting on a cardigan and finding the exercise very challenging with signs of frustration and anxiety.*

-3 carrying out a practical or physical self care with a signs of moderate ill being
example: getting flustered and anxious while struggling to put on a coat, putting shoes on the wrong feet and being in evident discomfort.

-5 carrying out a practical or physical self care with a signs of moderate ill being
example: putting shoes on the wrong feet and being taunted by staff for the mistake.

Note 1. These are tasks are only recorded if a person carries them out independently if the person receives either a verbal or a physical prompt the behaviour is noted under **P**.

P. RECEIVING OR TAKING PART IN PRACTICAL PHYSICAL OR PERSONAL CARE

+5 receiving or taking part in practical, personal or physical care with a great deal of empathic encouragement or achievement

example: receiving gestural prompts from the OT when attempting to put on a waistcoat with a great deal of empathic encouragement and a sense of accomplishment at the completion of the task.

+3 receiving or taking part in practical, personal or physical care with a some empathic encouragement or achievement

example: wiping face with a serviette after lunch with the help of a member of staff in a gentle and pleasant way, being helped to do up buttons with an OT with active encouragement.

+1 receiving or taking part in practical, personal or physical care in a routine manner

example: being given a tablet from a member of staff with little interaction, having hair combed in a routine fashion.

-1 receiving or taking part in practical, personal or physical care in a slight state of ill being

example: having toenails clipped by a carer who does not show any signs of involvement, having face hurriedly wiped by an careworker; being sat up in a wheelchair by two nurses who talked amongst themselves.

-3 receiving or taking part in practical, personal or physical care in a slight state of ill being

example: being wheeled off to lunch without being told what is occurring, having a cardigan put on with reluctance by staff.

P. RECEIVING OR TAKING PART IN PRACTICAL PHYSICAL OR PERSONAL CARE (Contd.)

-5 receiving or taking part in practical, personal or physical care in a slight state of ill being

example: having buttons done up in a hurried uncaring way criticising the person for undoing them.

R. TAKING PART IN A RELIGIOUS ACTIVITY

+5 taking part in any religious activity in a very attentive way with a great deal of personal satisfaction or meaning
example: saying a little prayer before lunch to a small table with a great deal of pride and conviction, saying the Lord's prayer with a member of staff with great meaning and emotional involvement.

+3 taking part in any religious activity with moderate degree of attention or satisfaction
example: singing hymns with others in the dayroom with some pleasure.

+1 taking part in any religious activity with a minimal degree of attention or satisfaction
example: watching 'Songs of Praise' on Sunday, reciting part of the Lord's prayer alone.

-1 taking part in any religious activity with some signs of ill-being
example: reciting the Lord's prayer with some anxiety while sitting by bed.

-3 taking part in any religious activity with moderate signs of ill-being
example: being interrupted to take medication while trying to pray in bed with no sensitivity.

-5 taking part in any religious activity with severe signs of ill being
example: being told to stop praying and concentrate on going to sleep with a total disregard to religious feelings, being forced to sit through a religious service which is contrary to beliefs.

S. STIMULATION OF THE SENSES

+5 deriving great benefit from a direct engagement of the senses
example: smelling some aromas of natural oils with obvious pleasure, being told by a member of staff how beautiful a particular perfume smells and both deriving momentary pleasure

+3 deriving some benefit from a direct engagement of the senses
example: being stroked on the hand by a staff member in a sensitive and gentle manner, smelling a bouquet of roses with some pleasure, applying perfume and enjoying the aroma.

+1 deriving minimal benefit from a direct engagement of the senses
example: feeling the softness of a blanket resting on knees in the wheelchair.

-1 in a slight state of ill-being from a direct engagement of the senses
example: smelling the contents of the lunch with some distaste, smelling the air of the ward with a facial expression which communicates displeasure.

-3 in a moderate state of ill-being from a direct engagement of the senses
example: being clearly startled by someone turning up the television set, a staff member referring to an unpleasant smell near to the patient which causes some embarrassment.

-5 in a severe state of ill-being from a direct engagement of the senses
example: feeling sick and disgusted by a smell on the ward, feeling a great sense of shock when the fire alarm goes off on a routine exercise.

T. TRANSERRING FROM THE STANDING OR SITTING POSITION

+5 transferring from standing or sitting position with a great sense of achievement or encouragement
example: being helped from sitting to standing by the physiotherapist with a great deal of empathic encouragement and sense of achievement at being upright, assisting a person to transfer from the dining table chairs to a wheelchair with a great deal of sensitivity.

+3 transferring from standing or sitting position with a moderate sense of achievement or encouragement
example: being helped by a member of staff to move from the bed to the wheelchair in a pleasant fashion. Hoisting a person from the wheelchair to the bed and talking pleasantly about the transfer with moderate encouragement from staff member.

+1 transferring from standing or sitting position with a minimal sense of achievement or encouragement
example: transferring from the tilt table to the standing position in a routine physiotherapy session, being instructed verbally by a staff member how to move from the chair to the bed.

-1 transferring from standing or sitting position in a state of slight ill-being
example: moving from the chair to the standing position with mild accompanying anxiety without reassurance from staff.

-3 transferring from standing or sitting position in a moderate state of ill-being
example: being helped from the wheelchair to standing and talking anxiously about feelings of tension and receiving a critical comment from the member of staff.

T. TRANSERRING FROM THE STANDING OR SITTING POSITION (contd.)

-5 transferring from standing or sitting position in a severe state of ill-being

example: being ridiculed after falling back in the chair following an attempt to move to a standing position.

Note 1: individuals who have had a stroke often find difficulty in transferring from sitting to standing or vice versa. However, in this category of most concern is how this event was handled by the member of staff.

U. RECEIVING NO RESPONSE WHEN TRYING TO COMMUNICATE

-1 receiving no response when trying to communicate
example: trying to attract the attention of staff without success and receiving no response.

-3 receiving no response when trying to communicate after thirty minutes
example; saying "nurse" every time one passes by without receiving a response for some 30 minutes

-5 receiving no response when trying to communicate after 60 minutes

Note 1. Before coding this category is it important to code this category only when there is no accompanying activity or signs of distress. If distress is occurring then the correct category is D. The 'combination' and 'degeneration' rule apply to this category.

W. PERFORMING ALL TYPES OF WORK

+5 engaging in work activity with immense pleasure or being given a great deal of encouragement
example: participating in some activity such as cooking or dusting with great pleasure or being encouraged sensitively by a staff member to carry out a task which is complex, such as following a recipe, and deriving a great deal of satisfaction.

+3 engaging in work activity with pleasure or being given encouragement
example: helping a nurse to lay out the utensils for lunch and deriving pleasure from this tasks, receiving some encouragement from an Occupational Therapy Assistant in making a cup of tea.

+1 engaging in work activity with minimal pleasure
example: putting soil into plant pots on own with minimal pleasure, wiping tables after lunch

-1 engaging in work activity with signs of slight ill being
example: attempting to cut up vegetables with limited use of one hand and finding the exercise frustrating without any active encouragement from a staff member.

-3 engaging in work activity with signs of moderate ill being
example: trying to lay the table and being criticised for not putting the knives and forks in the right places.

-5 engaging in work activity with signs of severe ill being
example: trying to carry out a gardening task with a great deal of anxiety after being shouted at by a member of staff.

Note 1: All housework (hovering etc) moving furniture, wiping, etc.), cooking, watering plants, gardening, and fixing things should be included in this code.

