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IMPAIRED SELF-AWARENESS FOLLOWING ACQUIRED BRAIN INJURY

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Thesis submitted in partial fulfilment for the degree of Ph.D., Oxford Brookes University

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ABSTRACT

Impaired self-awareness of everyday task ability following acquired brain injury (ABI) presents a serious obstacle to progress in rehabilitation. However, there is a lack of consensus about the optimal method of determining awareness level, how best to increase awareness, and even with regard to the very nature of impaired awareness.

Awareness level is usually ascertained by comparing self/third party ratings of task performance. A behavioural measure of task performance would circumvent some of the concerns regarding the validity of methods relying solely on verbal report.

Three main research questions were identified:

- 1. Is it possible to measure self-awareness of activity limitation and impairment?
- 2. Is it possible to increase self-awareness of activity limitation and impairment?
- 3. What is the nature of impaired awareness of activity limitation and impairment?

To address these questions, the research programme had four phases:

In phase 1, a cross-sectional design was used, incorporating behavioural observation and quantitative questionnaires, to develop a task battery that could be used as a behavioural measure of self-awareness. The resultant task battery consisted of six everyday tasks.

In phase 2, a group comparison design was used to establish the sensitivity of the task battery to impaired self-awareness. Questionnaires were administered to obtain a quantitative measure of awareness – including social skills - in the acquired brain injury (ABI) participants. Eighteen ABI participants, identified as having impaired

self-awareness, were compared with three comparison groups. The task battery was found to be sensitive to impaired awareness of everyday task ability.

In phase 3, a single-case, experimental design methodology was attempted in two ABI participants to determine the effectiveness of interventions designed to increase awareness. Four ABI participants were followed up longitudinally, as natural history case studies, to ascertain changes in awareness over time, and critical incidents contributing to change. The intervention programmes were not found to be effective.

Phase 4 included two qualitative studies to explore the nature of impaired awareness. In study 1, interview scripts from thirty-six clinicians were analysed thematically. In study 2, interview data from phase 3 were re-examined to explore 'objects' of awareness and factors contributing to fluctuations in awareness. Both phase 4 studies indicated that manifestations of impaired self-awareness were very varied in terms of 'objects' of awareness, severity of the awareness impairment, and the number of factors contributing.

Impaired self-awareness is complex in nature, necessitating repeated measures, of verbal report and behaviour within various functional domains, to determine awareness level. Detailed examination of further single cases could help identify profiles of impaired self-awareness for which specific interventions and explanatory models could be developed. It is argued that intervention to address impaired self-awareness within the social skills domain should be prioritised.

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CHAPTER ONE

THE NATURE OF SELF-AWARENESS IN RELATION TO ACQUIRED BRAIN INJURY

The purpose of the introductory chapter is to highlight what is known and, as yet, not known in relation to impaired awareness following acquired brain injury. The chapter starts with an attempt to define the terms in current usage relating to acquired brain injury, impaired awareness and 'objects' of awareness. Pertinent models are highlighted. This is followed by a brief overview of the history of research relating to impaired awareness phenomena, consideration of the potential underlying mechanisms and other factors associated with the aetiology of impaired awareness. Methods used to determine awareness level are then discussed, and intervention studies reviewed. The concluding section of the chapter summarises the statement of the problem. The search strategy is given in Appendix 1.

1.1 TERMINOLOGY AND INITIAL DEFINITIONS

The thesis will focus on impaired self-awareness in those with 'acquired brain injury'. 'Acquired brain injury is the term used to describe damage to the brain resulting from a discrete incident (or incidents) of traumatic injury, illness or infection during the lifetime of the individual. It excludes congenital or birth injuries, and is not used to describe degenerative conditions such as Alzheimer's disease, Huntington's disease, Parkinson's disease or multiple sclerosis. It includes traumatic brain injuries arising from, for example, assaults or road traffic accidents, strokes, tumours, cerebral infections and anoxia. Anoxic damage may occur secondary to other conditions such a diabetic coma, cardiac arrest or drug overdose' (British Psychological Society, 2005).

The two largest subgroups within non-progressive acquired brain injury (ABI) are stroke and traumatic brain injury. The focus of this thesis will be impaired self-awareness following acquired brain injury, that is, participants with acquired brain injury arising from stroke, trauma, anoxia or brain damage resulting from brain surgery. It is apparent

from the literature that researchers have sometimes chosen to look at stroke patients in isolation, or those with traumatic brain injury in isolation. However, it is usual to combine acquired brain injury participants when conducting research on self-awareness, since impaired self-awareness has been found in acquired brain injury – regardless of the cause of the brain lesion. (See Finsett and Andersson, 2000; Coetzer and du Toit, 2002; and Fischer et al., 2004.)

Within this thesis, impaired self-awareness is defined as a lack of agreement between an individual's subjective description of their abilities or performance of everyday tasks and objective measurement of the individual's abilities or performance of everyday tasks. Hereafter, the term 'impaired awareness' will be used to describe impaired awareness relating to the 'self'.

Malia (1997) asserts that the clinicians usually use the term 'poor insight' when referring to impaired awareness following acquired brain injury. However, Malia argues that the concept of 'poor insight' is not well understood by clinicians. Within the context of psychiatry, Simpson (1984) found that clinicians (psychiatrists, physicians and nurses) had vastly varying views concerning the symptoms encompassed by the term 'confusion'. Confusion, as with impaired awareness, has been defined in varying ways in medical texts and dictionaries. Within the context of acquired brain injury, no attempt has yet been made to clarify what clinicians understand by the term impaired awareness (or insight). Further research to make clear what clinicians do understand by the term would be helpful, particularly in view of the strong consensus that impaired awareness presents a formidable obstacle to rehabilitation (Deaton, 1986; McGlynn and Schacter, 1989; Fleming et al., 1996; Sherer et al., 1998a; Prigatano, 1999).

It is apparent in studies published into the late 1980s that 'denial' was used as a generic term (for example, Deaton, 1986) to describe organically based or psychologically motivated impaired awareness. Within this context, organically based awareness impairment is presumed to arise from physical damage to the brain. Psychologically motivated impaired awareness is deemed to arise from defensive reaction to brain damage. From the 1990s, published studies began to use interchangeably the terms 'unawareness phenomena', 'impaired awareness' or 'impaired self-awareness' as the preferred generic terms, often distinguishing between organically based and

psychologically motivated unawareness. The term denial is still used, but to denote psychologically motivated unawareness, i.e. a defence mechanism employed to protect the 'self' from a perceived threat (Prigatano and Klonoff, 1996; Toglia and Kirk, 2000). Denial is usually considered to be an unconscious mechanism (Prigatano and Klonoff, 1996).

As mentioned in the introductory paragraph to this chapter, objects of awareness vary. Individuals might have impaired awareness of, for example, a disease. Within the conduct of this thesis, the terms 'impairment', 'activity limitation' or 'participation restriction' will be used to describe awareness of different levels of function. These terms are taken from the International Classification of Functioning, Disability and Health (World Health Organisation, 2001).

Impairments are defined as 'problems in body function or structure such as significant deviation or loss' (ICFDH, 2001, p.10). Impairments resulting from an acquired brain injury can be physical, sensory or cognitive. Physical impairments might include: hemiparesis or weakness on one side of the body; homonymous hemianopia (loss of one half of the visual field). Cognitive impairments could include slowed information processing speed, or difficulties with working memory. Impairments vary in severity. For example, an individual might have hemiplegia or paralysis of the left arm or leg, or mild hemiparesis – causing slight clumsiness in gait when walking, or when attempting to carry out fine motor activities such as handwriting.

'Activity limitation' replaces the term 'disability', and 'participation restriction' replaces the term 'handicap', used in an earlier version of the classification. Activity limitation might result from an impairment: perhaps an individual is unable to drive because of visual field loss. Impairments do not necessarily result in activity limitation. Mild hemiparesis could lead to activity limitation for an athlete, but the same degree of hemiparesis may not result in activity limitation for a more sedentary individual.

Impairments and activity limitations can result in participation restriction or limitation to previously valued roles. Inability to drive after ABI would result in participation restriction for someone who drives a taxi for a living, whereas an inability to drive would make a negligible difference to someone who has little need or desire to drive.

The key focus of this thesis is impaired awareness of 'activity limitation', i.e. 'difficulties an individual may have executing activities' (ICFDH, 2001, p.10) and, to a lesser extent impaired awareness of 'participation restriction' and 'impairment' respectively. A large proportion of early research in the area of impaired awareness singled out 'physical impairment' as the primary focus but impaired awareness of physical impairment usually resolves quickly. Evidence of this will be presented below. The literature reviewed in this thesis used the term disability rather than 'activity limitation' and, therefore, the term 'disability' will be used in preference to 'activity limitation' in reviewing published literature. However, the more up-to-date term 'activity limitation' will be used where relevant in referring to research conducted within the context of the thesis.

1.2 CLINICAL RELEVANCE OF IMPAIRED AWARENESS

Clinically, impaired awareness of impairments, activity limitations and participation restrictions results in varying degrees of difficulty to engage patients in assessment and treatment. At an extreme end of the spectrum, some patients are observed to refuse to take part in therapy, stating that – and apparently believing that – there is nothing wrong with them. Other patients are observed to 'go through the motions' of rehabilitation but in a passive way, as though they do not understand why they are there. The resultant lack of commitment from the patient results in little progress, despite the strenuous efforts of the clinical team. This lack of engagement is problematic, not simply because it causes frustration to therapists, but because it is very wasteful of health service resources. In addition, failure to acknowledge impairments and activity limitations can result in behaviour that might put the individual or others at risk. One example is driving. Individuals could have physical, cognitive and/or visual impairments that would render them unsafe to drive. If they do not realise that they have impairments, which render them unsafe, they might opt to drive, if given an opportunity to do so. Commonly, patients are observed to be differentially aware of their impairments. Patients can be aware that they have difficulty in moving their legs, and therefore with walking, but remain unaware of obvious cognitive and social skills deficits throughout the rehabilitation process.

1.3 AWARENESS MODELS

The concept of impaired awareness is complex, and a number of models have been suggested to explain the underlying mechanisms that might account for it. Various neuroanatomical models of awareness (for instance, Prigatano, 1991; Damasio, 1999), and neuropsychological models (for instance, McGlynn and Schacter, 1989; Goldberg and Barr, 1991) have been proposed. Typically, proponents of neuroanatomical models seek to explain impaired awareness in terms of damage to particular areas of the brain assumed to be the neural substrates of awareness. Those espousing neuropsychological models tend to stress that impaired awareness arises from interference in information processing.

Later in this chapter, evidence will be presented to suggest that a number of factors such as emotional status and pre-morbid copying style, might contribute to impaired awareness.

1.3.1 <u>Hierarchical Model of Awareness (Crosson et al., 1989)</u>

The hierarchical model of awareness (Crosson et al., 1989) has been widely cited in relation to impaired awareness research over the past decade. Rather than focusing on speculative underlying mechanisms, the model provides a means of classifying awareness impairments and suggests that recovery of awareness follows a hierarchical pattern. Many researchers have observed that people are differentially aware of impaired functioning within different domains. Tyerman (1987) found that individuals with acquired brain injury became aware of impairment and disability within the physical domain before other domains. The Crosson model allows classification of people who might, for instance, have anticipatory awareness of physical impairments and emergent awareness of memory impairment. The comparatively concrete nature of the model provides a basis from which to generate assessment and intervention strategies that might have clinical utility and could be investigated by both qualitative and quantitative research methods.

The authors conceptualised awareness hierarchically with 'intellectual awareness' at the base of an awareness 'pyramid' (Figure 1.1). Intellectual awareness implied that an

individual understands, to some extent, that a given functional domain is impaired. A person with a more advanced level of intellectual awareness would understand the implications of his or her deficits. Knowledge, then, forms the basis of intellectual awareness, and the authors hypothesised that people with certain severe cognitive deficits in the areas of memory or abstract reasoning, might never be able to acquire the highest level of intellectual awareness. In keeping with the model, such people would not be able to initiate compensatory strategies, and so external strategies would be needed to enable them to function at their optimal level. The enduring nature of impaired awareness is supported by other investigators. Krefting (1989) used the term 'blind spots' (p.73) to refer to impaired awareness that she found amongst some people with traumatic brain injury. She observed that blind spots constituted an enduring way of experiencing life even twenty years after brain injury.

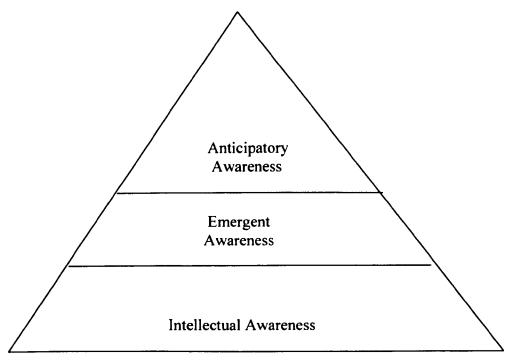


Figure 1.1 Hierarchical Model of Awareness. (From Crosson, B.C., Barco, P.P., Velozo, C.A., Bolesta, M.M., Werts, D. & Brobeck, T. [1989])

Crosson et al. (1989) contended that intellectual awareness was a prerequisite for more advanced levels of awareness. The intermediary level was termed 'emergent awareness'. This entails 'on-line' awareness, i.e. the ability to notice when a problem is occurring at the time it is occurring. The highest level of awareness was termed 'anticipatory awareness'. An individual with anticipatory awareness is able to anticipate that a problem

will result from a particular deficit. At the highest level of anticipatory awareness a patient would be able to initiate a strategy to compensate for the deficit; an obvious example would be compensating for poor memory by frequent checking of a diary. The authors claimed that intellectual awareness and emergent awareness were prerequisites for the highest level of awareness. An individual with an anticipatory awareness deficit would, logically, not initiate a strategy in advance of a situation that is likely to cause them difficulty, but might be able to initiate a strategy once they noticed that a problem was occurring.

Crosson et al. (1989) also allowed for the contributory effect of denial, viewing it as a potential 'additional barrier' to the acquisition of intellectual awareness and reducing the motivation to use compensatory strategies.

There is constant reference to this model in the neuropsychological literature in relation to acquired brain injury and Alzheimer's disease. It has provided a common semantic basis within the literature with which to compare studies. Nevertheless, to date, there is only one published study where an attempt was made to test the hierarchical nature of awareness (Abreu et al., 2001), with no evidence found to support such a hierarchy. There were notable shortcomings in the methodology used by Abreu et al. (2001) and in the way that the different levels of the hierarchy were conceptualised. Participants were asked to carry out four tasks. Before each task the participants were asked to predict how well they would do at the task (intellectual awareness), and, afterwards, how well they thought they did on the task – after task performance (to establish emergent awareness). The question to address anticipatory awareness was: 'How do you think your performance on the task might affect your ability to live independently, work, and have fun?' Potential problems in interpreting the results, considering these questions in relation to the specific tasks used, are considered below; the degree to which the chosen questions reflect the three levels of awareness is considered here. It is felt that the question addressing anticipatory awareness is the most problematic. It seems too vague to be addressing anticipatory awareness in the way described by Crosson et al. (1989). Indeed, it could be argued that the intellectual awareness question is really addressing anticipatory awareness. Regarding emergent awareness, some individuals might notice a problem while it is occurring but not bring it to mind after the task. So, asking the question after task performance might not be sensitive to emergent awareness.

In 1999, Meredith and Rassa made an attempt to align the levels of the hierarchy with the Stages of Grieving model (denial, anger, bargaining, depression and acceptance, Kublar-Ross, 1981). The study involved retrospective scrutiny of the medical notes of those with traumatic brain injury. They looked for the terms 'intellectual', 'emergent' and 'anticipatory awareness', and how often these coincided at similar time-points with terms from the Stages of Grieving model. Unfortunately, too little detail was given in this short report to gauge adequately the reliability of the findings. While 'clinicians' carried out the review of the notes, it is unclear whether clinicians were checking their own notes, which could have contaminated the results.

Sohlberg et al. (1998) showed that two people, some time after brain injury, could be trained to employ compensatory strategies and thereby improve performance within personally relevant domains (decrease in interrupting behaviour and increase in independence in grocery shopping), without any corresponding increase in awareness. Although very few participants were involved, the study provided preliminary evidence that some people with brain injury can use compensatory strategies without having intellectual awareness of their deficits. This finding cannot be explained within the framework of the model as it stands currently. The authors of the hierarchical model argue that recourse to compensatory strategies to overcome an impairment is a consequence of anticipatory awareness – the highest level of awareness. As mentioned above, the authors assert that intellectual and emergent awareness are a sine qua non for anticipatory awareness.

In view of the widespread use of this model, it would be worthwhile to ascertain whether people with ABI could, reliably, be placed within the hierarchy, on the basis of clinicians' descriptions of their awareness level.

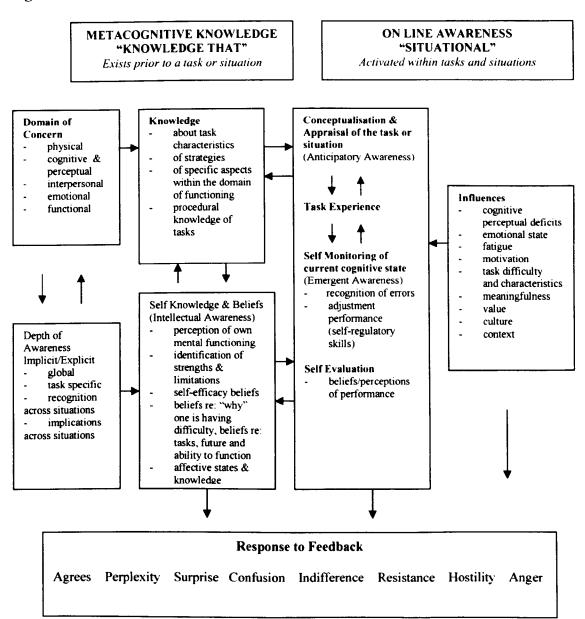
1.3.2 Model of Awareness (Toglia and Kirk, 2000)

Toglia and Kirk (2000) adopted the notions of intellectual, emergent and anticipatory awareness in developing their model of awareness (Figure 1.2). They presented a more complex model that was based on the cognitive psychological concept of metacognition. Metacognition entails the conscious knowledge of cognitive processes, as well as the capacity to monitor one's behaviour during task performance. Toglia and Kirk contend

that the relationship between metacognition and awareness is dynamic, rather than hierarchical.

The model allows for pre-morbid knowledge and belief relating to the self and differentiates this from knowledge and awareness activated during task performance. The authors contend that on-line awareness varies according to the particular task being performed and contextual factors. It is proposed that pre-morbid knowledge interacts with on-line awareness during tasks. The model includes many potential contextual factors, such as an individual's familiarity with the particular task being performed, and fatigue. It also allows for an individual's response to feedback about task performance.

Figure 1.2 Model of Awareness (Toglia and Kirk, 2000)



1.4 IMPAIRED AWARENESS OF SOCIAL SKILLS DEFICITS

The Toglia and Kirk model refers specifically to the interpersonal domain. This domain of function is highlighted here, since it has been observed that family members find changes in social skills to be the most distressing consequence of brain injury (Boake, 1991). A large body of literature supports the contention that social skills deficits are common after acquired brain injury, particularly traumatic brain injury (McDonald et al., 1999). Impairments in different aspects of communication and social skills may be apparent but there is evidence that disturbance in the 'pragmatics' or social rules governing inter-personal communication is most corrosive to the maintenance and formation of close relationships (Marsh, 1999). As such, these impairments can *result directly* in profound participation restrictions. Oddy et al. (1985) followed up 34 participants two and seven years after severe closed head injury. They found that social isolation was a major problem at two years and there was no improvement in this domain at seven years. This was especially true for individuals who were able to work.

In-depth examination of social skills deficits and awareness of these is outside the scope of this thesis. Nevertheless, due to the importance of impaired awareness of the social skills domain, attempts were made to identify a suitable measure of awareness of social skills. Such a measure could be used if individuals lacking awareness of social skills impairments were referred to later stages of the research programme. The Crosson model allows for intact awareness of a specific domain and impaired awareness of other domains within one individual. Within the International Classification of Function, social skills can be conceptualised as critical for adequate performance at the participation level of function, and often required within the activity level of function.