Y. SELF-STIMULATION OF A REPETITIVE NATURE

+1 doing a repetitive, self-stimulating action without any signs of ill-being

example: tapping finger repeatedly, rocking gently in a chair with no facial expression, pacing back and forth, sucking cheeks in and out repetitively .

-1 doing a repetitive, self-stimulating action in a state of slight ill-being

example: wringing hands together in an anxious fashion, twisting button on jumper round and round in an agitated manner, picking at a sore with some discomfort.

-3 doing a repetitive, self-stimulating action in a state of moderate ill-being (or after thirty minutes of slight ill-being)

example: pacing around in an agitated way, rocking back and forth with a great level of anxiety and discomfort

-5 doing a repetitive, self-stimulating action in a state of moderate ill-being (or after sixty minutes slight ill-being)

example: rocking gently to self and being treated in an insensitive and harsh manner, harming self through hitting incapacitated arm.

Note 1 The 'combination' rule applies here

Z. BEHAVIOURS THAT FIT NO EXISTING CATEGORY

This category is used where the behaviour fit no existing category.

PERSONAL DETRACTION CODING

Interactions which include verbal 'put-downs' to physical abuse.

Personal Detractions represent the measurable arm of the malignant social psychology. Personal Detractions (PD's) can be identified and recorded in SCM. On the following pages instances of PD's have been grouped together and numbered according to their severity. PD's range from mild (List A), moderate (List B), severe (List C), through to very severe (List D).

Personal Detractions are noted down on the raw data sheets and are identified by a number for easy reference. However, it is useful to write down the exact wording of the PD for future reference. When mapping an individual it can also be useful to note down all the PD's within earshot so that they can be discussed on the ward at a later date.

LIST A - MILD DETRACTION

1. Minimal interference with independence
example: a careworker cuts up a person's food when the patient can do a little for himself.

2. Slight outpacing
example: a careworker says 'come along we haven't got all day' as a patient tries to stand up.

3. Unresponsiveness
example: a patient asks a question (with low emotional loading) of caregiver and it is ignored.

4. Speaking about the participant in his/her presence
example: two careworkers have a conversation about a patient and he is in earshot and one says "you know it's the sort of thing we take for granted but they can't do it can they".

5. Infantilisation
example: a careworker looks at a patient and says (with real affection) "There you are my little beauty"

6. Naming error
example: a new careworker gets confused over a person's name and makes an error.

7. Slight disempowerment
example: a careworker interrupts a therapy session without apologising to the patient first.

8. Slightly disparaging remarks or put-downs
example: a careworker says to a patient (not unkindly) "Come on you can do better than that".

9. Practical mistakes
example: a patient has asked for no milk in her coffee and the careworker does not pay attention to request and serves up a milky coffee.

10. Minor biographical error
example: a careworker says to a patient, "How long have you lived alone" (when the participant lives with her husband).

LIST B - MODERATE DETRACTION

11. Interfering with independence
example: a careworker takes a piece of fruit out of a patient's hand saying, "no, you won't be able to manage to peel that, I'll do it."'

12. Moderate Outpacing
example: a careworker puts a person's cardigan on and causes the patient to feel rushed and ill at ease.

13. Moderate Infantilisation
example: a careworker says to a participant "Gosh, you're a hungry boy today, now eat up your dinner, that's it".

14. Moderate demand to perform correctly
example: a careworker says to a person "stand up straight, alright (with severe tone).

15. Disregarding personal dignity
example: a careworker leaves a person naked in the hoist.

16. Disruption
example: the TV is turned off while a patient was watching.

17. Minor deception
example: a careworker tells a patient that his wife will be visiting soon knowing that she is not due for several hours.

18. Gross invalidation
example: a patient begins to talk about his feelings and the careworker says "There's lots of others worse off than you".

19. Ethnic or Cultural slur
example: a patient of Irish origin is referred to by a careworker, not unkindly as "them Irish always like a tipple".

20. Being verbally offended by another patient
example: one patient is saying she would like to go home and another patient says "yes, I wish you would go home too!"

21. Disparaging remarks - or put-downs from staff
example: a careworker says to a patient "none, of that messing around today, alright."

22. Non-malicious blaming
example: (to a patient who has soiled his sheets) "There you go again, We'll have no sheets left in our store soon".

LIST C - SEVERE DETRACTIONS

23. Mistreating patient as an object
example: a careworker says to another "will you stick a piece of food in as you go by"
24. Hurtful infantilisation
example: a careworker says, unkindly or sarcastically "Good girls don't behave like that!"
25. Endangering physical health
example: a careworker leaves a patient in the toilet with some risk, even though nothing amiss occurs.
26. Ethnic or cultural discounting
example: a patient is told "You're different from all the rest of us, we can't understand your language".
27. Mild but unnecessary use of force
example: a careworker insensitively tries to ensure a patient takes her tablets by pushing them into her mouth.
28. Using threats
example: a careworker says harshly to a patient "If you hurt one of our girls by messing around, I'll be so annoyed".
29. Speaking disparagingly about a patient in his/her presence
example: a careworker says about a patient in his presence "I'll ram it down her throat soon, she gets me in a state".
30. Major invalidation
example: a careworker says to a patient "why can't you speak without crying, we don't need all the tears".
31. Extremely disparaging remarks from staff
example: a careworker rudely and loudly says to a patient "You are making me so cross with all your fussing around".
32. Unkind exclusion
example: a patient is wheeled back to their bed because they are complaining about their situation with no explanation.
33. Blaming
example: a patient knocks over their coffee in the carpeted dayroom and is obviously distressed, and the careworker tells her off saying that she has ruined the carpet.

LIST D - VERY SEVERE DETRACTION

34. Gross deception
example: a careworker deceives a patient by saying "if you don't try harder your wife won't want you anymore".
35. Cruel taunts or ridicule by staff
example: a careworker points at a patient who believes that the lamp is a telephone and says "she's a fruit and nut case"
36. Intimidation
example: a patient who is constantly asking to go to the toilet is told "Unless you stop going to the toilet anymore, we'll have to get you catherised."
37. Being hit by another patient
example: a patient who is sitting in the dayroom is whacked in the back by another patient.
38. Hurtful impingement
example: a wheelchair is pushed quickly by a careworker who uses it as a racing car to the alarm of the patient.
39. Cruel banishment
example: a patient is refused entry to the dayroom because they shouted at a careworker in there the other day.
Note. Being separated from others out of concern for the physical welfare of the others is not considered 'cruel banishment' when it is done in a sensitive manner.
40. Physical restraint
example: a patient who has the ability to walk independently at least some of the time is forced into a chair from which he cannot get out.
41. Physical coercion
examples: a slow patient is hurriedly 'frog-marched' into the bus by two careworkers, against her will.
42. Being subject to actions verging on sexual assault
example: a patient suffers great fear or disgust because another patient commits an act of indecent exposure.
43. Being subject to actions verging on physical assault
example:a harassed careworker taps the hand or leg of a patient who is being 'difficult'.

44. Cruel objectification

example: two careworkers roughly lift a patient out of her wheelchair and dump her into an armchair, ignoring her protest and cries of pain.

45. Severe verbal abuse - on ethnic or cultural basis

example: a patient is told, in a harsh and insulting way "Get back to your own bloody country".

LIST E EXTREME DETRACTION

46. Physical assault

example: an angry careworker slaps the face of a patient, or bangs a patient's head against the doorframe.

Note. Only use this category for assaulted by staff. For assault by fellow patients, use PD no.37.

PROCESSING THE DATA FOR AN INDIVIDUAL PROFILE

This provides an overview of the types and frequency of behaviour, experience values and goal activity observed, including interaction with the staff/others for an individual during an observation period. Generally speaking, the frequency of personal detractions are noted but no numerical operations are performed on the PD's These methods will be illustrated using the example of Mr Bonder who was mapped for 100 minutes.

Behaviour Category Processing (page 52):
Here the focus is on the patterns of behaviour that were typical of the environment as a whole for the patient being observed.

Experience Value processing (page 54):
To examine and analyse the experience values for a participant is the focus in this type of processing. The Individual Experience Score provides details on how an individual participant fared on average during the observation period.

Goal Activity Processing (page 57):
The focus of this type of processing is to calculate the frequency with which goals are carried out and by whom. This enables us to look at the amount of therapy received by examining the amount of time spent in goal activity.

Interaction with others Processing (page 59):
This provides information on the BCC's where staff members and others become involved with the participants during the mapping period and the associated experience values.

METHODS USED FOR BEHAVIOUR CATEGORY PROCESSING

BEHAVIOUR CATEGORY PROCESSING

In behaviour category processing the information entered onto a raw data sheet (see page 85) is transferred onto a behaviour category code grid summary (see page 86). The methods used in processing are described below with an accompanying illustration of 100 minutes of mapping of Mr Bonder (see page 56).

Frequency

To obtain frequency information count up the number of times each behaviour category code has occurred during the mapping period and enter this number onto the BCC grid in the row headed 'frequency'. Then add up all the numbers in the 'frequency' row and enter the total. This gives the total number of five minute time frames recorded during the mapping. From the raw data sheet for Mr Bonder, it can be seen that **J** was observed to have occurred 10 times. The number 10 is entered onto the grid in the 'frequency' row under the letter **J**. This is done for each BCC and the total is added up and put into the total box at the end of the 'frequency' row to make 20 time frames.

Time

In the row headed 'time' multiply each BCC frequency score by 5 to give the amount of time spent in the behaviour category in minutes. Then add up the time for each BCC to give the total amount of time observed in minutes. From the example of Mr Bonder, **J** was seen to have occurred 10 times. To calculate this into minutes 10 is multiplied by 5 to obtain a score of 50 minutes. This is entered into the 'time' row under the letter **J**. This is done for each BCC and the total is added up and put into the total box at the end of the 'time' row to make a total of 100 minutes mapped.

Percentage of time spent

To calculate the time spent as a percentage of the total time mapped divide time spent for each BCC by the total time mapped and multiply by 100. From the example, to calculate the percentage of time that **J** was observed occurred divide the 'frequency' score of 10 by the total frequency score of 20 and multiply by 100 to give a % score:

$$10/20 \times 100 = 50\%$$

METHODS USED FOR EXPERIENCE VALUE PROCESSING

Experience Value for each BCC

To calculate Experience values for each BCC add up every EV mapped for each BCC to provide a total EV and divide by the frequency of each BCC to provide the mean experience value for each BCC. Information from the raw data sheet is entered on the experience value grid summary sheet (see page 86).

Total EV

To obtain the total EV for **J** from the example of Mr Bonder add up:

EV: (+ 3) + (+3)+ (+3) + (+3) +(+3) +
(+3) + (+3) + (+ 3) + (+3)+ (+3) = 30

Frequency

To obtain frequency information count up the number of time frames for each BCC which has an Experience Value during the mapping period and enter this on the EV summary grid in the row headed 'frequency'. Then add up all the numbers in the 'frequency' row and enter the total. From the example, the frequency figure for the BCC of **J** is 10.

Mean EV

To obtain the mean for **J** divide the total EV by the frequency which is: 30/3 = +3. Therefore, the mean EV for **J** is +3.

Overall Mean Experience Value

Overall Mean Experience Value indicates how a person fared overall during the mapping session taking into account not only the EV for each BCC but also the amount of time spent in each BCC. To calculate the Overall Mean EV for a person add up all of the EV means for each BCC, then add up all of the frequencies, then divide the total mean EV by the total frequency score.

From the example for Mr Bonder:

EV: $\underline{(+2) + (+30) + (+1) + (+3) + (+3) + (+4) + (+3) + (+6) = 52}$
Frequency: 20

The overall mean EV for Mr Bonder is therefore $52/20 = 2.6$.

Participants name:	Date:	Time Period:	Observer:
Mr Bonder	16.10.98	1245 - 14.25	M.E.

Place:
Therapy Unit OT cubicle) / Back to the ward / Therapy Unit

Time	1245	1250	1255	1300	1305	1310	1315	1320	1325	1330	1335	1340	1345	1350	1355	1400	1405	1410	1415	1420
BCC	Jota	Jota	Jota	Jota	Jota	Jota	Jota	Jota	Jota	Jota	B	B	M	O	O	Pnu	Tpt	Lwh pt	Tpt	Lspta
Goals	2	2	2 1	2	2	2 1	1 2	2	2	2							7		7	6 7
EV	+3	+3	+3	+3	+3	+3	+3	+3	+3	+3	+1	+1	+3	+3	+1	+3	+3	+3	+3	+1

Behaviour Category Grid summary

	A	B	C	D	E	F	G	I	J	K	Lw	Ls	Lw h	M	N	O	P	R	S	T	U	W	X	Y	Z	Total
Freq uency		2							10			1	1	1		2	1			2						20
Time (m)		10							50			5	5	5		10	5			10						100
% time spent		10							50			5	5	5		10	5			10						100

Experience Value Grid Summary

	A	B	C	D	E	F	G	I	J	K	Lw	Ls	L wh	M	N	O	P	R	S	T	U	W	X	Y	Z	Total
Total EV		+2							+30			+1	+3	+3		+4	+3			+6						52
freq uency		2							10			1	1	1		2	1			2						20
Mean EV		+1							+3			+1	+3	+3		+2	+3			+3						2.6

METHODS USED FOR GOAL ACTIVITY PROCESSING

GOAL ACTIVITY PROCESSING

In goal activity processing raw data is transferred onto a Goal Summary Sheet (see page 86). The methods used are described below using the example of Mr Bonder (see page 56).

Frequency

To obtain the 'frequency' score for goals look at the raw data sheet and add up the number of times frames in which each goal was attempted, then enter this number under the relevant goal number. This frequency figure is not used to calculate time because two goals may have been attempted in the same five minute period. For example, from the raw data sheet for Mr Bonder it can be seen that Goal 1 was attempted 3 times, Goal 2 was attempted 10 times etc.

Percentage of Goals Attempted

To obtain the number of goals attempted over the mapping period look at the goal box and add up the number of goals that have frequency data attached. This will provide a figure on the overall number of goals that were attempted rather than the frequency for individual goals. From the example, there are 4 occasions when the goal box has attached frequency data out of a possible 10. Therefore, to calculate the percentage of goals attempted during the mapping session divide 4 by 10 and multiply by 100 to give 40%.

Time

To calculate the time spent in Goal activity add up the number of time frames where goals occur. If two or more goals appear in the same time frame they are only counted as a single time frame. To calculate the amount of time spent from the example of Mr Bonder add up the number of time frames to give a total of 13 time frames and multiply by 5 to give 65 minutes.

Percentage of time spent

To calculate the % of time spent in goal activity divide the amount of time spent working on goals with the total amount of time mapped. For Mr Bonder, take the 65 minutes spent on goal activity and divide by the total time spent mapping of 100 minutes and multiply by 100 to provide a percentage. Therefore: 65/100 x 100 = 65%. Out of the total time mapped 65% was spent on goal activity.