Skills theory, developed within the context of experimental psychology, underpins the notion of social skills training. Social skills are considered to be skills that can be taught in the same way as other skills, including motor skills (Trower et al., 1978). The clinical application of this theory came about through the development of social skills programmes in the 1970s, such as those propounded by Trower et al. (1978). The main elements of social skills training entail practice, feedback, modelling and guidance.

1.5 HISTORICAL CONTEXT

The concept of impaired awareness is not new and further historical context is given below to help clarify the background to current issues and terminology.

Bisiach and Germiniani (1991) cite Seneca, who, nearly 2000 years ago, gave a clear description of a woman who appeared to lack awareness of cortical blindness. However, the first recorded research efforts, which began in the late 19th century and continued through to the late 20th century, focused primarily on unawareness of 'impairments', notably unawareness of hemiplegia, hemianopia and cortical blindness. Munk in 1881 (cited by Blakemore, 1977) noted that experimental lesions in specific areas of dogs' brains brought about what he described as 'mind-blindness'. That is, the dogs still appeared to see but no longer responded to objects with attraction or aversion as they had previously. Cases of unawareness of cortical blindness were described by von Monakow and Anton in 1885 and 1889 respectively (cited by Prigatano and Schacter, 1991). Sigmund Freud introduced the term 'agnosia' in 1891 (cited by Bauer and Rubens, 1985), which replaced the term 'mind-blindness'.

Meanwhile, Charcot investigated unawareness of neurological deficit from a different perspective. He sought to ascertain the differences between organic and hysterical paralysis. In 1884, Charcot (cited by Ellenberger, 1974) demonstrated through hypnosis that individuals could be psychologically manipulated to produce what appeared to be neurological impairments. Freud spent several months in 1885 and 1886 with Charcot, observing individuals with hysterical paralysis (Ellenberger, 1974). It seems likely that Freud's description of psychological defence mechanisms (1900, cited by Prigatano and Schacter, 1991) was influenced by his observations of Charcot's patients.

In 1914, Babinski (cited by Prigantano and Schacter, 1991) used the term 'anosognosia' to denote unawareness of left hemiplegia following brain lesion. Although Babinkski introduced the term, Pick is credited as the first to describe the phenomenon of impaired awareness of hemiplegia (Gerstmann, 1942). These advancements in knowledge, mostly brought about by neurologists, emphasised the likely organic basis of impaired awareness of physical impairment, that is, unawareness arising directly from brain lesion. It

remained a matter of debate, however, whether unawareness of neurological impairment could arise from a focal lesion, or from a more generalised confusional state (Prigatano and Schacter, 1991).

Nathanson et al. (1952) found differential awareness for different concurrent diseases. Several participants asserted correctly that they had heart disease, hypertension, arthritis or were incontinent of urine but they denied hemiplegia. This would appear to indicate that participants' lack of awareness could not be accounted for by confusion.

Nevertheless, Charcot's work remained influential and gave credence to the idea that impaired awareness of genuine neurological impairments might be psychologically motivated. In 1955, Weinstein and Kahn wrote an influential monograph on the subject that emphasised the probable impact of emotional factors in the genesis of impaired awareness. This resulted in impaired awareness of 'impairments' being viewed within the context of defence mechanisms and thus belonging to the province of psychiatry, rather than neurology. This remained the case until the beginning of the 1980s. Renewed interest in the possible organic cause of impaired awareness phenomena arose from new knowledge about brain function that, in turn, spurred on neurologists to uncover the nature of human consciousness. More detailed knowledge about the functions of various parts of the brain also gave neuropsychology a firm underpinning. The field of neuropsychology began to gain ground, while behavioural psychology, with its emphasis on outward behaviour and the manipulation of behaviour lost the pre-eminent position it had held for a large part of the 20th century.

The nature of impaired awareness remains unclear and empirical investigation of the phenomena is still in the early stages (Sherer et al., 1998b). Studies are difficult to compare because of the varying measures employed and different aspects of awareness being measured. Many published studies (McGlynn and Schacter, 1989; Fleming et al., 1996) refer to the fact that impaired awareness phenomena are common following acquired brain injury, but, at the same time, prevalence estimates are absent. Prevalence rates remain difficult to ascertain since some studies include participants with acquired brain injury; others focus only on individuals who have experienced a stroke (sometimes excluding those who have had previous strokes, sometimes not); or only those who have sustained a traumatic brain injury. In addition, studies have included individuals at vastly

differing time points post lesion. Typically, studies addressing impaired awareness of physical impairment included participants within a few weeks of their stroke.

1.6 CLARIFYING THE CONCEPT

Early research addressing impaired awareness was largely conducted by neurologists who focused on impaired awareness of physical impairments within weeks of a stroke. Whilst explicit verbal denial of hemiplegia is a very striking manifestation of impaired self-awareness, it usually resolves within days or weeks, whereas more subtle forms of unawareness can persist for years (Prigatano, 1999). These more subtle aspects of impaired awareness include impaired awareness of disability, rather than impairment. Impaired awareness of a disability is potentially a much less discrete entity than impaired awareness of a specific impairment. For example, impaired awareness of paralysis in a left arm (impairment) is more straight-forward than impaired awareness of an inability to get dressed (disability). The motor impairment in the left arm may contribute to difficulty in getting dressed. However, even relatively simple activities, such as getting dressed, entail perceptual and cognitive abilities, as well as physical abilities. Perceptual and cognitive impairments may be contributing to the difficulty with dressing.

Current knowledge regarding impaired awareness phenomena has been aided by quantitative research methods targeted at impaired awareness of the impairment level of function. Specific motor and visual impairments are relatively easy to quantify. However, qualitative methodologies can make valid contributions to knowledge in this area. Indeed, the use of qualitative approaches may be more pertinent than quantitative approaches in determining awareness of less visible impairments such as cognitive impairments, and disabilities arising from a combination of physical and cognitive impairments. In ascertaining an individual's degree of self-awareness, it is not possible to access directly their thought processes. Such mental states can be inferred only by what individuals say and do (Underwood, 1999). These inferences often come through the potentially biased filter of third parties. For this reason, it is particularly pertinent to consider qualitative studies that shed light on factors affecting the research interview responses of individuals with acquired brain injury and their families. Two detailed studies illustrate these points, Krefting (1989) and Clare (2002).

Krefting (1989) carried out a detailed ethnographic study. Over a period of several months she spent many hours with 21 brain injured adults and their families. The methodology involved in-depth interviews, participant observation and examination of informal documents. The author does not say whether informants had an opportunity to review interview transcripts or how informants' reaction to her could have influenced the results. Nevertheless, the study aids our understanding of the way manifestations of impaired awareness can preserve a sense of self. Krefting found that all the participants experienced a 'loss of personhood' (p.75). She describes how participants, stripped of previously valued roles, had no means of establishing a new self-identity. This led some participants to resort to facades or concealment, to preserve a sense of identity or an appearance of being normal. Clare (2002) similarly describes the efforts of individuals with Alzheimer's disease to hide it from friends and even family members. The sample size was relatively small (12 individuals with Alzheimer's disease and their spouses). However, Clare makes the pertinent observation that recourse to concealment could be viewed as an indication of impaired awareness but can be construed more accurately as 'a natural preference for retaining one's status and dignity' (p.305). Krefting (1989) asserted that it took many months before the disabled persons revealed the more distressing aspects of their lives. This is important, as it implies that these individuals were more aware than they were prepared to acknowledge.

Taking a different methodological approach, Tyerman and Humphrey (1984) used a semantic differential scale to elicit ratings of Past (pre-morbid) Self, Present Self, Future Self, a Typical Person and a Typical Head Injured Person from individuals who had sustained a severe traumatic brain injury. The 25 participants were an average of seven months post lesion. Even though Past Self was viewed more positively than a Typical Person, the majority of participants confidently presumed a return to Past Self within one year. The authors concluded that denial accounted for this lack of realism in relation to future expectations. Deaton (1986) later proposed that this might not be denial, so much as an indication that changing self-concept is a slow and arduous process. Ellis-Hill and Horn (2000) similarly observed that self-concept was slow to change amongst stroke patients.

Denial has often been reported in the context of injury or disease not involving injury to the brain (Gasquoine, 1992). The nature of the denial in other disease contexts would appear to differ in a number of ways. Levine and Zigler (1975) compared people with stroke, cancer and heart disease. Although all groups exhibited denial, a larger proportion of stroke patients fell into this category. These authors hypothesised that it was the damage to the brain that made stroke more threatening to the sense of self, hence why stroke patients were more likely to resort to denial.

The above research indicates that qualitative research with oral reports of individuals with impaired awareness could be affected by their efforts to preserve or adjust their sense of self and their identity.

1.6.1 The relationship between consciousness and awareness

Logically, the capacity for self-awareness would appear to be closely related to being 'conscious'. Having touched upon the difficulties in defining awareness or selfawareness, similar difficulties are apparent in relation to consciousness. Consciousness has been defined in different ways (Chalmers, 1996). This is perhaps not surprising, because there are still major unanswered questions in relation to what consciousness is. Chalmers (1996) sheds light on salient issues associated with consciousness. He speaks of the easy and difficult questions of consciousness and how scientists often skirt around the issue of what consciousness really is, by concentrating on more obvious and measurable aspects of it. In a similar vein, in a dictionary of neuropsychology (Beaumont et al., 1999), no attempt was made to define consciousness; indeed, the 'consciousness section' neglected even to mention that there are still unanswered questions relating to the nature of consciousness. The author (Underwood, 1999) described how it is possible to ascertain that someone is conscious; that focused attention can be considered the highest degree of consciousness; and that sleepiness and drugs can be observed to affect a person's level of consciousness or arousal level. Clearly, in order to be self-aware, a certain degree of arousal can be deemed a prerequisite. Notwithstanding this, the relationship between consciousness and self-awareness would seem to be more pertinently related to what Chalmers described as 'the difficult questions of consciousness'. For example, why there is a subjective quality to experience, what Nagel (1974) described as 'something it feels like' to be a cognitive agent. Chalmers (1996, p.4) expands on this: 'Conscious experiences range from vivid color sensations to experiences of the faintest background aromas; from hard-edged pains to the elusive experience of thoughts on the tip of one's

tongue; from mundane sounds and smells to the encompassing grandeur of musical experience; from the triviality of a nagging itch to the weight of a deep existential angst; from the specificity of the taste of peppermint to the generality of one's experience of selfhood.'

Functional MRI scanning studies have begun to demonstrate which parts of the brain become activated when participants are required to reflect on the self. Johnson et al. (2002) demonstrated that the anterior medial prefrontal cortex and posterior cingulate were the only areas consistently to become activated on fMRI in all 11 healthy participants when they were asked to reflect on their abilities. Such studies are important in furthering knowledge but many more fMRI studies, including those with individuals with impaired awareness, will be required to elucidate the difficult questions of consciousness. The brains of individuals with acquired brain injury are frequently scanned. To date, studies have shown that impaired self-awareness can occur, no matter which part of the brain has been lesioned. Although the anterior medial prefrontal cortex and posterior cingulate are activated when healthy people reflect on self, it does not necessarily follow that these areas of the brain are damaged in cases of impaired selfawareness. Participants in the Johnson study were asked to self-reflect in a quite superficial way. It could be argued that individuals with acquired brain damage are faced with a much more challenging degree of self reflection that may activate a larger number and, possibly, very different areas of the brain.

Halligan and Oakley (2000) presented an original model of consciousness, appealing for its simplicity and the fact that it is not overly encumbered by a particular theoretical perspective that might limit its applicability. Halligan and Oakley contend that consciousness has two levels. The authors claimed that Level 1 accounts for conscious processing and Level 2 accounts for sub-conscious processing. Unconscious or sub-conscious processing of information is not a new idea but the originality of their thesis lies in the fact that they claim much of our decision-making happens at Level 2, and that Level 2 also determines what is allowed to filter through to Level 1. They claim that individuals are consciously aware of the content of Level 1 only. Disorders of self-awareness could be understood within this framework. It could be that the sophisticated conveying of information from Level 2 to Level 1 is disturbed to varying degrees in different people after brain injury. This might account for apparent fluctuations in brain

injured individuals' awareness over time, including an apparent mismatch between patients' verbalisations and behaviour, e.g. an individual stating, in answer to a question, that they are aware of an impairment but then attempting to behave as though they had no such impairment. Similarly, confabulation could arise when Level 2 has simply failed to provide Level 1 with any information in relation to what the patient is being questioned about. The patient is thereby left trying to give a coherent account without the assistance of material normally presented to Level 1 by Level 2. If consciousness arises from the integration of cognitive and affective states, it is possible that an affective mechanism may veto material passed to Level 1, in order to protect the integrity of the individual. Healthy individuals have been shown to resort readily to confabulation when 'tricked' in the context of psychological research (Nesbitt and Wilson, 1977). See Zeman (2001) for a detailed review of issues pertinent to the nature of consciousness.

1.7 **AETIOLOGY**

1.7.1 Anatomical basis of impaired awareness

Much early research in the area of impaired awareness focused on awareness of impairments such as hemiplegia. Models were generated on the underlying assumption that particular areas of the brain were responsible for awareness, and attempts were made to identify the specific areas. It has been shown repeatedly that the frontal lobes are implicated, particularly in impaired awareness of social skills deficits (McGlynn and Schacter, 1989; Prigatano, 1991). Despite the fMRI results reported by Johnson et al. (2002) above, Sherer et al.'s (1998b) assertion that there is little evidence to support the neuroanatomical basis of impaired awareness, remains true.

Claims that people with right-sided brain lesions were considerably more likely to exhibit impaired awareness than persons with left-sided brain lesions now seem unreliable. Many patients with left-sided brain damage were excluded from studies because of the presence of severe aphasia. Bisiach et al. (1986), in a study of impaired awareness of hemiplegia, justified their decision to exclude all people with left-sided brain damage resulting from a stroke, on the grounds that people with aphasia do not demonstrate impaired awareness 'behaviourally'. No evidence was cited to support this claim, though identifying impaired

awareness in people with severe expressive and probable receptive speech deficits is clearly problematic. This is especially the case where measurement methods have relied heavily on the oral report of research participants. Prigatano and Altman (1990) divided 64 research participants with acquired brain injury into three groups: those who overrated performance (compared with significant other ratings), underrated performance, and those whose ratings differed little from significant other ratings. Contrary to their original hypothesis, the individuals who were categorised as having impaired awareness (the overrating group) did not show a greater incidence of right-sided brain lesions.

Hibbard et al. (1992) examined awareness of physical, cognitive (memory and abstract thinking), and language deficits, and awareness of mood in left and right brain damaged stroke participants. Hibbard et al. found that left – and right – sided stroke participants were most likely (and equally likely) to be accurate in assessing their physical abilities and least likely to be accurate in judging their abstraction abilities. Half the participants in each group were accurate in assessing their mood and memory function. Neither time since stroke, nor severity of brain lesion, were significantly correlated with awareness of physical abilities, cognitive abilities, or mood. Participants in this study were, on average, one year post-stroke. This study provided further evidence that impaired awareness phenomena clearly do not occur only in the case of right-sided brain damage.

Fleming et al. (1998) applied a cluster analysis to 55 individuals with brain injury. They identified three clusters but found no evidence that site or severity of brain lesion (ascertained by Glasgow Coma Scale and length of Post-Traumatic Amnesia [PTA]) were associated significantly with either accurate or impaired awareness. Similarly, Port et al. (2002) found that neither PTA duration nor time since lesion were found to be predictive of level of awareness of deficits, in any of the domains measured. Port et al. (2002) assumed awareness impairment when there was a discrepancy between participant and significant other rating on a questionnaire. The two versions of the questionnaire were sent out by post, however, and it is possible that brain injured participants and significant others might have conferred. This could have contaminated the results. Nevertheless, the findings support the view that there is currently no evidence to support the prescriptive selection of participants for studies addressing impaired awareness phenomena on the basis of lesion location, severity of trauma, or even length of time post lesion.

Prigatano and Klonoff (1996), who had many years of experience working as neuropsychologists with brain-injured patients, independently categorised patients as having a primarily organically based or primarily psychologically motivated lack of awareness. They agreed on only 33 of 56 patients (58.9%). Despite this, for these 33, patients they attempted to identify the characteristics, compiling two scales typifying an organically based or psychologically motivated awareness impairment respectively. Subsequently, Prigatano and Klonoff independently rated the 33 patients again, stating whether each of 10 characteristics were present or not, and also assigned a severity rating (0-10, 0 indicating that the behaviour was not present). Reviewing these two sets of characteristics, it is striking that persons with psychologically motivated lack of awareness tend to react in a defensive, 'touchy' manner when questioned or challenged about their abilities. Conversely, those with an organically based lack of awareness are more open and appear 'perplexed' rather than defensive when challenged about their abilities. Results indicated that the two investigators differed in the severity of ratings. The study would have been enhanced by inclusion of comparison group data, but constituted a first attempt to distinguish between organically based and psychologically motivated lack of awareness. The study also illustrated the difficulty in teasing out the relative contribution of organic and psychologically motivated lack of awareness, and the likely close interplay of these two factors in most cases.

1.7.2 Contribution of cognitive deficits to impaired awareness

Although it is counter-intuitive, impaired awareness appears not to be reliably associated with the degree of cognitive impairment. Contrary to their predictions, Prigatano and Altman, (1990) found that a group of individuals with acquired brain injury, who overrated their ability, did not have worse performance scores on visuo-spatial problem solving, visuo-spatial memory, abstract reasoning or basic speed of information processing than the control group. Though cognitive deficits could conspire to delay patients' acquisition of full awareness of their deficits, there is little evidence that they cause them. Clare (2004) gives a clear description of ways in which cognitive deficits might contribute to, or exacerbate, impaired awareness within the context of Alzheimer's disease. For example, memory deficits may affect awareness as a result of forgetting or failing to register new information. Executive deficits may include difficulties in making

comparisons, judgements and decisions. This may impact upon awareness by limiting an individual's ability to make comparisons between past and present abilities.

1.7.3 Mood

Of many reported mood changes following stroke, anxiety and depression have been identified as the most common (Carota et al, 2002). High levels of anxiety and depression have also been found after traumatic brain injury (Fordyce et al., 1983; Wallace and Bogner, 2000). Moreover, there is evidence that anxiety and depression do not diminish over time in those who have sustained a traumatic brain injury. At seven year follow up, Brooks et al. (1987) reported anxiety in 65% of cases and depression in 63% of cases.

A number of clinical researchers has suggested that increasing awareness might increase distress (Fordyce et al., 1983; Bond, 1984; Fleming et al., 1998). In view of the severe, and often permanent, deficits faced by individuals with severe acquired brain injury, this is not an unreasonable supposition. Clear research to demonstrate this is lacking, however. In a group of 42 head-injured North American participants, Gasquoine (1992) found that increased awareness of cognitive and sensory change was correlated positively with emotional distress (anxiety, depression and/or hostility) and correlated negatively with positive affect. The magnitude of emotional distress was not related to severity of injury (as measured by duration of PTA). This was a group effect. The argument could be countered by the suggestion that it might be preferable for individuals to increase awareness whilst in a supportive clinical environment, rather than following discharge with no recourse to such support mechanisms. Indeed, Prigatano (1999) has argued that depression occurs most often when patients remain unaware but experience repeated life failures.

Considering the available evidence, there does appear to be some likelihood that intervening to increase awareness can cause distress in some individuals. For this reason, it was felt important to monitor mood (specifically anxiety and depression) in research participants. Clearly, if attempts to increase awareness were thought to be resulting in anxiety and/or depression, it would be necessary to question whether it would be ethically acceptable to continue the intervention.

1.7.4 <u>Demographic variables</u>

Years in formal education have not been shown to be significantly associated with impaired awareness (Fleming et al., 1998). Indeed, there are a number of detailed biographical accounts of neurologists and neurosurgeons who have experienced an acquired brain injury (German et al., 1964; LaBaw, 1969; Brodel, 1973). Although knowledgeable about ABI sequelae, they appeared unable to apply this knowledge in their own case. It is apparent from their accounts that they also had impaired awareness of their impairments and disabilities.

1.8 PSYCHOSOCIAL FACTORS

1.8.1 Personality factors

Despite being published some 50 years ago, Weinstein and Kahn's (1955) monograph provides the most in-depth account of the pre-morbid personality factors pertinent to impaired awareness. Fifty-two participants (consecutive admissions) who had sustained a stroke were seen. Semi-structured interviews were carried out with significant others conversant with the patient's current and pre-morbid behaviour. Prompts from a checklist were grouped under the following five headings: attitudes; character of drive; reaction to stress; interpersonal relationships and expressive symbols. Although these headings appear pertinent, no information was provided on how the investigators selected them, and there is a possibility that the prompt list could have biased the results. Nevertheless, amongst participants who demonstrated explicit verbal denial, Weinstein and Kahn found the following pre-morbid traits: a tendency to deny illness; delay seeking medical attention and avoid taking sick leave from work.

The authors also identified pre-morbid personality traits they found amongst those exhibiting 'a paranoid form of verbal denial' (p.79). They shared with the first group compulsive drive and need for prestige but, in the paranoid group, this was expressed more 'physically'; they tended to be physically restless, had a resentful or fearful attitude towards illness, and a greater interest in personal appearance and cleanliness.

The Weinstein and Kahn (1955) study suggests that pre-morbid personality traits, including coping style and attitudes towards health and illness, could be related and contribute to impaired awareness. More recently, Clare (2002) listed these factors as psychosocial factors, which may contribute to the impaired awareness in the context of Alzheimer's disease.

1.8.2 Social and cultural factors

Clare (2002) illustrated, by means of qualitative interviews, how participants' interactions with spouses and friends, social services, and representations of dementia projected within a given cultural milieu, may shape the manifestation of impaired awareness. Couples differed widely in the way they spoke about dementia. Clare noted that friends might collude unintentionally with an individual's denial of disease, by making reassuring comments. Over time, social networks were found to dwindle. This lessened occasions when people with Alzheimer's disease might make comparisons. All the above points could be made in relation to those who have experienced an acquired brain injury, although persons with an acquired brain injury are not usually faced with the prospect of certain cognitive decline. Such a prospect could heighten the experience of distress in those with Alzheimer's disease.

Clare (2002) found that some couples expressed fears about the Health Care Professionals' motives, wondering, perhaps, if they might be sent away. Clare contends that such fears, and the way in which the diagnosis is presented to a person, affect the manifestation of awareness as well.

Similarly, Clare (2002) made the point that research addressing awareness, which relies on self-report of persons with dementia, can be influenced by the circumstances of the interview. Factors such as the age, gender, ethnicity or perceived social class of the interviewer might affect how much a participant is willing to reveal. This point was raised earlier by Weinstein and Kahn (1955). The purpose of the interview could be misunderstood or the participant might doubt the researcher's motives.

Seeing only part of the picture can lead clinicians or researchers to conclude that certain verbalisations or behaviours indicate impaired awareness that, in reality, have another explanation. Prigatano (1999, p.265) stated, 'Because the physician, psychologist, and rehabilitation therapist may not follow a given patient from the emergency room through acute care to rehabilitation and beyond, their view of acquired disturbances in human consciousness or awareness may be limited, if not distorted.'

Despite the small sample size, many of Clare's (2002) observations have direct relevance in the context of acquired brain injury. Indeed, they show how application of a novel research method can begin to uncover hidden aspects of a phenomenon.

More recently, Yeates (2003) sought to explore how social context might influence the manifestation of awareness in individuals after traumatic brain injury (TBI). Adopting a social constructionist approach, Yeates carried out semi-structured interviews with three individuals and their significant other. He found that individuals with traumatic brain injury and their relatives used different sense-making resources when describing change, and the personal meaning of change, following brain lesion. Despite the small number of participants, Yeates made some interesting observations. He found that the brain injured participants had ready access to psycho-education from clinicians, whereas the relatives had very limited access to this and relied on informal sources such as books. This accessing of different sources of information appeared to contribute to family members 'constructing differing and competing accounts of change, vying for legitimacy as a shared form of understanding' (p.152). The brain injury survivors and their relatives sought to achieve a shared understanding of changes and both made attempts to bring the other around to their view. None of the informants felt that agreeing to differ was an acceptable option. Hence, Yeates observed that awareness in those with TBI and their relatives was interdependent, forming part of a communication system.

Yeates (2003) found that participants with TBI and their relatives frequently used notions of personality, identity and sense of self in describing changes in the aftermath of brain injury. Indeed, Yeates observed that 'the contested object of awareness for the participants in this study is not a hemiplegic arm but constructions of self or identity or subtle aspects of social behaviour. They are, therefore, culturally relative social

constructions, rather than embodied, visceral aspects of subjectivity.' (p.178) The brain injured participants were found to be particularly resistant to explanations of change that appeared to threaten their sense of continuity of self (integration of pre-morbid and present self). In fact, it was noted that feedback from others was accepted as a trusted monitoring adjunct only when it corresponded with context-relevant experiences.

Despite similarities between families, Yeates stressed other considerable variations between the families, noting, for instance, that two of the TBI participants were more willing to discuss short-comings within the family, but the third participant was more willing to acknowledge weakness to clinicians, apparently through valuing the role of successful high-achiever within the family context. The Yeates (2003) reference was read subsequent to the completion of data collection and did not influence the design of any of the studies within this thesis.

Studies comparing the manifestations of impaired awareness within different cultures are sparse but, nevertheless, suggest some differences. Prigatano and Leatham (1993) compared two groups of 21 traumatically brain injured New Zealanders and found that the 21 New Zealanders of English extraction overrated their abilities more than native Maoris (Prigatano and Leatham, 1993). Using the Patient Competency Rating Scale, Prigatano et al. (1997) found that a sample of 21 Japanese people with severe traumatic brain injury over-estimated abilities significantly in relation to self-care but not social interaction. This was in contrast to American patients who were more likely to overrate social skills. The authors suggested that this might be due to the social importance attached to the ability to attend to one's self-care in Japan. Despite the small number of participants, these studies provide some preliminary evidence that manifestations of impaired awareness may vary across cultures.

In relation to culture, it is important to bear in mind that the vast majority of research in the area of impaired awareness has been carried out in the United States. Much more research needs to be undertaken to be certain that findings in the United States are applicable in other cultures, even other Western cultures.

1.9 METHODS OF DETERMINING AWARENESS

1.9.1 Comparison of patient self-report and third-party report

To date, the most common means of determining awareness impairment has been to ask a brain-injured individual to rate his or her abilities in various domains, and then to compare these ratings with those assigned to the individual by a significant other (Fordyce and Roueche, 1986; Prigatano and Altman, 1990; Prigatano et al., 1990) or a clinician who knows them well (Fordyce and Roueche, 1986; Gasquoine, 1992). If an individual overrates his or her ability compared with a third party, the individual is deemed to have impaired awareness. The most commonly used questionnaire for this purpose is the Patient Competency Rating Scale (Prigatano et al., 1986). Participants are asked to rate the ease with which they would carry out a number of everyday tasks and the ease with which they would handle social interaction and emotional control in different situations. The questionnaire is described in detail in the methodology section of this thesis, together with evidence supporting its validity and reliability. Though most clinicians would concur that relatives and therapists provide extremely useful corroborating information about patients, the validity of the method has been questioned. Significant other report might be dubious (Cavallo et al., 1992; Fleming et al., 1996; Sohlberg, 2000). Manifestations of denial in family members include searching for a rehabilitation team that will say what they want to hear (Deaton, 1986), and denying illness in the early stages of a relative's stroke (Nathanson et al., 1952). McKinlay and Brooks (1984) found that relatives with higher 'neuroticism' scores are more likely to exaggerate deficits and problematic behaviours in their brain-injured relative. As mentioned above, Clare (2002) provided evidence that significant others might answer questions following an agenda unknown to the investigator; for example, they might feel that they could receive more, or better, quality healthcare by answering questions in a certain manner.

Similarly, clinicians might know patients more or less well, or observe them from the relatively narrow focus of their professional background. Clinicians, naturally, have little direct knowledge about the pre-morbid characteristics of patients and can mistakenly attribute certain traits to the brain injury. Some authors claim that clinicians' judgement

of patients varies through having unrealistic expectations (Sohlberg, 2000), sociodemographic variables (Cavello et al., 1992) and emotional factors (Gans, 1983).

1.9.2 Patient self-report compared with neuropsychological test results

Another approach has been to compare individuals' verbalisations with neuropsychological test results (Heaton and Pendleton, 1981; Allen and Ruff, 1990). This approach is open to criticism on the grounds that such impairment tests have disappointing predictive validity for everyday task performance (Schlund, 1999; Sohlberg, 2000).

1.9.3 Structured interview

Structured interview with brain injured people is a further method of ascertaining awareness. In practice, investigators using this approach have asked significant others for corroborating information (Ownsworth et al., 2000). An example is the Self-Awareness of Deficits Interview (Fleming et al., 1996). The questionnaire covers self-awareness of the following three areas: deficits; implications of deficits; future goals. The authors claimed that the questionnaire addressed participants' intellectual awareness of deficits. Fleming et al. (1996), have provided a comprehensive review of methods to assess brain-injured patients' verbalisations of awareness.

1.9.4 Patient self-report compared with observed task performance

More recently, two teams of investigators have looked at the verbalisations of people with acquired brain injury in relation to tasks that they are observed carrying out (Hart et al., 1998; Abreu et al., 2001). Hart et al. (1998) used a task battery in an attempt to measure brain-injured participants' 'on-line' (i.e. in the stream of action) awareness. On the basis of repeated observations of patients carrying out tasks, behavioural criteria were drawn up to indicate that patients were demonstrating on-line awareness of error. The study was carried out in the United States and it remains to be shown whether the criteria would be relevant within other, perhaps less outwardly expressive, cultures. This factor is not acknowledged by the authors. The authors also drew up criteria for behaviours that would be recorded as performance errors.

Participants were asked to complete three tasks twice, but with three constraints: 1) tasks could not be completed concurrently; 2) having completed one type of task the subsequent task could not be a repeat of the previous one; 3) a buzzer (out of sight in a drawer) had to be pressed after completion of each of the six tasks. The three tasks were making toast and jam, packing a child's lunch box and wrapping a gift. The first and third tasks have face validity as likely to be familiar and within the experience of most adults. It is felt that asking participants to perform the tasks in the specified manner is difficult to justify. No one would ever perform tasks in this way, therefore the approach seems to lack ecological validity. The approach is questionable on ethical grounds, as people with brain-injury frequently have difficulty performing tasks in a competent manner, and manipulating tasks in order to trigger additional errors might have a negative impact on self-esteem. On these grounds, the study could be considered methodologically and ethically flawed.

Abreu et al. (2001) asked the question: 'How well do you predict that you will do at the task?' Several authors have noted that the wording of the questions might be more or less sensitive in detecting awareness deficits. It could be that questions prefixed by 'how well?' are not sensitive to awareness impairments. In the Abreu et al. (2001) research, the selection of tasks and inclusion criteria might have skewed results. Participants were selected on the basis of having the potential to live independently, yet the tasks included putting on a sweat shirt. Amongst self-care tasks, putting on a sweat shirt is one of the easiest tasks. Ceiling effects would be expected when using such simple tasks with the relatively able-bodied participants. It has been well documented that individuals show more awareness of physical and simple self-care tasks, before more complex tasks (Tyerman, 1987; Hibbard et al., 1992; Sherer et al., 1998b). The question posed to tap into anticipatory awareness: 'How do you think your performance of the task might affect your ability to live independently, work, and have fun?' has doubtful relevance to this self-care task.

Furthermore, two of the four tasks selected by Abreu et al. (2001) related to numeracy skills. The results showed that these tasks achieved the same results and so could be collapsed to a single task. Both numeracy tasks, though arguably relevant to independent living, were more akin to tests of impairment, rather than disability. The remaining task of

writing out meal plans for two days, showing nutritionally balanced meals, might also have been very difficult to evaluate objectively. Furthermore, it is questionable whether this task would impact markedly on a person's ability to 'live independently, work, have fun'. Many adults with busy lifestyles survive on ready prepared meals.

In view of the weaknesses with the above studies, further studies to develop suitable task batteries are clearly warranted. Careful development of a suitable battery would provide a means of examining individuals' awareness of task performance in relation to observed tasks. Acquired brain injury participants could then be compared with suitable comparison participants. As no single methodology for ascertaining degree of awareness currently stands out as a gold standard, use of several different approaches remains the most sensible strategy when undertaking research in this area.

1.9.5 Other methodological considerations in relation to the measurement of impaired awareness

Where control groups have been used, these have consisted mostly of healthy individuals (Prigatano et al., 1998) or people with orthopaedic difficulties (Tyerman, 1987). No use of more suitable comparison groups, such as people with spinal injury (who also frequently experience a sudden onset of disability), have yet been recorded (Sherer et al., 1998b). A number of studies investigating the measurement of awareness have used parametric data analysis methods to measure non-parametric data such as Likert scale results (Sherer et al., 1998b). Such approaches can lead easily to unjustifiable claims that, in turn, could hamper clarity in this area.

1.10 INTERVENTIONS

Very few intervention studies have been conducted to date. A number of papers, especially from North America, describe strategies that have been found helpful in dealing with awareness deficits in individuals with acquired brain injury (Youngjohn and Altman, 1989; Chittum et al., 1996; Sohlberg et al., 1998). Although no substitute for carefully conducted research studies, the strategies warrant consideration for inclusion in

prospective research. For this reason, the most commonly recommended strategies or approaches are summarised below.

1.10.1 Summary of recommended intervention approaches

Dirette (2002) conducted a 'critical incidents', qualitative inquiry, with three brain injured participants judged to have completed successfully a cognitive rehabilitation programme. Her aim was to explore the development of awareness from the perspective of the brain injured individuals. Key clinicians (coincidentally all speech and language therapists) were interviewed to glean corroborative data. All participants described the process of gaining insight as slow and marked by occasional 'aha' moments. 'Aha' moments involved a comparison of pre-morbid and current performance of familiar everyday tasks. The therapists agreed that the process was slow but attributed the acquisition of awareness to feedback from therapists after clinical testing. For the three participants in this study, their primary cognitive impairment related to memory function. It seems possible that the participants had forgotten the contribution of feedback from therapists in their acquisition of awareness - they were interviewed after completion of the cognitive rehabilitation programme. Future studies aiming to elicit critical incidents could interview participants while they are undergoing therapy. Also, the speech and language therapists interviewed could have been less involved than occupational therapists in observing the participants in everyday activities. There might have been closer concordance between the perceptions of participants and their occupational therapists. Despite these methodological shortcomings, the study is interesting and suggests that asking brain injured individuals to perform familiar everyday tasks could be central to their acquisition of awareness, perhaps because such tasks provide a medium through which individuals can experience and assimilate what they are being told about their neuropsychological deficits.

In a similar vein, Sohlberg (1998) stressed the need for ecologically valid interventions, and suggested that intervention should start with the most helpful area to modify for the person and carer. Some studies concur with the need to maintain motivation and optimism. Herbert and Powell (1989) found that optimism and motivation were more predictive of successful outcome than insight. However, these were global group results and might mask a much more complex interaction of factors for any given individual.

Berquist and Jacket (1993) claimed that goal setting needed to be sensitive to that which a person is motivated to achieve and level of awareness.

A number of researchers stressed the importance of balancing positive and negative feedback (Deaton, 1986; Sohlberg, 2000). The need to focus on the present has also been suggested, since negative predictions about the future might be counter-productive (Deaton, 1986).

Use of individuals' own 'symbols' (analogies from the individual's own life, used to help them towards a clearer understanding of their current situation or difficulty) is considered helpful (Langer and Padrone, 1992; Tyerman, 2001, personal communication). The use of everyday activities is recommended, because their relevance to patients' future life could be easily transmitted (Deaton, 1986; Langer and Padrone, 1992). Giancino and Cicerone (1998) asserted that the discrepancy must become part of a patient's own current belief, rather than something he or she is told. In the relatively institutionalised setting of the rehabilitation unit, patients can become adept at saying what they believe clinicians wish to hear but may not necessarily have assimilated the knowledge they appear to possess.

Fleming et al. (1998) commented that it should be possible to re-organise services to allow the flexibility to readmit individuals with acquired brain injury when they have more awareness and more motivation to change.

1.10.2 Intervention studies

Four intervention studies have been published. Youngjohn and Altman (1989) reported on a self-awareness group for individuals with stroke and traumatic brain injury and provided data on six participants. Participants were presented with two cognitive tasks: a 12 - word free recall and a written arithmetic task. After an explanation of the tasks, participants were asked to predict how well they would perform, i.e. the percentage of sums calculated correctly and the percentage of words recalled correctly. These predictions were written on the blackboard next to each name, in view of the whole group. Participants then carried out the tasks and their scores written on the board. Participants were then presented with another version of each task and asked to make predictions for the second time. The second predictions were more accurate for the group

as a whole. To ascertain whether the beneficial intervention effect would remain constant, a second session was organised. The effect across the sessions at different time-points was significant in the case of the arithmetic task but not the oral recall task. Inclusion of a healthy comparison group might have helped clarify how easily healthy individuals were able to predict their performance of these tasks.

In a situation where individuals' results are being 'broadcast' to a group, there could be a strong inclination to save face, and the intervention might have been effective in coaching participants to 'save face', rather than altering their self-awareness. The tasks were tapping into cognitive impairment, not tasks with relevance for everyday life. Of the two, the arithmetic task has more tangible face validity with regard to everyday functioning and this could be why some improvement was maintained over time. It is unclear whether the improved awareness generalised outside the study situation. The selection of more realistic everyday tasks might promote greater generalisation and be more easily understood by individuals with acquired brain injury, some of whom have difficulty with abstract reasoning.

Chittum et al. (1996) sought to increase awareness in three male participants. Chittum et al. increased intellectual awareness in all three. The participants had experienced severe traumatic brain injury and were identified as experiencing severe behavioural problems. Chittum and colleagues achieved this by means of a teaching session, followed by a board game (Road to Awareness board game), to test knowledge. The researchers, not unreasonably, claimed that the advantages of this approach included capturing the participants' attention and interest through an enjoyable and non-confrontational medium. The large element of repetition was helpful for one participant with severe memory impairment. The approach entailed a large behavioural component, with participants winning tokens for correct answers, which they could exchange later for items such as CDs. The approach has promise and, as the authors reasonably point out, greater gains might be made with less disruptive, less severely brain damaged people. Further research could clarify whether the approach would work without the behavioural reinforcement. The authors do not say whether the participants' improvement in knowledge about their impairments, and the implications of impairments had any impact on their behaviour and, if so, whether it were long-lasting.

Schlund (1999) reported on a single case using an experimental design. The participant was a 21-year-old male who had sustained a severe traumatic brain injury. His cognitive and physical limitations were deemed so severe as to preclude standardised neurological testing. The participant claimed that his memory was normal but significant others reported severe memory impairment. A memory questionnaire was developed with 19 questions addressing different aspects of personal information that the participant had difficulty remembering and that were significant to him. The questionnaire was used once a day, 4 to 5 days a week. The participant was asked to judge the percentage of questions he anticipated answering correctly and those he had answered correctly on the previous occasion. The results showed an improvement in the accuracy of his judgements but the study was methodologically flawed by having only two baseline data points.

Tham et al. (1999) recruited four individuals with severe unilateral neglect, within 10 weeks of stroke. Tam et al. used an ABA (baseline, intervention, follow-up) experimental design. Data were collected four times during the baseline phase (twice weekly for two weeks; four times during the intervention phase (weekly for four weeks) and twice during the follow-up phase (eight and nine weeks after completion of the intervention phase). For the intervention, a purposeful daily occupation was chosen to act as a therapeutic change agent. These were different for each individual: making a meal; gardening; writing a postcard; reading a newspaper. The intervention consisted of practising the chosen task five times a week for the duration of the intervention phase, engaging the participant, in discussion, before and after to enable them to plan better, describe and assess their task performances. During task performance practice, the therapist would provide prompting and feedback as required. Visual inspection of plotted data points demonstrated that all participants increased awareness of task performance, to some degree, during the intervention phase. This tended to fall off, however, during the follow-up phase.

A number of factors made the Tham et al. (1999) study difficult to evaluate. It differs markedly from other intervention studies, in that the participants were very early post-stroke at a time when spontaneous recovery could be rapid. Having a larger number and greater frequency of data collection points might have helped in assessing whether rate of improvement was likely because of the intervention, rather than spontaneous recovery. As

the study stands, it is unclear whether it would be worthwhile replicating the intervention within a clinical context (in order to facilitate increase in awareness).