Example of Goal Activity for Mr Bonder

Below is a list of goals noted for Mr Bonder. To find out when the goals were mapped refer to page 56.

Goals

1. To gain more control of movement in L /leg
2. To gain more activity in L/ upper limb
3. To become more independent on the ward (espec. A.M)
4. To improve mobility with 2 nurses on the ward
5. To use relaxation to overcome anxiety
6. Improve quality and confidence with 1 in mobility
7. Improve balance
8. OT assessment
9. Fine motor movement
10.Stretching activities

Goal Summary Sheet

Goal Box	Goal 1	Goal 2	Goal 3	Goal 4	Goal 5	Goal 6	Goal 7	Goal 8	Goal 9	Goal 10
Frequency	3	10				1	3			
Percentage of Goals attempted: 4/10 = 40%										
Time: 65 minutes										
% of time spent: $\frac{\text{time spent on goals (65)}}{\text{total time of mapped period (100)}}$ x100 = 65%										

METHODS USED IN STAFF INVOLVEMENT PROCESSING

INTERACTION WITH OTHERS PROCESSING

Information interaction with others is obtained by entering data from the raw data onto the summary of interactions grid, an example of which is provided on page 87. This method is illustrated by using the example of Mr Bonder.

Staff/other involvement in Behaviour Category Codes

To calculate the amount of time the patient interacted with others add the amount of time frames spent in activity with people and multiply by 5 to provide the number of minutes spent and enter onto the grid in the BCC (mins) column, as shown on page 55. Next to the number of minutes add the relevant BCC's. For example, from the raw data sheet Mr Bonder was working on BCC with the **ot** (occupational therapist) for 10 time frames. To obtain the total amount of time spent multiply the number of time frames by 5 to obtain a total of 50 minutes. This figure can be entered on the grid and in brackets by the side the BCC's can be added for further information. To provide the total amount of time spent with 'staff' involvement, add up the number of minutes spent with different professionals and divide by the total time spent during the mapping session. This exercise can be repeated for 'other' involvement, which refers to other people which interact with the patient such as visitors or other patients. From the example, Mr Bonder did not spend any time during the mapping session other than with professional staff. The total for this is added to give 75 minutes.

Percentage of time spent

To calculate the % of time spent with others, divide the amount of time spent with each member of staff by the total amount of time spent mapping and multiply by 100. To examine the time spent with the **ot** as a percentage of the total time, from the example of Mr Bonder, take the total amount of minutes from the BCC column for the **ot** of 50 minutes and divide by 100

(the total number of minutes mapped) and multiply by 100 to express this as a percentage: 50/10 x100= 50%. This 50% figure is entered in the row headed '% of time spent' in the column headed **ot**. This can be done for each staff member and for 'others'. The percentage of total of time spent interacting with staff during activities can be calculated by adding the percentage of all staff's involvement to give a total of 75% of the time. The rest of the time Mr Bonder was engaged in solitary activities.

Time spent in goal activity

To calculate the amount of time spent in goals look at the row headed 'goals' from the raw data sheet and count up the number of time frames each member of staff was involved with goals and multiply by five to provide the number in minutes. To calculate the % of time spent on goals for each staff member divide the number of minutes involved in goal activity by the total number time frames and multiply by 100. To calculate the % of time spent out of the mapping session on goals the percentages for each member of staff can be added to provide a total % figure. For example, to calculate the amount time spent in goals for the **ot** from the mapping session with Mr Bonder add up the number of time frames spent in goal activity which makes 10 time frames or 50 minutes. To calculate the % of time spent on goals using the **ot** example from Mr Bonder, divide the number of time frames noted for this professional with the total amount of time mapped which is: 50/100 x 100 = 50%. The total time staff spent on goals can be calculated by adding together all time frames staff were involved in goal activity to give a total of 65 minutes. To calculate this as % of total time spent out of the mapping session on goals the percentages for each member of staff can be added to provide a total of 65%.

Experience Value

To obtain a mean experience value add up the EV's for each time frame spent with other people from the raw data sheet to give the total EV. Then enter this figure onto the interactions EV summary grid. Frequency is then calculated by dividing the number of time frames in which each profession was involved with the participant by the total EV. A mean EV can be found for all members of staff and others by adding together all of the mean EV's and dividing by the total number of time frames where staff members were involved during the mapping session. To obtain the mean EV using the example of the **ot** from Mr Bonder add:

EV: (+3) + (+3) + (+3) +(+3) + (+3) +
(+3) +(+3) + (+3) + (+3) +(+3) = +30

Total time frames: 10

Mean EV: +30 / 10 = +3

which is the mean EV for the patient during the time spent with the **ot** as shown on page 55. A total EV for all members of staff can be calculated by adding together all of the means as follows to obtain a total EV of 43 and dividing by the total frequency which is 15 to give a weighted mean EV of 2.9.

	nu	pt	ot	st	sw	cp	dr	c	v	p	o	TOTAL
BCC (mins)	5(P)	20(T,L wh, Ls)	50 (J)									75mins
% total time	5	20	50									75%
Time in Goals		15	50									65mins
% total time on goals		15	50									65%

Interactions Experience value summary grid

	nu	pt	ot	st	sw	cp	dr	c	v	p	o	TOTAL
Total EV	+3	+10	+30									43
Freq	1	4	10									15
Mean EV	+3	+2.5	+3									2.9

INDIVIDUAL PROFILE

The individual profile provides a summary of all the processed information onto a single sheet (see page 88). To complete the profile:

1. Enter the overall mean EV at the top of the form. See page 83 for the EV rating scale which provides a rough guide as to the quality of the experience for the individual.

2. Choose the five most frequently occurring BCC's and enter them in order of priority with the time/percentage and EV beside each of them.

3. Carry out the same process for interaction with others. This will include the time and percentage spent in BCC and the time and percentage spent in goal activity. At the bottom of the box the totals can be entered. This provides information on the total amount of therapy time denoted by the goal activity and the total amount of time a person spends with staff members during the course of the mapping session.

4. Personal Detractions and notes are also entered onto the profile.

The individual profile is illustrated using the example of Mr Bonder on Page 64.

INDIVIDUAL PROFILE

Name: Mr Bonder **Date**: 16.10.98 **Time period**: 13.00-14.30

Overall mean Experience Value - 2.6

Main Behaviour Categories	**Time/Percentage**	**EV**
Joints (active exercise)	50 mins 50%	+3
Locomotion (walking standing)	10 mins 10%	+1
Own Care	10 mins 10%	+2
Transfers	10 mins 10%	+3
Socially involved, passive	10 mins 10%	+1

Main Staff Member	**BCC Time/percentage**	**Therapy Goals Time/percentage**	**EV Mean**
ot	50 mins 50% (J)	50 mins 50%	3.0
pt	15 mins 15% (T, LWh)	10 mins 10%	3.0
pt	5 mins 5% (Ls)	5 mins 5%	1.0
nu	5 mins 5% (P)		3.0
Others			
Total	75 mins 75%	65 mins 65%	2.9

Personal detractions

_____

Notes

_____

_____

_____

PROCESSING THE DATA FOR THE GROUP PROFILE

A collective profile of a group of patients provides an overview of their experience on the ward in terms of behaviour category codes, experience values, goal activity and interactions with others. The group profile is useful, in that, firstly, individual profiles can be compared with it to ascertain the position of each participant using the average or mean for the group as a benchmark. Secondly, successive group profiles over a period of time can be compared with each other to assess whether, for example, average experience values vary as a result of changes in the composition of the patients and/or staff and/or therapists on the ward, and whether training sessions or other initiative towards improving the quality of care on the ward are achieving their objective and, if so, to what extent and in which areas.