1.11 IMPAIRED AWARENESS IN THE NON-BRAIN INJURED, 'HEALTHY' INDIVIDUAL

Impaired awareness in the healthy individual is clearly not a primary focus of this thesis. Nevertheless, any exploration of the nature of self-awareness in the acquired brain injured individual could be deemed incomplete without some reference to the healthy individual. If healthy individuals lack awareness in certain circumstances, or in relation to particular abilities or character traits, the underlying mechanisms might also be present in some of those with an acquired brain injury.

Weinstein (1989) described one such mechanism: 'optimistic bias in "self-other" risk comparisons.' (p.1232). Weinstein argues that, if comparisons were not biased, judgements of below average risk would be counterbalanced by judgements of above average risk. However, he demonstrated that the mean often falls within the below average rather than the balanced average position. In 25 of 32 risks, a significant optimistic bias was found. In this research, members of the public were questioned on their perceived risk of acquiring various diseases such as lung cancer, and, for example, becoming a drug addict. Similarly, those in high-risk groups might underestimate risk or refer to ineffective methods of countering risks. Homosexual men have been found to justify their view of low risk for contracting AIDS by referring to ineffective means of safeguarding their health, for example, maintaining a high degree of personal hygiene (Bauman and Siegel, 1987).

Weinstein (1989) contended that most data do not support the view that optimistic bias serves to protect us from the fear of harm, but rather, in some people, is due to a need to be better, or less susceptible, than others, in order to bolster our sense of competence and self-worth. For other people, optimistic biases might reflect simple cognitive errors, e.g. comparing oneself with a very high-risk group and concluding wrongly that one's own risk is below-average. Weinstein noted finally that pessimistic biases rarely exist.

1.12 CONCLUSIONS

In summary, further studies, to explore the measurement of impaired awareness in individuals with acquired brain injury, are warranted. In particular, there is a need to develop a battery of suitable everyday tasks that could be used to compare participant report of performance with observed performance. Having developed such a battery, awareness of everyday task performance could be examined in individuals with acquired brain injury and in pertinent comparison participants, such as those without brain injury but who experience an acquired disability. A group comparison approach could incorporate individuals with an acquired permanent disability, such as people with spinal cord injury, as well as healthy individuals. While batteries are being developed, use should continue to be made of third-party report – significant other and/or clinician who know the patient well. The different methodological approaches might capture different elements of impaired awareness phenomena. Although the comparison of self and third-party report might have shortcomings, this methodology has been employed extensively in North America. Further use of the methodology, but in a British context, could allow some useful insights into cultural differences in the manifestation of awareness.

Having first addressed gaps in the measurement of awareness, further work is needed in relation to the effectiveness of interventions in improving the awareness of individuals with acquired brain injury, particularly with regard to their abilities with everyday tasks. In view of the complexity of the impaired awareness phenomena, single case studies might be a sensible place to begin in order to identify the profiles of those individuals who would respond to different types of interventions.

At a more fundamental level, the literature review showed a lack of consensus regarding the exact nature of impaired awareness. In view of this, attention should also be paid to factors that shed light on the nature of awareness. Specifically, exploration of what clinicians understand by impaired awareness is considered to be important: the impetus to address impaired awareness comes largely from the barrier it poses to rehabilitation. In many studies it is clinicians who provide the supposedly 'accurate' account of people's abilities across different domains.

CHAPTER TWO

AIMS AND GENERAL METHODOLOGY OF THE STUDIES

2.1 INTRODUCTION

The research aims will address three main questions.

- Is it possible to measure awareness of activity limitation or impairment?
- Is it possible to increase awareness of activity limitation or impairment?
- What is the nature of impaired awareness of activity limitation and impairment?

2.2 RESEARCH AIMS

2.2.1 Is it possible to measure awareness of activity limitation or impairment?

In the 'phase 1: preliminary study' (Chapter 3) the *main* focus will be measuring awareness of activity limitation rather than impairment. The first main question will be addressed by the following means:

2.2.1.1 Subsidiary aims

- i) to develop a behavioural measure (task battery) of awareness of everyday task ability (activity level of function)
- ii) to identify questions likely to elicit verbal report from acquired brain injury participants regarding their everyday task performance (activity level of function), termed 'self-awareness' questions
- iii) to clarify the feasibility of using criteria devised by Hart et al. (1998), to guide observer judgement of errors made during task performance (Table 3.3, page 62)
- iv) to clarify the feasibility of using criteria devised by Hart et al., to assess participant awareness of error occurring during task battery performance (see Table 3.4, page 62)

- v) To identify whether administration of the task battery, in conjunction with preand post-test 'self-awareness' questions, could discriminate between participants with, and without, awareness deficits.
- vi) to explore the feasibility of using a questionnaire developed in the United States to ascertain awareness level in ABI participants: the Patient Competency Rating Scale
- vii) to determine the feasibility of using a questionnaire to ascertain ABI participants' awareness of their social skills deficits (impairment level of function): the Social Communication Skills Questionnaire
- viii)to determine the feasibility of using the Hospital Anxiety and Depression Scale to measure mood (anxiety and depression) in acquired brain injury participants.

Having clarified the subsidiary aims listed above, the 'phase 2: group comparison study' (Chapter 4) will address the first main question by the following means.

2.2.1.2 Subsidiary aims:

- To apply the methods developed in Chapter 3 to determine whether the awareness level of acquired brain injury persons (identified by clinicians as having impaired awareness) differs significantly from that manifested in individuals in three comparison groups: healthy; spinal-injured and brain-injured (identified by clinicians to have intact awareness)
- ii) To determine whether persons with acquired brain injury (ABI) demonstrate differing degrees of awareness in relation to different tasks within the activity level of function
- iii) To compare ABI individuals' awareness of everyday task performance (activity level of function) with a standardised questionnaire measuring awareness The Patient Competency Rating Scale
- iv) To explore whether mood is associated with inaccurate self-report of the activity level of function
- v) To determine ABI participants' awareness of social skills deficits (impairment level of function) by administration of the Social Communication Skills Ouestionnaire

- vi) To determine the inter-rater reliability of the task battery developed to measure the activity level of function
- vii) To determine the test-retest reliability of the task battery developed to measure the activity level of function.

2.2.2 <u>Is it possible to increase awareness of activity limitation or impairment?</u>

'Phase 3: case studies' (Chapter 5) will focus on the second main question: Is it possible to increase awareness of activity limitation or impairment?

This question will be addressed by the following subsidiary aims:

- i) To determine the effectiveness of interventions, to increase awareness of activity limitation, or impairment, in persons with acquired brain injury,
- ii) To determine the effectiveness of interventions, to increase awareness of social interactive impairments, in persons with acquired brain injury
- iii) To explore the natural history of recovery in respect of impaired awareness of social skills deficits or activity limitations, in persons with acquired brain injury,
- iv) To investigate the critical incidents impacting upon the awareness status of case study participants,
- v) To review the sensitivity of using an abbreviated version of the newly developed task battery.

2.2.3 What is the <u>nature of impaired awareness of activity limitation or impairment?</u>

Chapter 6 will focus on the third main question of the thesis: What is the nature of impaired awareness of activity limitation or impairment?

This question will be addressed by the following subsidiary aims:

- i) to explore what clinicians understand by impaired self-awareness following acquired brain injury
- ii) to explore the factors that clinicians believe to have an impact upon impaired selfawareness

- iii) to determine whether clinicians' descriptions of their patients' awareness can be used reliably to place individuals on the Hierarchy of Awareness (Crosson et al. 1989)
- iv) to explore the relationship between severity (numerical rating scale) scores of awareness and placement within the hierarchical model of awareness
- v) to explore the factors and critical incidents impacting upon the awareness level of participants

2.3 PROPOSED MODEL OF AWARENESS

The model below is proposed by the author on the basis of factors arising in the course of the literature review that appear to have an impact upon awareness. The model stresses an individual's sense of 'self-continuity'. This term is adapted from the notion of 'continuity of self' used by William James in 1890 (cited by Prigatano and Schacter, 1989). James believed that consciousness was intimately related to the self and self-identity and, since it resided in the memory, it was continuous. Self-continuity is used here to describe an individual's knowledge and experience of past life experiences, which would normally inform their expectations about their likely capability within a current task, and future tasks. Self-continuity is conceptualised as being interrupted following a brain lesion. Ellis-Hill and Horn (2000) refers to a similar notion: an interruption in life narrative following stroke. Ellis-Hill and Horn reported that participants found that they could no longer rely on past knowledge and experience to inform future expectations about the self.

It is proposed that an individual's response to task performance, which no longer meets his or her expectations may be mediated by one or more factors. It is suggested that most salient factors can be grouped under one of these headings: pre-morbid personality factors; emotional status; cultural and religious influences; cognitive deficits; social support; and therapeutic alliances. A few, or many, of such factors can interact and wax and wane over time.

It is proposed further that cognitive deficits, such as attention, memory and information processing impairments can hinder the assimilation of new information. For example, a

person may realise briefly that they are failing on one aspect of a task that they had been able to do. They might attribute this difficulty to external causes, such as an unfamiliar clinical setting, rather than relate this to a newly acquired physical or cognitive impairment. A problem with abstract thought might make it very difficult, for an individual with acquired brain injury, to make the connection between an impairment and the way in which the impairment could be hindering task performance.

An individual could be experiencing high anxiety about being in hospital, and this might also inhibit clear thought, such that the person cannot make connections between current impairments and how these will relate to future everyday living. Therapeutic alliance refers to the quality of rapport between the individual with an acquired brain injury and clinicians treating that individual. Poor rapport can result in an individual having a lack of confidence in the skills of a clinician, who might be perceived as very young and inexperienced or, conversely, overly officious. Lack of trust in a clinician, for whatever reason, could result in an individual going through the motions of rehabilitation but not really engaging in, nor really understanding the purpose of, assessments or interventions.

Similarly, good social support might either facilitate an individual's awareness or conspire against the acquisition of awareness. Family members might well have limited knowledge of the aftermath of brain injury, and it could take some time for them to appreciate the permanent nature of some deficits. This could result in family members seeking to reassure the brain injured individual, inadvertently bolstering unrealistic hopes of full recovery. Alternatively, some family members could be quick to realise the extent of the problem, perhaps after discussion with clinicians, and attempt to communicate this in terms the brain injured person is mostly likely to accept and understand. Likewise, the knowledge that social support will be there, no matter what the eventual outcome, might make it easier for some individuals with brain injury to begin to face the reality of their disabilities.

However, the model does not offer a comprehensive list of underlying mechanisms that may result in impaired awareness. Nor does it account for individuals who may be more

SELF-CONTINUITY PRESENT **PAST FUTURE** F \mathbf{C} Pre-morbid personality **Emotional status BRAIN** O Α LESION N C Т T **DISRUPTION** E 0 TO BELIEFS RELATING X R Culture/Religion Social support TO SELF Т S NEED TO ASSIMILATE NEW Cognitive Therapeutic KNOWLEDGE AND EXPERIENCE **Deficits** Alliances INTO SELF-CONTINUITY FAILURE TO ASSIMILATE KNOWLEDGE AND EXPERIENCE IMPAIRED SELF-AWARENESS FOR PRESENT AND FUTURE SELF OR FUTURE SELF

Figure 2.1 Theoretical Model of Awareness (based on the literature review)

aware than they are willing – or able – to acknowledge. The proposed model will be reviewed and amended, in the light of findings from the studies conducted within this thesis.

2.4 PARTICIPANTS

Individuals with acquired brain injury were recruited to the four phases of the research programme. Healthy individuals and those with spinal cord injury were recruited for

comparison purposes to the 'phase 1: preliminary study' and the 'phase 2: group comparison study'. Before selecting a spinal cord injury comparison group, the feasibility of including amputees was considered. A prosthetics service is based at the Nuffield Orthopaedic Centre in Oxford. The prosthetics consultant advised that, despite a large catchment area, it could take two years or more to recruit suitable age – and gender – matched comparison participants from the service. In contrast, clinicians at the National Spinal Injury Service considered that there was a good likelihood of recruiting suitable comparison participants within a six month period.

See Appendix 2 (page 2) for further details about the clinical settings.

2.4.1 Inclusion and exclusion criteria

ABI participants ('phase 1: preliminary study' and 'phase 2: group comparison study')

Inclusion criteria

Evidence of an acquired brain injury, male or female, between the ages of 18–80 years, actively engaged in neurological rehabilitation, on either an in-patient, or out-patient basis, in Oxford or Aylesbury.

Exclusion criteria

- 1) Presence of a concurrent neurological problem associated with impaired awareness (e.g. dementia, multiple sclerosis).
- 2) Presence of a concurrent psychiatric illness associated with impaired awareness (e.g. psychosis).
- 3) Severe receptive aphasia, such that an individual was unable to understand the assessment instructions. (In case of doubt advice was sought from the person's speech and language therapist. Fast cut-off scores 27 [up to age 60]; 25 [age 61+]).
- 4) Very severe cognitive impairment, such that the individual was unable to understand the assessment instructions/questionnaires (advice sought in every case from the relevant treatment team).

5) Severe physical impairment such that the individual was unable to engage independently in simple activities of daily living (e.g. no functional use of either hand because of severe bilateral ataxia or bilateral strokes).

6) Poor understanding of spoken English.

7) A diagnosis of clinical depression.

Spinal Cord Injury Participants ('phase 1: preliminary study' and 'phase 2: group comparison study')

Inclusion criteria

Evidence of spinal cord injury, male or female, aged 18-80 years, undergoing in-patient or out-patient treatment at the National Spinal Injury unit.

Exclusion criteria

- 1) Evidence of a brain injury (i.e. post-traumatic amnesia of more than 24 hours' duration).
- 2) High spinal cord lesion, resulting in inability to use hands functionally.
- 3) Poor understanding of spoken English.

Healthy Participants

Healthy participants were recruited via advertisements in the sports clubs, places of worship, libraries and the League of Friends (in hospitals) in Oxford.

Inclusion criteria

Male or female, aged 18-80 years.

Exclusion criteria

- 1) Evidence of a brain injury or concurrent diagnosis associated with impaired awareness, marked physical or cognitive impairment.
- 2) Poor understanding of spoken English.

2.4.2 Demographic data

Demographic data were obtained from the medical records (after consent of clinical participants) to identify possible sources of bias: age and gender were recorded in order to match participants; diagnosis; time since stroke, brain or spinal cord injury; length of time spent in rehabilitation. Although the literature to date has not demonstrated clearly that any of the above factors reliably predicts severity of awareness impairment, this does not mean necessarily that none of these factors is relevant. Studies, examining awareness in the context of acquired brain injury, routinely record such data and it seemed pertinent to do so in the context of the present study.

2.4.3 Ethical considerations

Formal approvals

Ethical approval was obtained from the relevant Local Research Ethics' Committees: AQREC in Oxford and AVLREC in Aylesbury (Appendices 3 to 6, pages 5 to 10). In all cases, potential participants were identified and approached by a clinician known to them, after careful consideration of their suitability. If those identified as suitable to take part were interested in taking part, the investigator explained the study in more detail and provided them with an information sheet to keep. In accordance with ethical committee guidelines, participants were given a minimum of three days to decide whether they wished to take part. See appendices 7, 8 and 9 for examples of the invitation letter, the information sheet, and the consent form (pages 11 to 15).

Vulnerability

Individuals with acquired brain injury are vulnerable, in that they might have any combination of deficits in the following domains: physical, cognitive, emotional, social skills. Intervention to address awareness might touch on individuals' 'sense of self'. Attempts to change individuals' view of their everyday task abilities could be threatening, but this would be undertaken in the context of working with the individual to overcome deficit areas (in the 'phase 3: cases studies'). The literature reviewed in Chapter 1 indicated widespread clinical consensus that interventions, capable of increasing awareness, need to be developed. Currently, there is no evidence regarding the optimal intervention which might increase awareness, and scant data regarding how participants might react emotionally to such intervention.

Taking account of the possibility that involvement with the research could cause distress in some individuals, safeguards were put in place to minimise this risk. The researcher adopted a flexible attitude towards consent. Participants were reminded that they would be free to change their minds and withdraw from the research at any time. In addition, throughout data collection, the investigator remained sensitive to verbal or behavioural signs indicating that the participant had changed his or her mind. In the event of a participant becoming distressed, the investigator would cease data collection, stay with the participant until they felt calmer, and then report back to a member of the treatment team, so that further support could be given to the participant.

Healthy participants were recruited by means of posters placed in local hospitals, libraries and places of worship. Healthy participants were assessed in Rivermead Rehabilitation Centre, the Radcliffe Infirmary or in their own homes. Clinical participants were recruited on a convenience basis, and assessed either in the clinical unit to which they were attached, or in their own homes.

2.5 PHASE 1: PRELIMINARY STUDY

The 'phase 1: preliminary study' would allow careful development of an instrument to capture awareness of the 'activity level' of function. The resultant task battery could then

be used in later stages of this project. Earlier studies developing task batteries (Hart et al., 1998; Abreu et al., 2001), have omitted this developmental stage, and could be criticised for having paid scant attention to the selection of tasks. This omission resulted in relatively large numbers of participants being committed to studies using inadequate or impracticable tasks. The design of this study would involve behavioural observation and questionnaire survey.

During the 'phase 1: preliminary study', the following issues would be addressed concurrently:

A task battery would be developed that would include a larger number, and wider range, of tasks than previously published batteries. However, in keeping with other studies, it was felt that participants should be able to complete the battery in one sitting. In the first instance, seven tasks would be chosen as this seemed a likely maximum number that could be completed in one sitting. These would be administered to individuals with mild, moderate and more severe physical, cognitive and perceptual impairments associated with acquired brain injury. Examples of deficits included hemiplegia, affecting the dominant arm and hand, memory and information processing impairments, and homonymous hemianopia. Tasks found to be too challenging would be modified or discarded and replaced. Modified and new tasks would then be administered to further participants until a suitable battery was identified. If the battery were found to take longer than one and a half hours to complete, the number of tasks would be reduced.

The feasibility of using the Hart et al. (1998) criteria to judge error, and 'on-line' awareness of error during task performance, would be examined in the course of task battery development. On-line awareness of error means that an individual becomes aware of error as this arises during task performance. An individual who realises that he or she has made an error, some time after the error was made (but not at the time), would not be considered to have on-line awareness of error. In the event of the Hart et al. criteria being inadequate, they would be modified, replaced and newly devised criteria re-tested with further participants.

During the 'phase 1: preliminary study', participants would be asked a number of questions, before and after task performance, to establish the relative usefulness of

different questions in capturing awareness. Earlier studies have paid little attention to the wording of questions used to elicit awareness.

In terms of numbers of participants, it was intended that the task battery be administered to sufficient acquired brain injury participants, in order to ascertain that the each task could be attempted by participants with physical and/or cognitive impairments, and mild, moderate, or severe impairments. In order to achieve this, it was proposed that each task be trialled with a minimum of three acquired brain injury participants, who had varying degrees and types of impairments. Although this number of participants is small, it is a considerable improvement on similar, earlier studies, where this phase of development was omitted totally. In addition, the 'phase 2: group comparison study' would afford further opportunity to examine critically each of the tasks making up the task battery, with the option of removing tasks found to be less sensitive to impaired awareness.

It was envisaged that the 'phase 1: preliminary study' tasks would be administered to some healthy and some spinal injured participants for comparative purposes. Since the main aim of the 'phase 1: preliminary study' was to develop a task battery that could be administered to a wide range of individuals with acquired brain injury, it was not considered necessary to attempt to match comparison participants to those with acquired brain injury. Having established a suitable task battery, participants would be matched within the 'phase 2: group comparison study'.

To establish the feasibility of using two questionnaires, to determine awareness of the activity level of function and social skills impairments, in individuals with acquired brain injury, and third-party versions with clinicians and significant others, the Patient Competency Rating Scale (Prigatano and al., 1986), and the Social Communication Skills Questionnaire were administered (McGann et al, 1997). However, since the *most important* aim of the 'phase 1: preliminary study' was to develop a suitable task battery, acquired brain injury participants would not be excluded should they have no suitable significant others who could complete third-party versions of the questionnaires. It was anticipated that sufficient numbers of participants with significant others would be recruited, in order to make a judgment on the relative usefulness of questionnaires – for later phases of the research.

The Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983) was administered, to establish the feasibility of using a measure of anxiety and depression with acquired brain injury participants.

2.6 PHASE 2: GROUP COMPARISON STUDY

The 'phase 2: group comparison study' would involve between-group comparison design (Hammond, 2000), using the methods (behavioural observation and questionnaire survey) developed during the 'phase 1: preliminary study'. Earlier studies had made limited use of suitable comparison groups. Once an acceptable task battery was developed, the group comparison design would allow careful examination of response to the battery within an acquired brain injury group and three comparison groups.

The tasks battery and associated questions to elicit awareness would be applied to a group of participants with acquired brain injury, identified as having impaired awareness, and three comparison groups, matched with the first group for age and gender: acquired brain injury participants with *intact* awareness; spinal cord injury participants; healthy participants. In view of the scant comparison data apparent in earlier studies in this field, careful consideration was given to the number of participants that would be required for the study. Previous studies had provided little guidance on the number of participants, with impaired awareness, who were likely to be referred to the study over a one-year period. Eighteen was considered the maximum number of participants who were likely to be recruited to each of the clinical groups over a one year period. Comparable studies have used relatively small numbers of participants. Hart et al. (1998) used 18 participants, and 18 comparison participants, in a study to develop an awareness battery for use with brain injured individuals. Clare et al. (2002) used 12 participants and their 12 spouses in a study to develop the Memory Awareness Rating Scale for individuals with Alzheimer's disease.

To examine the reliability of the task battery, inter-rater and test-retest reliability studies would be conducted concurrently. Task battery data relating to the impaired awareness group would be examined in more detail, to ascertain whether participants demonstrate differing degrees of awareness in relation to different tasks.

Standardised questionnaires designed to determine awareness and found to be informative and acceptable to informants during the 'phase 1: preliminary study' would be administered to all acquired brain injury participants in the 'phase 2: group comparison study' and, where feasible and relevant, to third parties. Standardised questionnaires are, to date, the preferred method of determining awareness. The questionnaires would provide an additional means of determining awareness in participants and, have almost exclusively been developed and administered abroad. Questionnaire data arising from British participants might provide useful insights in their own right, and could be compared with methods of determining awareness that involve behavioural observation.

Potential associations between awareness and anxiety and/or depression would continue to be examined by administration of a suitable scale to all participants (with the exception of the third-party informants).

2.7 PHASE 3: CASE STUDIES

The 'phase 3: case studies' used a single-case, repeated measure experimental design, encompassing structured behavioural observation, questionnaire survey and semi-structured interview. Acquired brain injury participants, identified as having impaired awareness, would be recruited to an intervention study using single-case experimental design, or a non-intervention, follow-up case study, tracking the natural history of recovery of awareness. It was envisaged that, where practicable, participants would be seen on an intervention basis; otherwise, they would be followed up on a non-intervention basis. For instance, after discussion with clinicians, it might be decided that a participant, who is not engaging in rehabilitation because of their awareness deficit, would be unlikely to engage in an intervention-based research study.

The single-case experimental design is considered suitable for examining behavioural change in individuals with complex problems, such as those with acquired brain injury. 'Severe' cases, and those with dual diagnoses, would be considered for inclusion in the 'phase 3: case studies' – provided that the main reason for the impaired awareness related to an acquired brain injury. The design is more flexible than group comparison designs and can legitimately be adjusted the better to suit individual participants.

2.8 PHASE 4: NATURE OF IMPAIRED AWARENESS

2.8.1 Exploration of clinicians understanding of insight or awareness

Clinicians referring participants to the study would be: [a] asked to give a Numerical Rating Scale score for participants referred by them (to identify the severity, or otherwise, of the awareness impairment) and [b] interviewed briefly to establish their perception of the participant's awareness. This would constitute a novel attempt to examine clinicians' conceptualisation of awareness. As clinicians would also be requested to provide further third-party data, it was decided that the interviews should be brief, to encroach less on clinical time and to facilitate the participation of clinicians. The scripts would then be analysed thematically. The thematic analysis might indicate that more in-depth qualitative studies are warranted, beyond the scope and main aims of the current thesis.

2.8.2 Exploration of longitudinal qualitative interviews arising from the 'phase 3: case studies

All case study participants, significant others and clinicians would be interviewed on a regular basis, during the 'phase 3: case studies' follow-up. This would provide a means of exploring intrinsic and extrinsic factors ('critical incidents') that might be impacting on awareness level in the case-study participants. A semi-structured interview schedule would be devised for this purpose.

2.9 OUTCOME MEASURES

A variety of assessments, involving structured observation and questionnaire survey, was selected to examine relevant aspects of awareness, behaviour and verbal self-report, highlighted in the literature (see Chapter 1) as being important.

2.9.1 Task battery

During the 'phase 1: preliminary study', a task battery would be developed, to address awareness of the activity level of function. Tasks that were found to be unsuitable for any reason would be altered, or removed and replaced by other tasks. The aim was to have a task battery with a range of tasks drawing, to different degrees, on the following domains: cognitive, physical, communicative. It was envisaged that the battery would, initially, include one or more domestic, office-based and leisure tasks. In addition, the battery should include tasks that could be attempted by those with severe brain damage that had resulted in hemiplegia and severe cognitive deficits.

2.9.2 Questionnaires

The published questionnaires detailed below were used in one or more studies within this thesis.

Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983)

This scale addresses briefly anxiety and depression. It was devised for use with medically ill persons, but has since been used widely with other clinical populations. When presented with statements relating to aspects of anxiety and depression, individuals are required to indicate which of four responses best describes how they have been feeling over the last few days. The Hospital Anxiety and Depression Scale (HADS) has been found to correlate well with psychiatric assessment: r = 0.70 and r = 0.74, for depression and anxiety respectively (Zigmond and Snaith, 1983). Since one aim, during the group comparison phase of the investigation, was to explore the relationship between mood and impaired awareness of abilities, a brief scale was considered appropriate. The scale was considered less intrusive than others that address suicidal ideation, such as the Beck Depression Inventory (Beck et al., 1961) or the Hamilton Rating Scale for Depression (Hamilton, 1967). The HADS was used throughout all phases of the study to monitor mood.

Patient Competency Rating Scale (Prigatano et al., 1986)

The purpose of the scale is to assess self-awareness in individuals, following acquired brain injury. The Patient Competency Rating Scale (PCRS) has 30 items, and participants use a five-point Likert scale to rate their degree of difficulty in various tasks and situations (personal and instrumental activities of daily living, behavioural and emotional function, cognitive abilities and physical function). Likert scale responses range from 5, 'Can do with ease', to 1, 'Unable to do'. Participant responses are compared with those of a third-party, who rates the participant on identical items. Impaired self-awareness is inferred from discrepancies between the two sets of ratings, such that the participant overestimates his or her abilities compared to the third party (See Appendix 10, page 16).

Normative data are scant. Prigatano et al. (1998) reported that a group of 28 Spanish control subjects obtained a mean of 144 (range 120-150), and third-party respondents produced a mean score of 145, suggesting close concordance between ratings, and also that most items were rated at the maximum competency (5, 'Can do with ease'). Test retest reliability of the scale has been reported as r=.97 for brain injured persons and r=.92 for relatives (Prigatano et al., 1990). Fleming et al. (1998) reported acceptable one-week test re-test reliability for traumatically brain injured participants, using intra-class correlations (ICC r=.85).

Interpretation of the PCRS is based on the assumption that the third-party ratings give a true measure of competency, against which to judge the accuracy of the participant's self-rating. This assumption has not been validated to date. The scale was included in the study as it is the most commonly referred to in the literature to date. It was used throughout the first three phases of the study.

Self-Awareness of Deficits Interview (SADI), Fleming et al. (1996)

The SADI is a structured questionnaire which is administered directly to individuals with acquired brain injury, and provides a measure of their 'intellectual' awareness of deficit areas. It has three parts addressing awareness of deficits, of the implications of deficits, and the ability to set realistic goals. Two inter-rater reliability studies indicated acceptable intra-class correlation coefficients (ICC of 0.85, Fleming et al., 1996, and ICC of 0.82.

Fleming et al., 1998). These ICCs were for the total scores, as opposed to the three subsections. Simmond and Fleming (2003) conducted a test-retest reliability study involving twenty participants with a traumatic brain injury. They found high test re-test reliability over a 2 to 4 week period, again ascertained by an ICC of 0.94 for the total score, and ICC of 0.85, 0.86 and 0.86 respectively for three subsections. The use of checklists was incorporated into the study, to provide collateral information from clinicians and significant others. A drawback of the study was that all interviews were conducted and scored by six fourth-year occupational therapy students, five of whom had no prior experience of brain injury rehabilitation. This weakness is acknowledged by the authors.

The scale was used in the 'phase 3: cases studies' only (See Appendix 11, page 18).

The procedure for each phase of the research is described in detail in the relevant chapters.

CHAPTER THREE

PHASE 1: PRELIMINARY STUDY – DEVELOPING A TASK BATTERY TO CAPTURE AWARENESS OF ACTIVITY

3.1 INTRODUCTION

The main aim of the 'phase 1: preliminary study' was to establish a task battery to address measurement of the activity level of function, for use in subsequent phases of the research. An integral part of the task battery development entailed identifying questions sensitive to participants' awareness of their own performance of tasks. By asking a participant to rate his or her performance, and comparing this rating with an observer's rating, it was possible to obtain a measure of awareness. This was calculated by subtracting the participant's rating from the observer's rating. The resultant discrepancy score was termed the 'awareness score'. This method has face validity as a logical means of establishing awareness, and has been used in the administration of an earlier task battery developed to determine awareness (Abreu et al., 2001). The method could be criticised, on the grounds that it is over-reliant on the subjective judgement of an observer. However, an observer's judgement can be examined by means of an inter-rater reliability study.

The battery would provide a structured means of observing participant behaviour whilst the participant was engaged in everyday tasks. A review of the literature indicated that, in measuring awareness at the 'activity' (formerly 'disability') level (ICIDH, 2001), it was important to observe behaviour, rather than relying solely on verbal report.

The 'phase 1: preliminary study' also provided an opportunity to ascertain the suitability of standardised questionnaires, designed to measure awareness level and mood respectively. The questionnaires are dealt with in Section 3.9 (page 83) of this chapter.

3.2 AIMS OF THE 'PHASE 1: PRELIMINARY STUDY'

- i) To identify a range of tasks varying in complexity and drawing on different ability domains: primarily physical abilities, primarily cognitive abilities; and at least one with a marked communicative component, to form part of a task battery.
- ii) To identify the questions most likely to elicit verbal report from participants, regarding their everyday task performance (activity level of function), termed 'self-awareness' questions.
- iii) To clarify the feasibility of using the criteria devised by Hart et al. (1998), to guide an observer's judgement of participant errors made during performance of tasks (see Table 3.3, page 62).
- iv) To clarify the usefulness of criteria devised by Hart et al. (1998), to assess participant awareness of error occurring during task performance (see Table 3.4, page 62).
- v) To identify whether administration of the task battery, in conjunction with preand post-test 'self-awareness' questions, could discriminate between participants with, and without, awareness deficits.

During the 'phase 1: preliminary study', three attempts were made to identify a suitable configuration of tasks for the battery. These are described below as three 'stages'. Within each stage, participants continued to be recruited, until sufficient data were gathered to ascertain the relative usefulness of each task for inclusion within the battery.

In developing the task battery, a number of principles were identified to overcome flaws identified in earlier studies by Hart et al. (1998) and Abreu et al. (2001). (See section 1.9.4, pages 26-27)

It was considered important to have sufficient range and variety of tasks. However, this requirement needed to be balanced against the need for participants to be able to complete the battery in one sitting. Many individuals experience increased fatigue following an acquired brain injury and it was felt that the battery should not take no more than one hour to complete. The Hart et al. study was criticised on the grounds that one task showed marked ceiling effects. To limit ceiling (and floor effects) the cognitive demands of tasks would be graded where possible.

The literature indicated that impaired awareness is not confined to particular cerebral lesion sites; neither does lesion size, nor extent of disability, reliably predict the degree, or even the presence of, impaired awareness. Therefore it was important that tasks selected could be administered to participants with varying degrees of physical and cognitive ability.

Self-awareness questions

In Stage I of the 'phase 1: preliminary study' participants were questioned regarding the 'ease' of task performance. This dimension was chosen since it is used with the widely used Patient Competency Rating Scale. In Stage II, further questions were added to ascertain which types of questions might be the most useful in elucidating level of awareness of task performance. In the Abreu et al. (2001) study, participants where asked questions relating to the quality of task performance: 'How well did you do the task?' These scales for ease and quality were used exactly in the format described by Prigatano et al. (1989) and Abreu et al. (2001) respectively, in order to clarify the usefulness of existing scales. Questions about additional dimensions of task performance were included because it seemed, at least possible, that Prigatano et al. (1986) and Abreu et al. (2001) had not posed the questions which were the most sensitive to impaired awareness of task performance. In Stage III, participants were asked about the two aspects of task performance: ease and quality, since these aspects had been highlighted as the most helpful in Stage I and II of the 'phase 1: preliminary study'.

3.3 PARTICIPANTS

Participants were recruited on a convenience basis.

Since the main focus of interest within the thesis was persons with acquired brain injury, a greater number of acquired brain injury participants was seen in the 'phase 1: preliminary study' of the research programme, compared with healthy and spinal cord injury participants. Demographic data, relating to all ABI participants included in the 'phase 1: preliminary study', are shown in Table 3.1 (page 57) and Table 3.2 (page 58).

3.4 PROCEDURE

3.4.1 Stages I-III

The following procedure was common to all three stages of the 'phase 1: preliminary study', though the tasks within the battery, and the self-awareness questions, were altered (changes are indicated in the relevant sections below). The battery was administered to each participant once only. Before attempting each task within the battery, participants were asked to gauge, on a 5-point Likert scale, the ease with which they anticipated carrying out each task. After completion of each task, participants were asked to rate how easy or difficult they had found the task, using the same Likert scale.

The procedure relating to questionnaire administration is given in Section 3.9.

3.5 STAGE I

3.5.1 Participants

Seven ABI participants were seen in the first stage of the 'phase 1: preliminary study'. All were white with an average age of 47 years (range: 31 to 61 years), five were male. The ABI participants had a range of physical and cognitive activity limitations – including severe activity limitation (See Table 3.2, page 58, for further details). Time since lesion ranged from five months to eight and a half years. One participant was wheelchair dependent, one had severe ataxia. All participants had moderate or severe cognitive impairments.

Two of the participants were identified as having 'very poor insight' by clinicians treating them (a 61-year-old woman and a 50-year-old man). The main focus of the 'phase 1: preliminary study' was to develop measures that could be administered to people with varying degrees of 'impairment' and 'activity limitation'. Thus, participants were included whether, or not, they were identified as having impaired awareness.

Table 3.1 'Phase 1: preliminary study' – Demographic information relating to the acquired brain injury participants

	STAGE I	STAGE II	STAGE III
Number of ABI participants recruited	7	3	3
Number of male ABI participants	5	2	2
Ages (years)	47 mean (range 31-61)	22, 37, 57	29, 30, 50
Number of participants who sustained: a stroke a traumatic brain injury other acquired brain damage	4 3 0	2 0 1	0 2 1
Number of participants identified as having impaired awareness	2	0	0
From where recruited (RRC): Out-patient service In-patient service Headway	3 2 2	0 1 2	2

Table 3.2 Demographic data relating to the acquired brain injury participants' impairments

Stage I	Participant Impairments	
1	Lest neglect, lest homonymous hemianopia, visual object	
	agnosia, attention and concentration, ideomotor and	
	ideational apraxia, working memory	
2	Working memory, concentration and attention	
3	Severe ataxia, memory (delayed recall)	
4	Memory (delayed recall), executive function (problem	
	solving)	
5	Memory (severe impairment of working memory and	
	delayed recall), executive function	
6	Ataxia, balance, information processing speed and accuracy	
7	Memory (severe amnesia), executive function (initiation,	
	planning, abstract reasoning), verbal fluency	
Stage II		
1	Left neglect, left homonymous hemianopia, concentration	
	and attention, executive function (planning and organising),	
	information processing speed and accuracy, new learning	
	and relearning previously attained skills	
2	Left hemiparesis, visuo-spatial orientation, attention and	
	concentration, new learning, memory (delayed recall),	
	executive function (planning and sequencing)	
3	Memory (working memory and delayed recall), executive	
	function (initiating, planning and organising), information	
	processing speed	
Stage III		
1	Right hemiparesis, speed of information processing, memory	
	(delayed recall of verbal information), mild expressive	
	dysphasia (word finding)	
2	Working memory, attention and concentration, abstract	
	reasoning, executive function (planning and sequencing)	
3	Left hemiplegia, concentration, executive function (initiation	
	and problem solving)	

Eight healthy participants were seen (two male). All were white. The mean age of the healthy participants was 37 years (range: 25 to 54 years).

3.5.2 <u>Task battery development</u>

Initially, the Patient Competency Rating Scale (PCRS) was examined to ascertain the feasibility of using the ADL tasks, included in the scale, as a basis for the task battery. The PCRS entails asking participants about the ease with which they would be able to complete the following tasks: preparing meals; getting dressed; taking care of personal hygiene; washing dishes; doing the laundry; driving a car. Meal preparation was considered a feasible task choice, provided that 'task parameters' were made explicit. After careful consideration, it was felt that there was a number of problems with including the remaining tasks (from the PCRS) within the battery. No description is given of the task parameters, which leaves them open to differing interpretation. Getting dressed, for example could be as simple as pulling on a T shirt and shorts, or as complex as putting on a suit, including buttons, belt, shirt and tie. With regard to driving, many impairments potentially render people unsafe to drive after an acquired brain injury. It is usual practice for the Driver and Vehicle Licensing Agency (DVLA) to revoke the licence of individuals who have sustained, for example, a stroke or severe head injury. Practical assessment of on-road driving was clearly impracticable and potentially dangerous.

Seven tasks were identified, to form an initial battery to administer to all participants in Stage 1 of 'phase 1: preliminary study'. In selecting these tasks, the lead investigator drew on extensive clinical experience from working as an occupational therapist. Taken together, these seven tasks included elements that would be sensitive to: physical impairments, such as hemiparesis and ataxia; visual and perceptual impairments, e.g. homonymous hemianopia; executive impairments, relating to the ability to initiate, plan and organise tasks; and memory and attentional impairments.

The kitchen and cleaning tasks were chosen from a standardised observational test used by occupational therapists: the Assessment of Motor and Process Skills (Fisher, 1999). The test lists a large number of tasks that are arranged hierarchically according to degree of physical difficulty and cognitive difficulty. The task hierarchy was established through the

use of multi-faceted Rasch analysis (Fisher, 1999, See Appendix 12, page 20). Once trained, a user can match suitable tasks to individuals who have different degrees of physical and cognitive impairment. The kitchen and cleaning tasks are described in more detail below.

Kitchen task

After a brief discussion with each participant, to establish their degree of skill and familiarity with various kitchen tasks, he or she was requested to carry out a kitchen task deemed to be a suitable challenge.

Participants were shown the whereabouts of utensils and food items within the kitchen. Immediately before the participant commenced the task, the investigator reiterated what was required, and also asked him or her to indicate when they had finished the task. It was explained to participants that, in case of difficulty encountered during the task, they should try to resolve this by themselves in the first instance but, if unable to do so, they might ask for assistance. Kitchen tasks included: making scrambled or fried eggs, toast and a hot drink (higher than average challenge); making a hot drink (average challenge).

Cleaning task

The same format was followed for the cleaning task, as for the kitchen task. Tasks included washing up (easier than average challenge), ironing a shirt (average challenge), vacuuming a room (average challenge). These tasks form part of the hierarchical list of tasks mentioned above.

The remaining five tasks were chosen to reflect a variety of tasks that people perform regularly. The rail enquiry task and the phoning a restaurant task involved verbal communication. It was considered important that the task battery include at least one task involving communication. The hierarchical model of awareness allows for variation in awareness level across functional domains.