The processing of the data is similar to that of the individual profile except that the data needs to be collated and summarised. To demonstrate the methods used, the following example illustrates the experience of five participants mapped during the course of one week during the day from approximately 9.00-16.00 hrs, with one person is mapped each day. To simplify the process of summarising the data the information for each participant has already been entered from the raw data sheets onto the behaviour category grids, goal summary sheets and staff involvement summary forms. The methods employed to summarise the data are illustrated on the following pages and illustrated using behaviour category summary grids for five patients who have been named Mrs Jones, Mr Black, Mr Seymour, Mrs Pike and Mrs Best.

METHODS USED FOR BEHAVIOUR CATEGORY AND EXPERIENCE VALUE PROCESSING USING EXAMPLE PROVIDED FOR A GROUP OF INDIVIDUALS

BEHAVIOUR CATEGORY PROCESSING

In behaviour category processing information from the behaviour category grids of the participants can be assimilated and entered onto the collated behaviour category grid, an example of which is provided on page 90. This is illustrated by using the example of five participants whose summary grids are presented on pages 67-68.

Frequency

All the frequency information is added for each behaviour category code. For example, for A the frequency data is added for all five participants so that: 8+17+13+13=51 time frames. This calculation is done for each BCC.

Time

All of the times are worked out from the frequency data for each BCC by multiplying by 5. For example, for A the 51 time frames works out at 255 minutes in total. To arrive at the total amount of time mapped add up the time row to make a total time mapped of 1440 minutes.

Percentage of time spent

To calculate time divide the time for each BCC in the collated behaviour category code grid by the total time mapped and multiply by 100 for a percentage and round to the nearest figure. For example, for A: 255/1440 x 100 = 17.7% which is rounded to 18%. This is done for each BCC.

Behaviour Category Summary Grid for Mrs Jones

	A	B	C	D	E	F	G	I	J	K	Lw	Lwh	Ls	M	N	O	P	R	S	T	U	V	W	X	Y	Z	total
freq	13	10				9				3	6				8		2										51
time (m)	65	50				45				15	30				40		10										255
% time	25	20				18				6	12				16		4										101

Behaviour Category Summary Grid Summary for Mr Black

	A	B	C	D	E	F	G	I	J	K	Lw	Lwh	Ls	M	N	O	P	R	S	T	U	V	W	X	Y	Z	total
freq		20				6		9						6		2	5			2							50
time (m)		100				30		45						30		10	25			10							250
% time		40				12		18						12		4	10			4							100

Behaviour Category Summary Grid for Mr Seymour

	A	B	C	D	E	F	G	I	J	K	Lw	Lwh	Ls	M	N	O	P	R	S	T	U	V	W	X	Y	Z	total
freq	13	17				10					2	2		4	8		3			1							60
time (m)	65	85				50					10	10		20	40		15			5							300
% time	22	28				17					3	3		7	13		5			2							100

Behaviour Category Summary Grid for Mrs Pike

	A	B	C	D	E	F	G	I	J	K	Lw	Lwh	Ls	M	N	O	P	R	S	T	U	V	W	X	Y	Z	total
freq	8	19				8				6	7			7		7	8										70
time (m)	40	95				40				30	35			35		35	40										350
% time	11	27				11				9	10			10		10	11										99

Behaviour Category Summary Grid for Mrs Best

	A	B	C	D	E	F	G	I	J	K	Lw	Lwh	Ls	M	N	O	P	R	S	T	U	V	W	X	Y	Z	total
freq	17	11				9	7	4			3					3	3										57
time (m)	85	55				45	35	20			15					15	15										285
% time	30	19				16	12	7			5					5	5										99

Collated Behaviour Category Summary Grid

	A	B	C	D	E	F	G	I	J	K	Lw	Lwh	Ls	M	N	O	P	R	S	T	U	V	W	X	Y	Z	total
freq	51	77				42	7	13		9	18		2	17	16	12	21			3							288
time (m)	255	385				210	35	65		45	90		10	85	80	60	105			15							1440
% time	18	27				15	2	5		3	6		1	6	6	4	7			1							101

EXPERIENCE VALUE PROCESSING

Experience Value for each BCC

In EV processing information can be assimilated onto the collated EV grid, an example of which is shown on page 92. This is illustrated using the example of the five participants whose EV grids are presented on pages 70-71.

Mean EV

Add up the EV in each of BCC's and enter these figures onto the collated experience value grid on page 64 under total EV in the collated EV grid summary table. Next add up the frequency for each BCC for all participants, then divide the total EV by the total frequency for each BCC and round to the nearest first decimal point. For example, for A the total EV is (+3) + (2.2) + (+3) + (2.0) = 10.2. The total frequency is 4, so 4 divided by 10.2 is 2.55, which is rounded up to 2.6. This figure is then entered in the collated experience value grid on page 64 under mean EV for A.

Overall Mean Experience Value

Divide the total EV by the total frequency to give the overall mean EV. From the example take the total EV of 566.4 and divide by the total frequency of 288 to give an overall mean EV of 2.0.

Experience Value Grid Summary for Mrs Jones

	A	B	C	D	E	F	G	I	J	K	Lw	Lwh	Ls	M	N	O	P	R	S	T	U	V	W	X	Y	Z	total
total EV	39	16				15.3				9	18				8		6										111.3
freq	13	10				9				3	6				8		2										51
mean EV	3.0	1.6				1.7				3.0	3.0				1.0		3.0										2.2

Experience Value Grid Summary for Mr Black

	A	B	C	D	E	F	G	I	J	K	Lw	Lwh	Ls	M	N	O	P	R	S	T	U	V	W	X	Y	Z	total
total EV		20				9.6		28.8						6		6	15			6							91.4
freq		20				6		9						6		2	5			2							50
mean EV		1.0				1.6		3.2						1.0		3.0	3.0			3							1.8

Experience Value Grid Summary for Mr Seymour

	A	B	C	D	E	F	G	I	J	K	Lw	Lwh	Ls	M	N	O	P	R	S	T	U	V	W	X	Y	Z	total
total EV	28.6	17				18					6		6	4	8		5.1			1							93.7
freq	13	17				10					2		2	4	8		3			1							60
mean EV	2.2	1.0				1.8					3.0		3.0	1.0	1.0		1.7			1.0							1.6

Experience Value Grid Summary for Mrs Pike

	A	B	C	D	E	F	G	I	J	K	Lw	Lwh	Ls	M	N	O	P	R	S	T	U	V	W	X	Y	Z	total
total EV	24	22.8				8				13.8	23.1			21		21	16.8										150.5
freq	8	19				8				6	7			7		7	8										70
mean EV	3.0	1.2				1.0				2.3	3.3			3.0		3.0	2.1										2.2

Experience Value Grid Summary for Mrs Best

	A	B	C	D	E	F	G	I	J	K	Lw	Lwh	Ls	M	N	O	P	R	S	T	U	V	W	X	Y	Z	total
total EV	34	11				18	17.5	12			9					9	9										119.5
freq	17	11				9	7	4			3					3	3										57
mean EV	2	1				2	2.5	3			3					3	3										2.1

Collated Experience Value Grid Summary

	A	B	C	D	E	F	G	I	J	K	Lw	Lwh	Ls	M	N	O	P	R	S	T	U	V	W	X	Y	Z	total
total EV	125.6	86.8				68.9	17.5	40.8		22.8	56.1		6	31	16	36	51.9			7							566.4
freq	51	77				42	7	13		9	18		2	17	16	12	21			3							288
mean EV	2.6	1.1				1.6	2.5	3.1		2.5	3.1		3.0	1.8	1.0	3.0	2.5			2.3							2.0

METHODS USED FOR GOALS ACTIVITY PROCESSING USING EXAMPLE PROVIDED FOR A GROUP OF INDIVIDUALS

GOAL ACTIVITY PROCESSING

The information for the group has already been summarised onto the goal summary sheets for the five participants (see pages 73,74). This information is then entered onto the collated goal summary sheet on page 94.