Rail enquiry task

Participants were requested to make a phone call to obtain information on rail travel. following written information (Appendix 13, page 21). They were required to write the answers on the instruction sheet, or to dictate answers to the observing investigator if unable to write (e.g. due to hemiplegia affecting the dominant hand). Healthy and clinical participants, with mild or no apparent cognitive deficits, were required to ascertain the time of the next train from Oxford to Paddington, time of arrival in Paddington and the price of a ticket if returning the next day before 9am. Clinical participants with cognitive deficits were required to find out the time of the next train and time of arrival, or only the time of the next train - according to the severity of their cognitive impairment. Severity of cognitive impairment was ascertained by a clinician involved in their care (occupational therapist, physiotherapist, speech and language therapist or clinical psychologist). After careful consideration, it was decided not to use cognitive test scores as a basis for categorising degree of cognitive impairment. As mentioned in Chapter 1, cognitive tests have not been shown to have robust predictive validity for everyday task performance. Clinicians were asked therefore whether the individual's cognitive impairment was mild, moderate or severe – according to their knowledge of the patient.

Phoning a restaurant

Participants were asked to phone a specific local restaurant, to obtain information about times during the week when it was possible to make a reservation. (Appendix 14, page 22)

The remaining three tasks involved organising thoughts and planning and were therefore sensitive to executive impairments:

Describing a recipe

In this case, participants were asked to describe how to make a snack, or meal, in sufficient detail, that someone unfamiliar with the recipe could reproduce it. Instructions could be written down or spoken aloud by the participant. In the latter case, the investigator wrote down the participant's instructions.

Planning a day out

Participants were asked to plan a day out in London, following written guidelines, and to calculate the costs involved. (Appendix 15, page 23)

Planning a shopping list

Participants were asked to write (or dictate) a shopping list, according to written guidelines. (Appendix 16, page 24)

3.5.3 Development of judgement criteria

Whilst participants were performing each task, the observer noted errors made and participants' awareness of error, according to the criteria devised by Hart et al. (1998). See Tables 3.3 and 3.4.

Table 3.3 Hart et al. (1998) Criteria for judging participant error

- 1. Sequencing errors
- 2. Substitution of incorrect for correct objects
- 3. Use of objects with incorrect gestures
- 4. Spatial misestimations
- 5. Spatial misorientation of objects
- 6. Omission of tool/utensils
- 7. Addition of actions not relevant to the task
- 8. Quality errors such as producing inexact quantities of materials

Table 3.4 Hart et al. (1998) Criteria for judging participants' on-line awareness of error

- 1. Verbalisations (questions or comments) acknowledging errors
- 2. Audible non-word exclamations, such as gasps, 'oops' etc.
- 3. One of three facial expressions (grimacing, smiling or laughing, or a 'distinctive' surprised look)
- 4. A strictly defined type of head shaking
- 5. Two manual gestures: throwing hand/s up rapidly and slapping forehead

Following the Hart et al. (1998) method, the observer also noted:

- 1. error is neither noticed nor corrected
- 2. error is noticed but not corrected
- 3. error is noticed and corrected

The observer, who was a very experienced occupational therapist, used clinical judgement to assign an ease/difficulty score after participant task performance. As mentioned above, this dimension of task performance was chosen as it is the dimension used within a widely used measure of awareness: the Patient Competency Rating Scale (PCRS). Thus, it was pertinent to include this dimension, whilst trialling additional dimensions. The opinion of experienced clinicians is frequently used as a gold standard within research. It was used within the Abreu et al. (2001) study. Nevertheless, it is deemed important to question the reliability of just one observer's judgements, and so the observer's clinical judgement was subjected to an inter-rater reliability study in the 'phase 2: group comparison study'.

In Stage I of the 'phase 1: preliminary study', participants were questioned only regarding the ease or difficulty pre-task (i.e. predicted) and post-task to elicit the participant's awareness of task performance. The participant and observer used the same 5-point Likert scale (See Appendix 17, page 25). Further 'self-awareness' questions were added in Stage II of the 'phase 1: preliminary study'.

3.5.4 Results

3.5.4.1 Task battery development

The *kitchen* and *cleaning tasks* were well tolerated by participants, who also appeared readily to understand the rationale for carrying out tasks of a suitable challenge. These were retained, therefore, without further alteration.

Rail enquiry

Employees from National Rail Enquiries answered the telephone within a reasonable time, and enquiries were dealt with in a clear and consistent manner. The task was retained, but altered, so that future participants were provided with the telephone number of National Rail Enquiries, because searching through a phone book greatly increased task duration in some instances.

It was not possible to standardise the task, so that each enquiry was dealt with in exactly the same way by the same employee. It was decided that the 'ecological validity' of the 'real life' task outweighed this disadvantage. It was considered that participants were more likely to be motivated if engaged in a real task rather than role-play.

Restaurant reservation

This task posed a number of problems. The restaurant employees dealing with the enquiries did not speak English as a first language, and proficiency of spoken English varied widely. A further difficulty was that some participants interrupted the call several times, to seek clarification from the observer. This led to a concern that the restaurant employees would detect that they were being approached as part of a therapy-related exercise, which might have affected their level of co-operation at a later stage of the study. Also, the task was similar in format to the rail enquiry task: use of the phone to obtain predetermined information. For these reasons the restaurant task was discarded.

The planning a day out, shopping list and describing a recipe tasks were quite similar in several respects. They were pen-and-paper tasks, relatively unstructured and require participants to generate information. One planning task was deemed to be sufficient in the interests of time, and to avoid a predominance of tasks of the 'pen-and-paper' type that could be considered more suitable within the context of cognitive impairment testing, rather than everyday task assessment. The 'planning a day out' task was retained for use in the next stage of the 'phase 1: preliminary study'.

3.5.4.2 Development of judgement criteria

With one exception – a healthy participant – none of the participants exhibited the behaviours listed by Hart et al. (1998) as demonstrating awareness of error. These behaviours include: verbalisations acknowledging errors; audible non-word exclamations, such as gasps or 'oops'; manual gestures: throwing hand/s up rapidly and slapping forehead. (See Table 3.3 above, for the complete list). Thus, this was considered an ineffective method of determining emergent ('on-line') awareness. An obvious alternative method, for determining emergent awareness of error, would involve stopping and questioning participants every time they made an error. This method was not attempted for

the following reasons. Stopping participants in this way might prompt participants into realising that errors had been made (of which they otherwise would not have been aware); some participants might be stopped many times and, potentially, this would be annoying to participants and very time-consuming.

Similarly, the Hart et al. criteria for determining error were found to be too vague and insufficiently comprehensive. This led to a concern that the criteria left too much to the interpretation of an individual rater, which could result in poor inter-rater reliability. Therefore, the investigator, who had assigned a score to each participant after task performance (on the basis of clinical experience as an occupational therapist), re-examined the notes she had made whilst observing all Stage I participant, in order to make explicit the criteria used to assign specific scores. These notes would form the basis of new judgement of error criteria. The investigator's notes were very detailed, and included, for every task, the sequence of steps used by each participant, errors made and whether errors were corrected or not. It was apparent from these notes that some errors were negligible, having little impact on the process or outcome of task performance, other errors had a serious impact. For example, some participants required the investigator to intervene, to prevent imminent danger, such as scalding.

Two additional occupational therapists, experienced in assessing individuals with acquired brain injury, agreed to examine the notes made of task performance, and the provisional criteria generated. The resultant criteria incorporated these dimensions: assistance required, speed, mistakes made, hygiene, safety, and the quality of the outcome. These categories were chosen, because all observed mistakes and problems affecting task performance could be grouped under one of these headings. The two additional occupational therapists agreed that the criteria were sufficiently comprehensive. As the lack of 'expressiveness' on the part of participants clearly presented a difficulty in judging their awareness of errors, it was decided to change the focus, from awareness of errors occurring in 'the stream of action', to a slightly more global and tangible perspective – namely, participant awareness of the relative ease or difficulty of performance, elicited by verbal enquiry, immediately after each task.

3.5.4.3 Self-awareness questions

The self-awareness questions in Stage I related to the ease/difficulty dimension only. The awareness (discrepancy) score was calculated by subtracting the participant's post-task score from the observer's post-task score. Hence, a score prefixed by a minus sign indicated that a participant had over-rated performance by comparison with the observer. The maximum discrepancy score range for an individual task was -4 to +4, and the maximum total score range for a battery of seven tasks was -28 to +28.

For the seven ABI participants, the overall discrepancy (between self-rating and observer rating) in total post-task scores (i.e. awareness score) ranged from -4 to -15 (mean -11.28). The healthy participant total discrepancy post-task scores ranged from 0 to 3 (mean 1.75). Discrepancies between self-rating pre- and post-test scores ranged from 0 to -8 (mean -3.1) for ABI participants, and 0 to -4 for healthy participants (mean -1.8).

As might be expected, the ratings for healthy individuals assigned by the observer differed little from those assigned by the participants themselves. Even the least discrepancy for the ABI participants was greater than any discrepancy score for any healthy individual. This was a clear indication that measurement of the ease/difficulty dimension was yielding ratings sensitive to participants' awareness of task performance.

On the basis of Stage I of the 'phase 1: preliminary study', the number of questions posed to participants was expanded, in order to attempt to identify the questions most likely to elicit participant views regarding performance. These additional questions were piloted in the next stage of the 'phase 1: preliminary study'. Specifically, participants were asked about the quality of their task performance; assistance needed to complete the task; the number of mistakes; length of time taken; in addition to the original question about ease/difficulty.

3.5.4.4 Participants identified as having very poor 'insight'

The two ABI participants identified as having impaired awareness gave the same pre- and post-task ratings. The first, a 61-year-old woman, had difficulty with most of the tasks. The

overall discrepancy (between her total battery rating, compared with the total rating assigned by the observer) was -15 (jointly, the highest score). She reported that she could do all seven tasks easily ('5 – Very easy to do'), before and after task performance, whereas the observer had assigned a score of '2' for four tasks ('2 – Very difficult to do') following task performance. The second participant, a 50 year old man, assigned a score of '4' before and after each task. This time, the observer ratings were more in keeping with this participant's judgements, the discrepancy rating being much less: -5. Further examination of scores in the 'phase 2: group comparison phase' of the research programme might indicate whether the task battery is more sensitive to some individuals with impaired awareness, and the possible reasons for this.

3.6 STAGE II

3.6.1 Participants

Three ABI participants were seen. All participants were white, one was male. Participants were aged: 22, 37 and 57 years. One female participant was independently mobile, the other was wheelchair dependent. Both had moderate-to-severe cognitive impairment. The third participant had severe amnesia and was very impulsive. He had no physical impairments. None of these participants was identified as having markedly impaired awareness. See Table 3.2 (page 58) for further demographic data relating to participants' main impairments.

3.6.2 Task battery development

In addition to the kitchen, cleaning, rail enquiry and planning a day out tasks, two further tasks were included within the provisional battery used in Stage II.

Watercolour task

For this task, participants were presented with a palette of water colours, a paint brush and carton of water, together with the simple outline of a flower in a pot to colour. This task was included because it was felt desirable that the battery should have a wide range of different tasks. Painting is a form of leisure activity for many.

Mail sorting task

The second novel task involved posting 24 envelopes into one of nine pigeon-hole slots in a wooden box. Each pigeon-hole was labelled; e.g. personnel department; supplies department; catering department, and so on. All the envelopes had hand-written addresses, but in different styles of handwriting. In some cases, the address was incomplete, in which case participants had to use problem-solving skills to identify where the envelope should be placed.

3.6.3 Results

3.6.3.1 Task Battery development

The kitchen, cleaning and rail enquiry tasks continued to be well tolerated by participants and were retained for Stage III of the 'phase 1: preliminary study'.

Watercolour task

All three participants managed this task easily. This was surprising, in view of the considerable cognitive and/or physical impairments present in the participants. The task was thus considered not sufficiently challenging and was discarded.

Mail sorting task

It quickly became apparent that this task was highly dependent upon intact visual acuity. It was believed that a manual task, which involved sorting items, would add a further dimension to the task battery, but this particular task was discarded as visual deficits affecting acuity are common following acquired brain injury. It was replaced by a task involving filing bills (according to written instructions) in a lever arch file. In the light of the experience with the mail sorting task, enlarged versions of all written and pictorial information were made available for individuals with reduced visual acuity.

Planning a day out

Participants in Stage II interpreted this task in different ways. In particular, participants varied in terms of the degree of detail that they included in their plan. Results also appeared to be overly dependent upon participants' experience of travelling to London. It

was decided to replace this task by a more structured planning task, less dependent on knowledge of travelling to, and spending time in, a particular place.

Because the above tasks were found to be unsuitable after the trial with three ABI participants, no further participants were seen in Stage II.

To avoid the battery taking too long to complete, at the conclusion of Stage II it was decided that the battery should have a maximum of six tasks. In order to fulfil the criterion that the task battery have a sufficiently broad range of tasks, a search was undertaken to identify a suitable 'object assembly' task, a filing or sorting task, and one pen and paper task involving planning.

A large number of object assembly tasks was considered but were discarded without being trialled for the reasons given below:

- too big and unwieldy and considered unsuitable for participants who were wheelchair dependent or with use of only one arm
- 2) too demanding in terms of fine motor skills prohibitive for participants with functional use of only one arm; in some cases their non-dominant arm
- 3) too abstract in design (e.g. some adult jigsaws and puzzles) when complete, it was unclear what the finished product represented. The product could be considered, therefore, to lack ecological validity;
- 4) not age-appropriate; e.g. the object was obviously designed to be assembled by a child.

3.6.3.2 Development of judgement criteria

The six dimensions, devised to guide observer judgement of performance, were found to be sufficiently comprehensive. When applied to participant task performance in Stage II, all observable areas of difficulty were detected by the criteria. Those for assistance required, speed, mistakes and safety seemed most relevant to consider in relation to the ease/difficulty rating. Outcome and hygiene were most appropriate to judgements relating to how well the task had been performed. Evidently, some of the dimensions were applicable only to some of the tasks; to illustrate, hygiene was most pertinent to the

cooking and cleaning tasks. Further refinement of the criteria seemed advisable, to make the observer's judgements more explicit; e.g. to demonstrate when a mistake was sufficiently serious to warrant a score of '1' ('Can't do') rather than a score of '2' ('Very difficult to do'). The refined criteria could then be tested as part of an inter-rater reliability study in association with the task battery, to facilitate psychometric testing during the next (group comparison) phase of the research programme. The first draft of these refined criteria were reviewed by the two occupational therapists who had examined the criteria in Stage I. Changes were made to the draft criteria by consensus.

As only three participants were seen in Stage II, it was felt important to consider the criteria in respect of participants' task performance in Stage III, before refining them further.

3.6.3.3 Self-awareness questions

Since asking several questions regarding different dimensions of task performance, was found to be unproductive (and possibly overwhelming for participants with cognitive impairment), it was decided to limit questioning to two dimensions for the third stage of the 'phase 1: preliminary study'. Participants were asked to make an ease/difficulty rating, before and immediately after, task completion (as for Stages I and II). In addition, they were asked to make a before and after rating about how well or badly they expected to perform each task and how well or badly they thought they had done (Appendix 17, page 25). It was considered that these dimensions covered two different aspects of task performance (process and outcome). It is unknown which of these two dimensions is the more sensitive to awareness. Inclusion of both within the 'phase 2: comparison study' would give an opportunity to compare the merits of these two dimensions.

3.7 STAGE III

3.7.1 Participants

Nine participants were seen in Stage III: three ABI, three healthy and three individuals who had sustained a spinal cord injury.

The three ABI participants were white, aged 29, 30 and 50 years. Two were male and the third was female. All were independently mobile, two had the functional use of one arm only and moderate cognitive impairment. One participant had severe cognitive impairment but no physical impairments. (See Table 3.2, page 58).

The three participants with spinal cord injury were all recruited from the in-patient service at Stoke Mandeville Hospital and all were male, aged 21, 23 and 53 years. Two had sustained traumatic lesions, one had a spinal abscess, all had paraplegia. The oldest participant was Afro-Caribbean.

The three healthy participants were all female, aged 27, 44 and 63 years.

The ABI participants and the healthy participants were seen in the Occupational Therapy department at Rivermead Rehabilitation Centre. The participants with spinal cord injury were seen in St Joseph's ward kitchen at the Spinal Unit in Stoke Mandeville Hospital.

3.7.2 Task battery development

Three further tasks were added to the kitchen, cleaning and rail enquiry tasks, retained from Stages I and II. As some of the kitchen task options involved making time-consuming meals, a decision was taken that all future participants would be asked to do only the hot drink and toast task. According to the task hierarchy (Appendix 12, page 20), this task is above average in challenge.

Object Assembly task

Participants were asked to assemble 13 pieces of wood to make a plant stand (Appendix 18, page 26). The kit included four screws, four bolts and a spanner. A line drawing of the finished product served as a guide (Appendix 19, page 27).

Filing task (to replace the mail sorting task).

Participants were presented with six types of household bills, a lever arch file, three plastic wallets and a bulldog clip. They were asked to file the bills according to written instructions (Appendix 20, page 28).

Timetable task

This task replaced the three planning tasks trialled in earlier stages of the 'phase 1: preliminary study'. Participants were presented with a page listing the activities that needed to be scheduled into a working day (Appendix 21, page 29). They were requested to write, on a separate page, (or dictate) the order in which the tasks would be carried out (including the time each task would begin).

3.7.3 Results

3.7.3.1 Task battery development

Object assembly task

(Appendix 18, page 26). Both ABI participants with monoplegia (paralysis in one arm) were able to complete the object (plant stand) without prompting, finding alternative ways to stabilise the object, whilst tightening screws and bolts. The third ABI participant required some minimal prompting to complete the task. All ABI participants were able to complete the task while seated.

In order to reduce the amount of time for participants to complete the model (to keep the overall time for task battery administration within reasonable limits), it was decided, for the 'phase 2: group comparison study', to present the object to participants with the 'feet' blocks already attached to the lower 'legs', and the 'head' already attached to the 'torso'; that is, in 10 pieces, rather than 13. This task was different from the others, in that all participants were equally disadvantaged by never having seen the object.

The three participants with spinal cord injury, and two of the healthy participants, were able to complete the model with comparative ease. An exception was the oldest healthy participant, who spent a long time (half an hour) trying to work out how the plant stand should fit together, before giving up.

Timetable task

Some participants asked for similar points of clarification (and a map), which were incorporated into the instructions subsequently. In addition, a 'diary' page, divided into half-hour slots, replaced the blank page (Appendix 22, page 30).

This task involved planning but circumventing the problems encountered with the three earlier planning tasks. Organising tasks to be performed during the day could be considered to come within most people's experience. The task was more straight forward to score than the earlier planning tasks, because it allowed for less subjective interpretation. The final version is shown in Appendix 21, page 29.

Participants who were unable to write (perhaps because of hemiplegia affecting their dominant hand), were permitted to dictate responses to the observer. A matrix was devised for scoring the timetable task (Appendix 23, page 31).

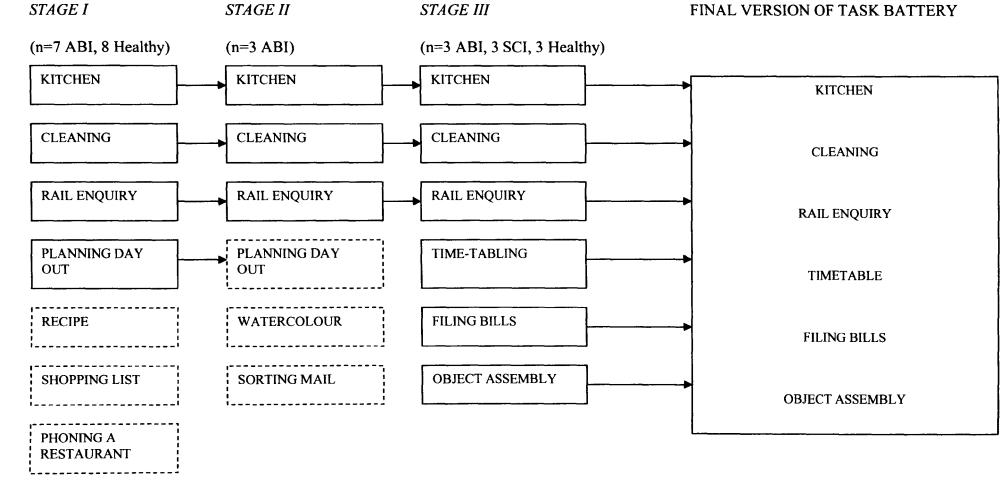
Filing task

Although not all the participants filed household bills regularly, the task of filing papers was familiar. An exception was the Afro-Caribbean participant with a spinal cord injury, who struggled with the task. This participant was suspected by his therapists of having some degree of cognitive impairment. This assumption highlighted the need to screen people with a spinal cord injury in the 'phase 2: group comparison study', in an attempt to exclude those with cognitive impairment.