Time

The time spent in goal activity or therapy is entered onto the collated goal summary sheet for each individual.

Percentage of time spent

The percentage of time spent on goals for each individual is entered onto the collated goal summary sheet. It is possible to summarise this information and provide a total figure of the average amount of time the individuals mapped spent in goal activity. To calculate the overall mean percentage for the group divide the total amount of minutes spent in goal activity (325 minutes) by the total number of minutes mapped (1440minutes) and multiply by 100 and round to the nearest round number, which in this example gives a percentage of 23%.

Goal summary sheet for group example

Goal Summary Sheet for Mr Jones

Goal Box	Goal 1	Goal 2	Goal 3	Goal 4	Goal 5	Goal 6	Goal 7	Goal 8	Goal 9	Goal 10
Freq uency		3	3		1	1				
Percentage of Goals attempted: 40%										
Time: 35mins										
% of time spent: time spent on goals / total time frames of mapped period x100 14%										

Goal Summary Sheet for Mr Black

Goal Box	Goal 1	Goal 2	Goal 3	Goal 4	Goal 5	Goal 6	Goal 7	Goal 8	Goal 9	Goal 10
Freq uency		5	5		4	3				
Percentage of Goals attempted: 40%										
Time: 70mins										
% of time spent: time spent on goals / total time frames of mapped period x100 28%										

Goal Summary Sheet for Mr Seymour

Goal Box	Goal 1	Goal 2	Goal 3	Goal 4	Goal 5	Goal 6	Goal 7	Goal 8	Goal 9	Goal 10
Freq uency	1		4		5					
Percentage of Goals attempted: 30%										
Time: 65mins										
% of time spent: time spent on goals / total time frames of mapped period x100 22%										

Goal Summary Sheet for Mrs Pike

Goal Box	Goal 1	Goal 2	Goal 3	Goal 4	Goal 5	Goal 6	Goal 7	Goal 8	Goal 9	Goal 10
Frequency			5		2			5		
Percentage of Goals attempted: 30%										
Time: 75mins										
% of time spent: time spent on goals / total time frames of mapped period x100 26%										

Goal Summary Sheet for Mrs Best

Goal Box	Goal 1	Goal 2	Goal 3	Goal 4	Goal 5	Goal 6	Goal 7	Goal 8	Goal 9	Goal 10
Frequency	1	1		3		2				
Percentage of Goals attempted: 40%										
Time: 75mins										
% of time spent: time spent on goals / total time frames of mapped period x100 26%										

Collated Goal Summary Sheet

Participants	Time spent on goals	% of time spent
Mr Jones	35 mins	14%
Mr Black	70 mins	28%
Mr Seymour	65 mins	22%
Mrs Pike	80 mins	23%
Mrs Best	75 mins	26%
Total	325 mins	23%

METHODS USED FOR INTERACTION WITH OTHERS PROCESSING USING EXAMPLE PROVIDED FOR A GROUP OF INDIVIDUALS

INTERACTION WITH OTHERS PROCESSING

The information for each participant can be summarised from each individual profile which is presented for all five participants on pages 78-79. Information is then entered onto the collated summary of interaction with others on page 80 (see page 95 for a empty form).

Interaction with others in Behaviour Category Codes Staff Involvement

To calculate the amount of time spent in interaction with staff add up the amount of minutes spent with each professional and/or other person involved. The total amount of time is entered onto the BCC column of the collated summary. The highest amount of minutes is presented first. For example, for the nursing staff the amount of time spent in BCC is added: 25mins for Mr Jones; 15 mins for Mr Black; 5 mins for Mr Seymour; 45 mins for Mrs Pike and 15 mins for Mrs Best. This makes a total of 105 mins. Alongside the amount of minutes make a note in brackets of the BCC's involved. The total of amount of staff involvement can be calculated by adding together all of the minutes noted down in the collated summary box which makes a total of 475 minutes and entered in the subtotal box. The same is done for all of the people, other than staff who have been involved during the course of mapping a person's experience. The total amount of time spent with others can be added to give a figure of 235 minutes and this is entered in the subtotal box for other involvement.

Total amount of interaction with others

To calculate the total amount of time spent with others add up the to totals for the staff and for others which is 475 + 235 = 710 minutes.

Percentage of time spent in interaction with others

To express the amount of time spent percentages can be worked out for each type of professional: for example, for the nurse to express 105 minutes as a percentage we need to divide it by the total amount of time spent being mapped which is 1440 and multiply by 100 which gives 7.3%, which is then rounded to 7%. This can be done for each type of professional. To calculate interaction with staff as a percentage of total time divide 475/1440 and to obtain a percentage score this amount is multiplied by 100 to give a figure of 33%, which tell us that, on average, the participants spent only one third of the total mapped time interacting with the various professionals on the ward.

To express the amount of time spent with every other type of person the participant has been involved with during the course of the mapping time as a percentage the same calculation is used, so divide the total amount of time spent with others who are not staff members (235mins) by the total time mapped (1440mins) and multiply by 100, which gives a figure of 16% in this example and which figure is then entered onto the sub-total for 'others' column.

To express the percentage of the total amount of time spent with others divide 705/1440 x 100 = 49%. This can be subtracted from 100% to provide the total amount of time a person spends without any interaction, which is 51% of the time for the individuals mapped. The group figures represent averages for the participants as a group and therefore provide a benchmark against which individual participants can be measured.

Experience Value

To calculate the mean experience in respect of each person that a participant has interacted with during the course of mapping add up each entry and experience value and divide by the total number of entries. For example, for the nurse add up (+4) + (+2) + (+1) + (+2.3) + (+3) = 12.3. Divide this by the number

of entries which is 5 which makes 2.5. This can be done for each person and a mean EV can be calculated for all of the staff involvement of 2.7. The same procedure is followed for involvement with others. To obtain the EV for the person in general terms with all interactions with staff and others a mean can be obtained to give a general indication of the well-being of the person. To do this the EV means are added together and divided by the number of others involved. From this example the overall mean EV for involvement with others is 2.7.

Time spent in goal activity by professional

To calculate the amount of time spent in goal activity with a professional the amount of time spent with therapy goals is taken from the summary of staff involvement for each person and added together to express a total. For example, for the nursing profession add up 10mins + 10mins + 5mins to make a total of 25mins. Information for all of the professionals can be added to provide a subtotal of minutes spent during mapping time in goal directed activity. Other individuals, such as carers, also become involved in goals and when this takes place the same procedure is followed.

Percentage of time spent in goal activity by professional

To calculate the percentage of time spent in goal activity divide the amount of minutes spent by each professional and divide this by the total amount of time mapped and multiply by 100. For the example of the nurse the total amount of 25 mins is divided by 1440 and multiplied by 100 which means that 2% of the total time mapped was spent in goal activity with a nurse.

The total amount of time spent in goal activity can also be expressed as a percentage. To calculate this divide the total amount of 325/1440 x 100 to give a figure of 23 %.