The remaining two participants with a spinal cord injury and the three healthy participants managed the filing task reasonably easily. The two ABI participants with monoplegia affecting an upper limb (in one case involving the dominant hand), had physical difficulty with the task but managed it eventually without assistance from the observer. The third ABI participant also had difficulty with the task, because of cognitive deficits.

Figure 3.1 (page 74) shows how the final version of the task battery was determined during the 'phase 1: preliminary study.

Figure 3.1 Development of the final version of the task battery



Discarded tasks (reasons for discarding tasks are given in the text)

3.7.3.2 Development of judgement criteria

The criteria used to guide the observer judgement of participant task performance continued to seem relevant and comprehensive. Minor changes were made to the criteria following participants' performance in Stage III. The criteria are shown below in Table 3.5.

Table 3.5 Criteria for judging task performance in relation to 'Ease' and 'Quality'

1. EASE OR DIFFICULTY

Each observer should give an overall score from the following scale (the participant also uses this scale when judging the ease or difficulty of the task).

- 1 = Can't do
- 2 = Very difficult to do
- 3 =Can do with some difficulty
- 4 = Fairly easy to do
- 5 = Can do with ease

However, in judging the relative ease or difficulty that a given participant has with any task, the following dimensions should be taken into consideration: assistance required; number and gravity of mistakes made; safety whilst engaged in the task; speed. The observers should use their own discretion in making the ease or difficulty judgement but some guidelines are given below to assist this judgement.

Assistance required

- 1 = Considerable amount of assistance required in terms of physical assistance or verbal prompting (due to physical and/or other difficulties, such as cognitive deficits).
- 2 = Unable to complete one component of task without major assistance verbal and/or physical; needs slight assistance (physical or verbal) repeatedly (four or more times)
- 3 = Needs moderate amount of verbal or physical assistance once, or slight assistance up to three times.
- 4 = Needs negligible amount of assistance once or twice.
- 5 = Requires no assistance (other than very minor, sensible clarification on one occasion). Clarification questions occurring prior to task performance are not scored.

Note: Generally, assistance would be given only if requested, and participants are made aware of this before starting each task. If the participant 'gives up' before completing a task, this should be scored accordingly. For example, if very little of the task has been completed, or completed wrongly, this would equate with a score of '1', and so on.

Assistance may be offered on other occasions, should this seem warranted, e.g. participant puts himself or herself at risk; takes an inordinately long time to do something, and so on.

Mistakes (Examples are given below – they are not intended to be exhaustive)

- 1 = Drops major utensil more than once; use of completely inappropriate utensil (e.g. tries to fry eggs on a plate).
- 2 = Drops minor items several times; makes minor mistake repeatedly (three or more times).
- 3 = Drops major item once; drops minor items twice.
- 4 = Chosen utensil incorrect but not majorly so.
- 5 = No mistakes; one minor mistake that is resolved quickly and effectively.

Safety

- 1 = In imminent danger of cutting self with utensil; falling; scalding; setting fire to food etc., e.g. requires intervention from observing therapist.
- 2 =Danger less imminent than 1.
- 3 = Puts self in some danger on one occasion, but realises this and takes necessary evasive or corrective action.
- 4 = Safety questionable on one occasion.
- 5 = Safe.

Speed

- 1 = Unquestionably too slow; too fast in a way that affects task adversely.
- 2 = Very slow, but makes progress.
- 3 = Not very slow, but still clearly slower than average.
- 4 = Questionable; reasonable pace overall, too slow for short periods.
- 5 = Reasonable rate.

Note: At times participants might 'struggle' noticeably with the task, but this might not necessarily impact on their speed or safety. Examples include: laboured breathing and marked signs of pain, during task performance. Where these (or comparable) behaviours are marked, they should be interpreted as indicating that the participant is having difficulty with the task. The score given would depend on the severity of the difficulty.

2. QUALITY

Ouality should be judged mainly according to the outcome/end result.

The observing therapist should give a single overall score from the following scale (the participant will also use this scale, in judging how well or badly they believe they have performed the task).

- 1 = Badly
- 2 = Not very well

- 3 = Reasonable
- 4 = Quite well
- 5 = Well

As before, the observer should use their discretion but bear in mind these guidelines.

Outcome/end result

- 1 = Unacceptable outcome; e.g. burn mark onto garment; prepared food is inedible or burnt; made something markedly different from what was originally agreed.
- 2 = Outcome is poor but not completely unacceptable; e.g. only half correct/complete.
- 3 = Slightly different end product, or end product only reasonable (but more than half correct/complete).
- 4 = End product is acceptable but in some way imperfect (incomplete in some minor way).
- 5 = No problem.

Note: Hygiene should be taken into consideration in relation to the quality of the outcome. Unacceptable hygiene would equate with a score of 1; poor hygiene with a score of 2 and questionable hygiene with a score of 3 or 4.

3.7.3.3 Self-awareness questions

Participants were required to give 'before' (predictive) and 'after' scores of their task performance for each task within the battery. However, it became apparent, during the 'phase 1: preliminary study', that the key score, for identifying awareness impairment with regard to the task battery, was the discrepancy between participant self-ratings and the score assigned by the observer after task performance. Because some participants with ABI had not undertaken all of the tasks in the battery since their stroke or brain injury, the pre-task (predicted) score inevitably involved guesswork. The observer did not assign a pre-task score since previous knowledge of participants' ability with everyday task performance was limited. For exploratory purposes, pre-task ratings continued to be elicited from participants.

The participants with ABI and spinal cord injury frequently made a distinction between task difficulty and quality of the outcome, assigning a different score for each of these dimensions, both before and after task completion. Questions addressing 'ease' and 'quality' dimensions were retained, therefore, for the group comparison study. The tendency to make a distinction between the two dimensions was less manifest amongst the

healthy participants, because, mostly, they gave the maximum available pre- and post-test score. Thus, ceiling effects were apparent with healthy participants.

The overall discrepancy score for each participant (i.e. discrepancy between the ratings given after task performance by the participant and the observer) was termed the 'awareness score', and was calculated by adding up the discrepancy for each of the six tasks. (This was calculated for the ease/difficulty ratings only, since all 'phase 1: preliminary study' participants used this rating, whereas the quality of outcome rating was introduced in Stage II of the 'phase 1: preliminary study'.) The range of discrepancy between the observer and healthy participants was 0 to -3, the range for the spinal participants was -1 to -12 (although the score of -12 was attained by the participant suspected of having concurrent cognitive impairment). The range for the ABI participants was -4 to -17. The ABI participant, identified by clinicians as having very poor insight, attained an awareness score of -15. The participant with the highest awareness score (i.e. the poorest level of awareness) was one of the participants from Headway, and who had been discharged from Rivermead Rehabilitation Centre several years earlier. He lived alone and had not been in touch with clinical services since discharge, so it was not possible to obtain third-party data in relation to his level of awareness. As the main focus of the 'phase 1: preliminary study' was to develop a task battery, participants were not excluded on the basis of having no significant other.

3.7.3.4 Participants identified as having very poor 'insight'

Stages II and III

No participants were seen in Stages II or III who were identified (by their clinicians) as having impaired awareness.

3.8 DISCUSSION – TASK BATTERY DEVELOPMENT

3.8.1 Task battery development

In the 'phase 1: preliminary study', the inclusion of ABI participants, with a wide range of cognitive and physical disability, gave some grounds for ensuring that the resultant task

battery could be attempted by a large proportion of persons with acquired brain injury. Grading the cognitive demands of the harder tasks did facilitate the willingness of some participants to attempt tasks of which they felt unsure. On this matter, the observer (who had limited knowledge of participants' everyday task abilities) was guided largely by participants' views of their abilities. In some isolated cases, 'capable' participants claimed that they could only attempt the most 'easy version' of some tasks. This resulted in more accurate judgements, i.e. their ratings coincided more closely with the observer's. This might have affected the overall group results, but only to a limited extent. In view of this experience, further advice was sought from referring clinicians in the 'phase 2: group comparison study', in order to grade tasks effectively.

Major practical difficulties were encountered with several tasks sampled during the 'phase 1: preliminary study'. In a number of cases this resulted in the discarding, or revamping, of tasks. This underlines the importance of piloting tasks. Experienced clinicians or researchers might feel they have good intuitive knowledge of which tasks might be suitable – the 'phase 1: preliminary study' illustrated that intuition is not a substitute for sampling tasks 'in vivo'. In effect, the 'phase 1: preliminary study' served as a pilot study. The main aim was to develop a task battery and the design was flexible: although a number of tasks were identified at the outset of the 'phase 1: preliminary study', no assumption was made that any of the initial tasks would form part of the final task battery. Although some tasks were retained, even these were modified following testing with 'phase 1: preliminary study' participants.

3.8.2 <u>Self-awareness questions</u>

The ease or difficulty (self-awareness) measure of task performance was used in Stages I to III and was found to be sensitive to awareness impairment, within the limited context of the 'phase 1: preliminary study'. The attempt to generate other questions that were also sensitive to detecting impaired awareness was mostly fruitless. An exception was the 'quality' rating (participants were asked 'How well do you expect/did you perform...?' each task). In Stages II and III participants did appear to make a distinction between ease and quality ratings. However, the majority of participants were seen in Stage I (n=15), and too few participants were seen (n=12) in Stages II and III to make a clear judgement on the

relative usefulness of the 'quality' rating. This became one of the aims of the next 'phase 2: group comparison study'.

The ease/difficulty rating yielded disparate (awareness) scores, which did appear to distinguish between groups, notably the acquired brain injury and healthy participants. This was so, even though only two of the thirteen participants with acquired brain injury were identified (by clinicians) as having markedly impaired awareness. One caveat to this was that four of the ABI participants had been out of contact with clinical services for a long time, so clinician judgements regarding their degree of awareness were not available. Nevertheless, the result gives grounds for speculating that impaired awareness might lie on a continuum, with most persons with ABI having some degree of impaired awareness, compared with healthy matched counterparts. Further clarification on this point will be sought in the next phase of the study.

It became apparent, at an early stage of the 'phase 1: preliminary study', that acquired brain injured participants' responses to predictive (pre-task) questions were quite random and therefore less useful than post-task ratings. This, of course, raises a further doubt regarding the reliability of methodologies relying on verbal report alone. Such questionnaires could be picking up similar 'random' guesses from participants. For example, the Patient Competency Rating Scale involves asking brain injured people how easily they can perform 30 different activities. It is probable that those being interviewed have not attempted all 30 activities since their brain injury. In this case, their judgement would be based on a best guess, rather than actual experience.

3.8.3 Development of judgement criteria

Criteria for judging awareness of error

The apparent lack of applicability of the Hart et al. (1998) criteria with this sample might be due to cultural differences in behaviour between the United States and the England – the English counterparts being less expressive generally. This highlights the importance of piloting criteria, which have been developed in a different culture, before using them in a longer study. Hart et al. (1998) failed to mention that their criteria might have limited applicability outside the United States. In this initial part of the' phase 1: preliminary

study', the only way of realising that a person had become aware of an error, was that they corrected it; for example, when an individual dropped a spoon and picked it up immediately.

Criteria for judging error

Establishing criteria for judging error demonstrated that existing published criteria might not be transferable from one task battery to another. Indeed, existing criteria could be found lacking in detail and leave too much to the interpretation of an individual observer. The final criteria identified were determined by careful and painstaking effort to tease out, and make explicit, the judgements being made by the investigator, who acted as the main observer. It is postulated that it would be difficult to replicate a study for which judgement criteria were not made explicit. Hart et al. (1998) circumvented this issue by stating that occupational therapists, with at least 10 years' experience, should judge task performance. It is argued that, if judgement criteria can be made explicit, this should be done. In the 'phase 1: preliminary study', a task similar to a task from the Hart et al. battery was used: writing out a recipe for a nutritionally balanced meal. In the 'phase 1: preliminary study', this task was rejected because participants interpreted the instructions so divergently that it was found to be extremely difficult to score consistently. Recourse to expert judgement alone should be used only when no other method is possible.

One possible short-coming of the ease dimension is that some aspects of difficulty, experienced by participants, might not be observable to the investigator. It is possible, for example, that some participants could act as though they were not in pain (when, in fact, they are).

3.8.4 Participants identified as having very poor 'insight'

The two participants identified as having impaired awareness, gave pre- and post-task scores that did not vary. This could be taken to indicate a certain lack of flexibility in altering judgements in relation to self. If this lack of flexibility were entrenched, and extended to other domains, this could explain why clinicians' rehabilitative efforts had been thwarted, resulting in participants being considered to have impaired 'insight'. Neither participant demonstrated defensive ('over-sensitive') reactions during testing,

which might be an indication of a primarily, organically based, awareness impairment (Prigatano and Klonoff, 1998). Prigatano and Klonoff also suggested that organically based awareness deficits might be the most resistant to treatment. Other participants demonstrated impaired awareness (as compared with healthy participants) but, in most other cases, acquired brain injury (ABI) participants did modify their post-task score to some degree. Data on further ABI participants could help clarify whether this inflexibility is common in participants identified as having impaired awareness.

Not withstanding this, the male participant with impaired awareness had little reason to change his post-task scores, because his pre-task scores were reasonably accurate. The fact that the battery - in conjunction with the self-awareness questions - seemingly was not detecting impaired awareness in the case of this participant might be an indication of the ceiling effects in the task battery, or the multi-dimensional nature of impaired awareness. In order to try to understand what was happening in this participant's case, the observer approached the treating psychologist and occupational therapist for further enlightenment. The psychologist stated that she considered the man to lack insight because he had obtained low scores on tests of cognitive impairment, but seemed unconcerned by this, supposedly not seeing the relevance of it. This is interesting, because the participant managed most tasks in the battery 'fairly easily', so he did seem to be performing everyday tasks at a higher level than would be expected from the cognitive impairment test results. This might, in turn, explain why he seemed unconcerned by the cognitive test results. As already noted, cognitive impairment tests have not been shown to have reliable predictive validity for everyday task performance (Allen and Ruff, 1990; Heaton and Pendleton, 1981). The occupational therapist had difficulty pinpointing why she considered the participant to have impaired awareness, stating that the participant seemed not quite 'with it'. Both psychologist and occupational therapist acknowledged that despite several weeks of therapy, there had been no functional change in the participant and that they were unsure why this was so.

The above was an illustration of two clinicians, on the same team, conceptualising a participant's lack of awareness in contrasting ways. A closer examination of therapists' reasons for identifying participants as having poor insight might help identify patterns of impaired awareness that are particularly challenging to the treatment team. In order to examine this in more depth, it was decided that ABI participants in the 'phase 2: group

comparison study' should incorporate one group of ABI participants who would be identified specifically by their clinicians as having impaired awareness, as well as a comparison group of ABI participants identified as having intact awareness. In both cases, clinicians would be asked for a numerical rating scale rating of severity of the impaired awareness, as well as verbal report of manifestations of impaired (or intact) awareness. This could help to increase the existing knowledge base regarding the characteristics or manifestations of awareness deficits that are most problematic clinically.

3.9 THE QUESTIONNAIRES

3.9.1 Aims relating to the questionnaires

- i) To explore the feasibility of using a questionnaire developed in the United States to ascertain awareness level in acquired brain injury (ABI) participants: the Patient Competency Rating Scale
- ii) To determine the feasibility of using a questionnaire to ascertain ABI participants' awareness of their social skills deficits: the Social Communication Skills Questionnaire
- iii) To explore the feasibility of using the Hospital Anxiety and Depression Scale with ABI participants (to examine the effect of mood anxiety and depression on awareness).

The aims relating to the Patient Competency Rating Scale and the Social Communication Skills Questionnaire are included because the literature review indicated that no single method for determining awareness stood out as a 'gold standard'. In view of this, it was deemed to be important to measure awareness by a variety of methods. The most commonly used approach in determining awareness is comparison of self/third-party verbal report. The Patient Competency Rating Scale is the questionnaire that is most widely cited in relation to measuring awareness of everyday abilities by self/third-party comparison approach. To determine awareness of social skills, the Social Communication Skills Questionnaire was selected. Both questionnaires were developed in the United States and mostly used with North American patients. To date, there are no published studies demonstrating that these questionnaires have been used with English persons. In view of

this, it was felt important to test out the questionnaires with English participants, prior to using them in later phases of the research programme.

3.9.2 Procedure

The Hospital Anxiety and Depression Scale (HADS) was administered to all participants throughout the three stages of the 'phase 1: preliminary study'; the PCRS was administered to all ABI participants, and third parties where possible (clinician and significant other). The Social Communication Skills Questionnaire (SCSQ) was introduced in Stage 3 and administered in the same manner as the PCRS, that is, to ABI participants and third parties only. The sequence of administration of the questionnaires is shown diagrammatically in Figure 3.2 (page 85).

Questionnaire details – see Chapter 2, Section 2.9.2, page 50.

Participant details – see Chapter 3, Section 3.3, page 55.

3.9.3 The Hospital Anxiety and Depression Scale

3.9.3.1 Results

For the thirteen ABI participants recruited, one attained a borderline score, and another recorded an abnormal score for anxiety (see Table 3.6, page 86). For depression, five had either a borderline or abnormal range score. All the participants with a spinal cord injury attained scores within the normal range. Four, of the eleven healthy participants included in the 'phase 1: preliminary study', had either a borderline or abnormal score for anxiety. All healthy participants had scores within the normal range for depression.

HADS and Task Battery Awareness Scores

The 'awareness scores' mentioned above were correlated with the anxiety and depression ratings respectively (for all participants). No correlation was found between the anxiety and discrepancy ratings (Spearman's rho = 0.08), but there was a moderate positive correlation between the discrepancy and depression ratings (rho = 0.63, P=0.01, n=27)).

Figure 3.2 Sequence of administration of questionnaires in the 'Phase 1: preliminary study'

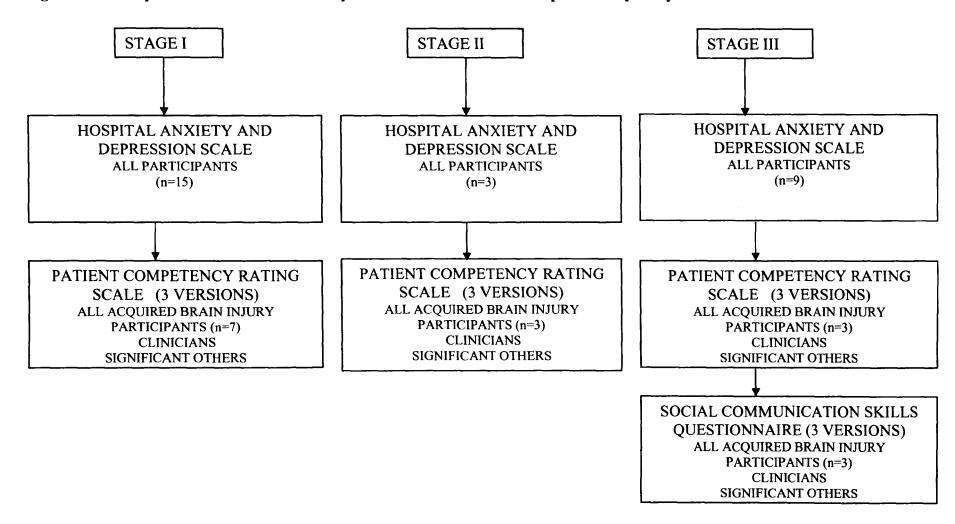


Table 3.6 Hospital Anxiety and Depression Scale – Raw scores

Healthy Participants (n = 11)

Anxiety Score	Depression Score
6	1
4	3
3	0
9*	2
3	0
11**	5
3	0
8*	1
4	3
9*	2
5	0

ABI Participants (n = 13)

Anxiety Score	Depression Score
13**	10*
5	11**
0	3
8*	11**
	4
6 5	1
6	5
3	4
11**	7
3	9*
2	1
7	7
7	12**

Spinal Participants (n = 3)

Anxiety Score	Depression Score	
4	3	
3	3	
3	6	

Score range for each of the scales: anxiety and depression: 0 to 21

0 to 7 = normal score

In respect of the two participants identified by their clinicians (Stage I) as having impaired awareness, the female participant had scores within the normal range for anxiety and depression. The male participant had a borderline score on the depression scale.