Interaction with others individual profiles for each participant

Summary of interaction for Mr Jones

Staff/ other	BCC Time/percentage	Therapy Goals Time/percentage	EV Mean
pt	30 (Lw) 12%	30 12%	3
nu	25 (P, A) 10%		4
sw	15 (K) 6%	5 2%	3
pta	5 (A) 2%		3
subtotal	**75 30%**		
Other			
v	30 (A) 12%		1
dom	15 (A) 6%		3
subtotal	**45 18%**		
TOTAL	120 48%	35 14%	2.8

Summary of interaction for Mr Black

Staff / other	BCC Time/percentage	Therapy Goals Time/percentage	EV Mean
cpa	45 (T) 18%	40 16%	3.2
ot	25 (P) 10%	20 8%	3
nu	15 (T, F) 6%	10 4%	2
subtotal	**85 34%**		**2.7**
Other			
p	25 (F) 10%		2.2
subtotal	**25 10%**		2.2
TOTAL	110 44%	70 28%	2.5

Summary of interaction for Mr Seymour

Staff/ other	BCC Time/percentage	Therapy Goals Time/percentage	EV Mean
cp	30 (A) 10%	30 11%	
pt	20 (Ls, Lw) 6%	20 6%	3
ota	15 (P) 5%	15 5%	1.7
nu	5 (T)		1
subtotal	**70 21%**		
Other			
v	25 (A) 8%		2.8
p	20 (F,A) 6%		2.3
subtotal	**45 14%**		2.2
TOTAL	115 38%	65 22%	2.3

Summary of interaction for Mrs Pike

Staff/ other	BCC Time/percentage	Therapy Goals Time/percentage	EV Mean
nu	45 (K,A) 15%	10 3%	2.3
ot	45 (P) 11%	35 10%	2.1
pt	35 (Lw) 10%	35 10%	3.3
subtotal	**125 36%**		
Other			
p	25 (F,A) 7%		3
v	20 (A) 6%		3
subtotal	45 13%		
TOTAL	165 47%	80 23%	2.2

Summary of interaction for Mrs Best

Staff/ other	BCC Time/percentage	Therapy Goals Time/percentage	EV Mean
st	35 (A) 12%	35 12%	3
ota	35 (G) 12%		3
ot	20 (I) 7%	20 7%	3
pt	15 (Lw) 5%	15 5%	3
nu	15 (P) 5%	5 2%	3
subtotal	120 41%		
Other			
v	50 (A) 18%		2.5
p	25 (F) 9%		2.2
TOTAL	195 68%	75 26%	2.8

Collated summary of interaction

Staff/ other	BCC Time/percentage		Therapy Goals Time/percentage		EV Mean
nu	105(A,T,P)	7%	25	2%	2.5
pt	100 (Lw,Ls)	7%	75	5%	2.7
ot	90 (P,I)	6%	100	7%	2.3
ota	50 (G,P)	3%	15	1%	1.7
cpa	45 (I)	3%	40	3%	3.2
st	35 (A)	2%	35	2%	3.2
cp	30 (A)	2%	30	2%	
sw	15 (K)	1%	5	>1%	3
pta	5 (A)	> 1%			3
subtotal	475	33%	325	23%	2.7
Other					
v	125 (A)	9%			2.3
p	95 (A,F)	7%			2.4
dom	15 (A)	1%			3
subtotal	235	16%			2.6
TOTAL	710	49%	325	23%	2.7

GROUP PROFILE

The group profile sheet provides an opportunity to enter all of the collated information onto a single sheet. The process is the same as for the individual profile. The group profile for the example provided is set out on page 82 (see page 96 for a blank form). The EV rating scale on page 83 can be used as a rough guide as to the quality of experience for the individual.

GROUP PROFILE

Name: Rehabilitation ward
Date:10.01.99-15.01.99
Time period: 9.00-16.00 hrs

Overall Group Experience Value Mean - 2.0

Main Behaviour Categories	**Time/Percentage**	**EV**
Socially involved but passively	385 mins 27%	1.1
Articulation	255 mins 18%	2.5
Eating and drinking	210 mins 15%	1.6
Personal Care	105 mins 7%	2.5
Locomotion Walking	90 mins 6%	3.1

Group profile of interaction

Staff/ other	**BCC Time/percentage**	**Therapy Goals Time/percentage**	**EV Mean**
nu	105(A,T,P) 7%	25 2%	2.5
pt	100 (Lw,Ls) 7%	75 5%	2.7
ot	90 (P,I) 6%	100 7%	2.3
ota	50 (G,P) 3%	15 1%	1.7
cpa	45 (I) 3%	40 3%	3.2
st	35 (A) 2%	35 2%	3.2
cp	30 (A) 2%	30 2%	
sw	15 (K) 1%	5 >1%	3
pta	5 (A) > 1%		3
subtotal	475 33%	325 23%	2.7
Other			
v	125 (A) 9%		2.3
p	95 (A,F) 7%		2.4
dom	15 (A) 1%		3
subtotal	235 16%		2.6
TOTAL	710 49%	325 23%	2.7

PERSONAL DETRACTIONS_____

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EXPERIENCE VALUE RATING SCALE FOR INDIVIDUAL AND GROUP PROFILE

3.0 and above	excellent
2.2-2.9	very good
1.5-2.2	good
0.8-1.5	fair, room for improvement
0.7 and below	much improvement needed

The above table provides a useful starting points with which to evaluate the quality of experience for the individual patient.

SCM FORMS

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BEHAVIOUR CATEGORY CODE GRID SUMMARY/ EXPERIENCE VALUE GRID SUMMARY/ GOAL SUMMARY GRID	Page 86
SUMMARY OF INTERACTIONS GRID	Page 87
INDIVIDUAL PROFILE`	Page 88
BEHAVIOUR CATEGORY CODE SUMMARY GRIDS	Page 89
BEHAVIOUR CATEGORY CODE SUMMARY GRIDS AND COLLATED BCC GRID	Page 90
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EXPERIENCE VALUE SUMMARY GRID AND COLLATED GRID	Page 92
GOAL SUMMARY SHEETS	Page 93
COLLATED GOAL SUMMARY SHEET	Page 94
COLLATED SUMMARY OF INTERACTION GRID	Page 95
GROUP PROFILE	Page 96

Raw Data Sheet

Participants name:	Date:	Time Period:	Observer:
Place: Rehabilitation Unit			

Time												
BCC												
Goals												
EV												

Notes

Personal detractions

Goals

1.
2.
3.
4.
5.
6.
7.
8.
9.
10.

Behaviour Category Code Summary Grid

	A	B	C	D	E	F	G	I	J	K	Lw	Lwh	Ls	M	N	O	P	R	S	T	U	V	W	X	Y	Z	total
freq																											
time (m)																											
% time																											

Experience Value Grid Summary

	A	B	C	D	E	F	G	I	J	K	Lw	Lwh	Ls	M	N	O	P	R	S	T	U	V	W	X	Y	Z	total
total EV																											
freq																											
mean EV																											

Goal Summary Sheet

	Goal 1	Goal 2	Goal 3	Goal 4	Goal 5	Goal 6	Goal 7	Goal 8	Goal 9	Goal 10
Frequency										

Number of Goals attempted:

Time:

% of time spent: $\frac{\text{no of time frames of goals}}{\text{total time frames of mapped period}}$ x100

Summary of Interactions Grid

	staff involvement							'other' involvement				
	nu	pt	ot	st	sw	cp	dr	c	v	p	o	TOTAL
BCC (mins)												
% total time												
Time in Goals												
% total time on goals												

INDIVIDUAL PROFILE

Name: **Date:** **Time period:**

Overall Individual Experience Value mean -

Main Behaviour Categories	Time/Percentage	EV

Main Staff Member	BCC Time/percentage	Therapy Goals Time/percentage	EV Mean
subtotal			
Other			
subtotal			
Total			

PERSONAL DETRACTIONS

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Behaviour Category Summary Grid

	A	B	C	D	E	F	G	I	J	K	Lw	Lwh	Ls	M	N	O	P	R	S	T	U	V	W	X	Y	Z	total
freq																											
time (m)																											
% time																											

Behaviour Category Summary Grid

	A	B	C	D	E	F	G	I	J	K	Lw	Lwh	Ls	M	N	O	P	R	S	T	U	V	W	X	Y	Z	total
freq																											
time (m)																											
% time																											

Behaviour Category Summary Grid

	A	B	C	D	E	F	G	I	J	K	Lw	Lwh	Ls	M	N	O	P	R	S	T	U	V	W	X	Y	Z	total
freq																											
time (m)																											
% time																											

Behaviour Category Summary Grid

	A	B	C	D	E	F	G	I	J	K	Lw	Lwh	Ls	M	N	O	P	R	S	T	U	V	W	X	Y	Z	total
freq																											
time (m)																											
% time																											

Behaviour Category Summary Grid

	A	B	C	D	E	F	G	I	J	K	Lw	Lwh	Ls	M	N	O	P	R	S	T	U	V	W	X	Y	Z	total
freq																											
time (m)																											
% time																											

Collated Behaviour Category Summary Grid

	A	B	C	D	E	F	G	I	J	K	Lw	Lwh	Ls	M	N	O	P	R	S	T	U	V	W	X	Y	Z	total
freq																											
time (m)																											
% time																											

Experience Value Grid Summary

	A	B	C	D	E	F	G	I	J	K	Lw	Lwh	Ls	M	N	O	P	R	S	T	U	V	W	X	Y	Z	total
total EV																											
freq																											
mean EV																											

Experience Value Grid Summary

	A	B	C	D	E	F	G	I	J	K	Lw	Lwh	Ls	M	N	O	P	R	S	T	U	V	W	X	Y	Z	total
total EV																											
freq																											
mean EV																											

Experience Value Grid Summary

	A	B	C	D	E	F	G	I	J	K	Lw	Lwh	Ls	M	N	O	P	R	S	T	U	V	W	X	Y	Z	total
total EV																											
freq																											
mean EV																											

Experience Value Grid Summary

	A	B	C	D	E	F	G	I	J	K	Lw	Lwh	Ls	M	N	O	P	R	S	T	U	V	W	X	Y	Z	total
total EV																											
freq																											
mean EV																											

Experience Value Grid Summary

	A	B	C	D	E	F	G	I	J	K	Lw	Lwh	Ls	M	N	O	P	R	S	T	U	V	W	X	Y	Z	total
total EV																											
freq																											
mean EV																											

Collated Experience Value Grid Summary

	A	B	C	D	E	F	G	I	J	K	Lw	Lwh	Ls	M	N	O	P	R	S	T	U	V	W	X	Y	Z	total
total EV																											
freq																											
mean EV																											

Goal Summary Sheet

Goal Box	Goal 1	Goal 2	Goal 3	Goal 4	Goal 5	Goal 6	Goal 7	Goal 8	Goal 9	Goal 10
Frequency										
Percentage of Goals attempted:										
Time:										
% of time spent: time spent on goals / total time frames of mapped period x100										

Goal Summary Sheet

Goal Box	Goal 1	Goal 2	Goal 3	Goal 4	Goal 5	Goal 6	Goal 7	Goal 8	Goal 9	Goal 10
Frequency										
Percentage of Goals attempted:										
Time:										
% of time spent: time spent on goals / total time frames of mapped period x100										

Goal Summary Sheet

Goal Box	Goal 1	Goal 2	Goal 3	Goal 4	Goal 5	Goal 6	Goal 7	Goal 8	Goal 9	Goal 10
Frequency										
Percentage of Goals attempted:										
Time:										
% of time spent: time spent on goals / total time frames of mapped period x100										

Goal Summary Sheet

Goal Box	Goal 1	Goal 2	Goal 3	Goal 4	Goal 5	Goal 6	Goal 7	Goal 8	Goal 9	Goal 10
Frequency										
Percentage of Goals attempted:										
Time:										
% of time spent: time spent on goals / total time frames of mapped period x100										

Goal Summary Sheet

Goal Box	Goal 1	Goal 2	Goal 3	Goal 4	Goal 5	Goal 6	Goal 7	Goal 8	Goal 9	Goal 10
Frequency										
Percentage of Goals attempted:										
Time:										
% of time spent: time spent on goals / total time frames of mapped period x100										

Collated Goal Summary Sheet

Participants	Time spent on goals	% of time spent
Total		

Collated summary of interaction grid

Staff/ other	BCC Time/percentage	Therapy Goals Time/percentage	EV Mean
subtotal			
Other			
subtotal			
TOTAL			

GROUP PROFILE

Name: **Date:** **Time period:**

Overall group Experience Value mean -

Main Behaviour Categories	Time/Percentage	EV

Main Staff Member	BCC Time/percentage	Therapy Goals Time/percentage	EV Mean
subtotal			
Other			
subtotal			
Total			

PERSONAL DETRACTIONS

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Appendix 4

Section C - A case study evaluation of mobile phones as a new external memory aid

Consent form

I consent to take part in this project..... Yes/No

I have read the information sheet about the project
and have had time to think about it..... Yes/No

I have had the study explained to me and have been
given adequate time to ask any questions concerning it .....Yes/No

I have been told that I can withdraw my consent at any
stage without giving reason and without any effect on
my treatment.....Yes/No

Signed.....
Print Name.....
Date:.....

Appendix 4 (contd)

INFORMATION SHEET

We are conducting a project to test the effectiveness of using a mobile telephone system for people who have memory difficulties and need help to organise their day to day routine. The mobile phone will be provided free of charge, this will include the rental charge and the calls will be received free of charge. However, there will be a charge should any call be made. Participants in the project will be asked to take part for 12 weeks and when the trial is over you will have the option to continue to use the service if it has been of benefit.

The first stage of the study will measure how often people forget things that they intend to do, such as taking their medication or checking a things-to-do list. This stage involves filling in a diary each day with information on what was forgotten. From this diary a list will be made of the things you might like to be reminded about. This list is then entered onto the computer. At the arranged time the computer will send the reminder. When the message is received the person's mobile phone will ring, and when it is answered the message will be heard. The mobile telephone is easy to use and messages can be received throughout Jersey.

Appendix 5

Section C: A case study evaluation of mobile phones as a new external memory aid

Example of Diary for GH

DATE	TABLETS	TEETH am	TEETH pm	SHOPPING	SHOWER	DEODORANT	PACKED LUNCH
MONDAY 9TH	✓	✓	✓	✗	✗	✓	✗
TUESDAY 10TH	✗	✓	✓	✗	✓	✓	✗
WEDNESDAY 11TH	✓	✓	✓	✓	✓	✗	✓
THURSDAY 12TH	✓	✓	✗	✓	✓	✗	✓
FRIDAY 13TH	✗	✓	✗	✓	✓	✓	✗
SATURDAY 14TH	✗	✓	✗	✓	✓	✓	
SUNDAY 15TH	✓	✗	✓	✓	✓	✗	