3.9.3.2 Discussion

The HADS was retained for use in later phases of the research programme, since it was found to be well tolerated – perhaps because of its brevity – and well understood by all participants, including those who had marked cognitive impairment. The scale was sufficiently sensitive, even detecting mild anxiety in four healthy participants. For this sample, ceiling effects were not found in relation to either the anxiety or depression sections of the scale.

The moderate positive correlation between depression scores and awareness scores indicates that mood could be a factor affecting participants' self-ratings. The relationship between mood and self-awareness will be explored further in the 'phase 2: group comparison study'.

^{*8} to 10 = borderline score

^{* 11} to 21 = abnormal score

3.9.4 The Patient Competency Rating Scale

3.9.4.1 Results

Where third-party ratings were available, these were computed and compared with participant ratings. The number of items was calculated for which each participant's score was greater than (i.e. 'over-estimating'), equal to, or less than (i.e. 'underrating') a therapist and/or significant other. If the largest number of items fell into in the 'greater than' category (than into either of the other two categories), it was assumed that the participant was over-estimating his or her behavioural competence (Prigatano et al., 1990).

Significant other ratings were obtained for seven ABI participants. In this case, five participants came within the category of overestimating behavioural performance. The remaining two participants had the most items within the 'equal to' category. Clinician ratings were obtained for nine ABI participants, of which seven were found to be overestimating performance. Two were underestimating performance.

Therapist and significant other ratings were obtained for five participants. For these five participants, therapist and significant other discrepancy ratings placed participants in the 'over-estimating' behavioural competence category. A closer examination of ratings revealed that the therapist ratings were more severe than significant other ratings in three instances, and more lenient in two cases.

The five participants, for whom therapist and significant other ratings were obtained, included the two ABI participants identified as having markedly impaired insight. In both cases, therapist ratings were more severe than significant other ratings, but only marginally so: 23 (out of a total possible awareness score of 30) compared with 21, and 22 compared with 18 respectively.

Two participants were categorised as 'underestimating' behavioural performance. Both had normal range scores for anxiety; one had a normal range score for depression (but was on anti-depressant medication), the other had a score within the abnormal range for depression.

3.9.4.2 Discussion

Although there are no published studies demonstrating that the PCRS has been used with a UK population, none of the questions seemed culturally inappropriate to this sample.

In keeping with other studies, most of the ABI participants in the 'phase 1: preliminary study' over estimated their behavioural competence, according to the PCRS discrepancy ratings. This was so, even though only two of the participants were specifically identified by clinicians as having impaired awareness.

3.9.5 The Social Communication Skills Questionnaire

The Social Communication Skills Questionnaire (McGann et al., 1997) was introduced in Stage III of the 'phase 1: preliminary study', to explore ABI participants' awareness of social interaction difficulties. In Stages I and II of the 'phase 1: preliminary study' several significant others stated, in response to items in the Patient Competency Rating Scale, that it was lack of awareness of social skills deficits that put most pressure on familial relationships. As noted in Chapter 1, this finding was in keeping with Boake's (1991) observation that family members found changes in social skills to be the most distressing consequence of brain injury.

Within the International Classification of Function, social skills deficits can be conceptualised as impairments. Nevertheless, social skills are critical for adequate performance at the participation level of function, as well as being a prominent aspect of some everyday tasks – activity level of function.

A search of the literature indicated many measures of social skills deficits but not many measures designed to determine awareness of such deficits. Few were appropriate to administer directly to individuals with brain injury. Even those measures designed for this purpose used language unlikely to be understood by a lay person without brain injury and were not selected.

McGann et al. (1997) described the Social Communications Skills Questionnaire, which was being used as a tool in a rehabilitation programme in the United States. Brain injured

individuals were asked to rate the frequency ('Always', 'Often', 'Sometimes', 'Rarely', or 'Never') with which they engaged in social interaction behaviours – eliciting their views regarding both appropriate, and inappropriate, social interactive behaviour. Importantly, the psychometric properties of the scale have not been tested to date. The scale was selected in preference to other scales, because none of the existing validated scales was designed to be administered directly to individuals with acquired brain injury (ABI). Indeed, the terminology in these scales was considered too technical for this purpose. As the aim was to address ABI individuals' awareness, the ability to administer the questionnaire directly to individuals with acquired brain injury, using everyday language, was imperative. For the purposes of this thesis, third party versions of the SCSQ were devised so that the questionnaire could be analysed in the same way as the Patient Competency Rating Scale. Having established that the questionnaire was suitable, it was used throughout the remaining phases of the research programme. (See Appendix 24, page 32.)

3.9.5.1 Results

All three participants in Stage III had over estimated their social interaction skills, compared with their therapists' ratings (i.e. they had more items in the 'greater than' category, than in either of the other two categories). This was most marked for the female patient who had assigned herself a maximum score for all 26 items. There were data from this participant's mother, whose scores were similar to the therapist's, although somewhat more lenient.

Despite being administered to a very small number of ABI participants and associated third parties in Stage III, the SCSQ did appear to be addressing relevant aspects of everyday social behaviour. Participants seemed to understand the meaning of all the questions, and did not appear to find any of the questions 'unacceptable'.

3.10 DISCUSSION – QUESTIONNAIRES

As with the Patient Competency Rating Scale (PCRS), the Social Communication Skills Questionnaire (SCSQ) had not been used previously with a UK population. Nevertheless, none of the items seemed culturally inappropriate, when used in Stage III of the 'phase 1:

preliminary study' – although it was administered to only three participants, their therapists and one significant other. Some items of the scale seemed very similar to each other, and it is therefore possible that the scale could have been shortened. However, as the scale has not been subjected to any psychometric testing to date, a decision was taken to continue to use the scale, in its original form, during the 'phase 2: group comparison study'. The literature suggests that reduced awareness of impaired social skills is a major, and often long-term, problem following acquired brain injury. It was considered that the social skills domain is a critical for everyday living, and thus warranted further investigation.

The 'phase 1: preliminary study' demonstrated that the SCSQ – in addition to the PCRS and the HADS could be used reliably with ABI participants who have mild to severe cognitive impairment.

3.11 CONCLUSIONS – TASK BATTERY DEVELOPMENT AND

QUESTIONNAIRES

The main outcome of the 'phase 1: preliminary study' related to development of a task battery that would be the main measure in the next phase of the research programme: the 'phase 2: group comparison study'. Through a number of trials, tasks were refined, or discarded and replaced by others. Careful sampling of the tasks helped to ensure: that they could be administered to persons with varying degrees of physical and cognitive impairment; that they did not take too long to complete and that they could be rated consistently. Administration of the battery to a larger number of participants in the 'phase 2: group comparison study' might indicate whether any specific tasks are more sensitive to awareness impairment, and whether the task battery could be refined further.

In view of the negligible use made of pertinent comparison groups in earlier studies, and having developed a suitable battery with great care, it was decided that response to the battery would be examined more fully by use of three comparison groups. The 'phase 1: preliminary study' indicated that not all individuals with acquired brain injury lack self-awareness. Bearing this in mind, an acquired brain injury group, identified as lacking awareness, would be selected and compared with three further groups. The further groups would consist of: acquired brain injury but having no apparent awareness impairment; spinal cord injury; healthy.

Because clinicians would be responsible for identifying individuals as having impaired or 'intact' awareness, this would provide an opportunity to explore how clinicians are conceptualising awareness. This area has received scant attention in the literature. Clinicians' descriptions will be addressed in Chapter 6.

The Hart et al. (1998) criteria, for judging error during task performance, were found to be incomplete in the context of the task battery developed here, and were replaced by more specific, detailed guidelines. These guidelines made explicit the criteria being used by the investigator in judging task performance. Since observer judgement of task performance is critical in calculating a participant's 'awareness score', the guidelines were subjected to inter-rater reliability analysis during the 'phase 2: group comparison study'.

Measurement of awareness of post-task performance along the ease or difficulty continuum appeared to be sensitive to detecting impaired awareness. The comparative sensitivity of an additional dimension, 'quality' of outcome, will be examined in the next phase of the research: the 'phase 2: group comparison study'.

The Hart et al. (1998) criteria, for assessing participants' awareness of error during task performance in this study, were found inapplicable to participants, and could suggest that the criteria are less culturally relevant to English nationals. The Hart et al. criteria aimed to assess 'emergent' or 'on-line' awareness. Alternative means of assessing emergent awareness of error were ruled out as being too impracticable. It is argued that asking an individual about task performance immediately afterwards is still a measure of emergent awareness, albeit indirect.

In the course of the 'phase 1: preliminary study', lack of awareness of social skills deficits, was highlighted by some significant others as being particularly disruptive to family life. Despite the small numbers seen in the 'phase 1: preliminary study', there was an indication that awareness was variable across domains within some individuals. That is, some individuals appeared to lack awareness of everyday task ability but not social skills deficits, and vice versa. A questionnaire to address social skills was included therefore in the last stage of the 'phase 1: preliminary study'. Although not the main focus of the 'phase 2: group comparison study', this questionnaire could be used to explore this issue

further. It seemed probable that individuals, who primarily lack awareness of the social skills domain, might be referred to the 'phase 3: case studies'.

There was little indication in the 'phase 1: preliminary study' that anxiety or depression might have an effect on participants' self-rating. Nevertheless, the literature review indicated that this might be an important factor, and that the relationship between mood and impaired awareness should continue to be explored in the next phase of the research programme.

Results from the small numbers of participants included in the 'phase 1: preliminary study' indicated that the measures used were sensitive to impaired awareness. This was demonstrated by the larger discrepancies between ABI participant ratings and observer ratings (in the case of the task battery), and by participants' therapists and/or significant others (in the case of the questionnaires).

Apart from development of a task battery to capture awareness of activity, the 'phase 1: preliminary study' provided an opportunity to test out all of the measures that would be used in the 'phase 2: group comparison study'. In this sense, it served as a pilot study.

CHAPTER FOUR

PHASE 2: GROUP COMPARISON STUDY

4.1 INTRODUCTION

The dearth of suitable measures of awareness of everyday task ability has been discussed in Chapter 1. Development of a measure of awareness of everyday task ability was the focus of Chapter 3. The main aims of the 'phase 2: group comparison study' relate to the application of these methods to an acquired brain injury group, identified as lacking in awareness, and three comparison groups.

4.2 AIMS OF PHASE 2: GROUP COMPARISON STUDY

- To apply the methods developed in Chapter 3 to determine whether the awareness level of acquired brain injury persons (identified by clinicians as having impaired awareness) differs significantly from that manifested in individuals in three comparison groups: healthy; spinal-injured and brain-injured (identified by clinicians to have intact awareness)
- ii) To determine whether persons with acquired brain injury (ABI) demonstrate differing degrees of awareness in relation to different tasks within the activity level of function
- iii) To compare ABI individuals' awareness of everyday task performance (activity level of function) with a standardised questionnaire measuring awareness
- iv) To explore whether mood (anxiety and depression) is associated with impaired awareness of the activity level of function
- v) To determine ABI participants' awareness of social skills impairments by administration of the Social Communication Skills Questionnaire
- vi) To determine the inter-rater reliability of the task battery developed to measure the activity level of function
- vii) To determine the test-retest reliability of the task battery developed to measure the activity level of function

viii) To determine the measure stability level in the task battery developed to measure the activity level of function.

4.3 METHODOLOGY

4.3.1 Design

A matched group comparison design was chosen to examine response to a task battery carefully developed to capture awareness of everyday task ability (activity level of function). Two earlier studies (Hart et al., 1998 and Abreu et al., 2001), proposing task batteries for this purpose, had given insufficient attention to the selection of tasks for their respective batteries, and had made scant use of comparison groups. In both instances, this had resulted in inconclusive results. The design incorporated structured behavioural observation and questionnaire survey.

In order to assess the reliability of the task battery, an inter-rater reliability study, a test-retest reliability study (to determine reliability of participant and observer ratings over time) and a measure stability study (to determine the stability or variability of 'awareness scores') were conducted.

The Patient Competency Rating Scale and the Social Communication Skills Questionnaire were administered as an additional measure of awareness of the activity level of function, and a measure of awareness of social skills, respectively. The Hospital Anxiety and Depression Scale was administered to explore the relationship between mood and awareness.

4.3.2 Participants

Eighteen individuals with impaired awareness, and eighteen in each of the remaining two clinical comparison groups, were identified by clinicians involved in their care and, following the LREC approved informed consent process, participated in the study. A third comparison group included 18 healthy individuals.

Table 4.1 below shows the demographic data gathered for the 4 groups included.

Table 4.1 Demographic data collection

Demographic data	ABI Impaired Awareness	ABI Intact Awareness	Spinal Cord Injury	Healthy
Age	V	√	√	V
Gender	√	V	V	√
Diagnosis	V	V	V	
In-patient/out-patient status	√	V	٧	
Time since lesion	√	√	√	
Duration of time in Rehabilitation	٧	V	√	

Table 4.2 Demographic data: age and gender for group participants

Groups	Number of Male	participants Female	Group mean age (SD)		Age Range
ABI Impaired Awareness	14	4	46.4	(17)	20-79
ABI Intact Awareness	11	7	45.4	(19.2)	20-79
Spinal Cord Injury	18	0	44.2	(11.8)	23-58
Healthy	12	6	44.4	(17.2)	21-77

Where possible, participants in the three comparison groups were matched, for age and gender, with participants in the impaired awareness acquired brain injury group. Despite recruitment taking place over a period of one year, no appropriate women with a spinal injury were recruited to the research. The overall mean ages across groups were very similar (See Table 4.2.)

Within the intact awareness group only, men were found to be significantly older than women (t = 2.24, df = 16, p < 0.05, two-tailed). To date, no studies have shown that age, or gender, are associated with impaired awareness. So, despite the significant difference shown here, a much larger number of participants would be required to demonstrate that a difference in age or gender would be likely to influence the results.

Table 4.3 Diagnostic data: Acquired brain injury participants

	Impaired Awareness Group	Intact Awareness Group
Stroke	9	11
Traumatic Brain Injury	8	6
Brain Surgery	1	1

The impaired and intact awareness groups had a similar distribution of patients who had sustained a stroke, brain injury, or who had had brain surgery (Table 4.3). None of the spinal cord injury group had sustained a brain injury.

For the impaired awareness group, eleven in-patients and seven out-patients were seen. For the intact awareness group, four were in-patients and fourteen were out-patients. Fifteen participants in the impaired and intact awareness groups were recruited from four specialist neurological rehabilitation services based in Oxford and Aylesbury. The remaining three participants in both groups were recruited from an elderly rehabilitation ward, specialising in stroke care. There was a statistically significant difference between the proportion of inand out-patients in the impaired and intact awareness groups (U = 99.00, N1, = 18, N2, = 18, p < 0.05). All of the spinal-injured participants were in-patients recruited from a single specialist spinal injury unit.

Table 4.4 Time (months) since lesion for clinical group participants

Groups	N	Mean Tim	ne (SD)	Range	Inter-Quartile Range
ABI Impaired Awareness	18	14.1	(12)	1 - 46	16.1
ABI Intact Awareness	18	30.2	(32.1)	1 - 97	52
Spinal Cord Injury	18	18.5	(40.3)	1 - 137.5	4.1

The mean length of time since lesion for the intact awareness group was 30.2 months (see Table 4.4), twice as long as the impaired awareness group (14.1 months). The mean for the spinal injury group was inflated by two participants who had their original injury many years earlier (11.5 and 10 years respectively). These participants were currently undergoing rehabilitation due to a change in their clinical and social circumstances.

Table 4.5 Time (months) spent in rehabilitation for clinical group participants

Groups	N	Mean Time	SD	Range	Inter-Quartile Range
ABI Impaired Awareness	18	5.9	(5.7)	0.5 - 20	2.7
ABI Intact Awareness	18	7.4	(8.9)	0.5 - 36	7.1
Spinal cord Injury	18	2.9	(1.7)	0.5 - 6	2.7

Despite the disparity in time since lesion between the two acquired brain injury groups, the time spent in rehabilitation was not dissimilar (Table 4.5): with a mean time of 5.9 months

for the impaired awareness group; 7.4 months for the intact awareness group. The mean for the spinal cord injury group was less.

4.3.3 Measures

Task Battery

A task battery, developed during the 'phase 1: preliminary study', entailed structured observation of all participants' everyday task performance. Before and after ratings of performance were elicited from participants in the four groups included in the 'phase 2: group comparison study', for both 'ease' and 'quality' for each task. The investigator rated each participant's performance according to guidelines developed during the 'phase 1: preliminary study' of the research programme.

The following tasks were included on the basis of the 'phase 1: preliminary study' in Chapter 3:

- 1. A rail (phone) enquiry task
- 2. An object assembly task
- 3. A time-tabling (pen and paper) task
- 4. A filing bills task
- 5. A kitchen task
- 6. A cleaning task

Questionnaires

The following questionnaires were used during the 'phase 2: group comparison study': The Hospital Anxiety and Depression Scale, The Patient Competency Rating Scale and The Social Communication Skills Questionnaire. Table 4.6 summarises all ordinal level data arising from the questionnaires used.

Table 4.6 Summary of ordinal data arising from questionnaire ratings

Task battery	Score Range	Self Rating	Clinician Rating	Significant Other Rating	Reliabi Inter- rater	ility Test- retest
Phone Enquiry Ease rating Quality rating	1 - 5 1 - 5	√ √	7 7		77	7
Object Assembly Ease rating Quality rating	1 - 5 1 - 5	77	7 7		7 7	7 7
Timetable Ease rating Quality rating	1 - 5 1 - 5	77	7		√ √	7 7
Filing Bills Ease rating Quality rating	1 - 5 1 - 5	7	V		√ √	√
Kitchen Ease rating Quality rating	1 - 5 1 - 5	7 7	√ √		√ √	77
Cleaning Ease rating Quality rating	1 - 5 1 - 5	7 7	√ √		√ √	7 7
Full battery Ease rating Full battery Quality rating	5 - 30 5 - 30	7	√ √		√ √	√ √
Numerical rating of Awareness	0-10		√			
HADS Anxiety	0-21	√				
HADS Depression	0-21	√				
PCRS (30 questions)	30-150	√	√	√		
SCSQ (27 questions)	27-135	√	V	√		

4.3.4 Procedure

Task Battery and Questionnaires

The task battery, and the Hospital Anxiety and Depression Scale, were administered to all participants in each of the four groups. The Patient Competency Rating Scale, and the Social Communication Skills Questionnaire, were administered by the investigator to individuals in each of the two acquired brain injury groups, a clinician and a significant other. All in-patient participants were tested in the hospital or unit to which they were attached. Out-patient and healthy participants were seen either in a participating hospital or in their own homes according to convenience. Clinicians were interviewed in their work place. Significant others were interviewed in their own homes, or in hospital, according to their preference.

Inter-rater reliability study

Eighteen participants, drawn from the four groups (ten from the acquired brain injury groups), were seen by two assessors in addition to the lead investigator in order to test the reliability of the scoring schedule, the criteria developed to guide scoring, and the reliability of the lead investigator.

Test-retest reliability study and Measure stability study

It was intended that eighteen participants would be drawn from the acquired brain injury groups only, and would be seen on two occasions by the lead investigator to establish the test-retest reliability, and measure stability, of the task battery.

4.3.5 Data analysis

The Statistical Package for the Social Sciences, Version 10 was used to analyse the data arising from the group comparison study. Descriptive statistics were used to explore the discrepancies between participant and observing investigator scores for task battery performance. Mann-Whitney U comparisons (for independent samples) were used to compare each group with every other group for each individual task within each dimension

(ease and quality), and for the overall 'awareness' scores for each dimension. Weighted Kappa was used to analyse the non-parametric data arising from the inter-rater reliability study. Wilcoxon Signed Ranks Test (for related samples), and Kappa measure of agreement were used to analyse non-parametric data from the test-retest reliability study and the measure stability study respectively. For the test-retest reliability study and measure stability study, the length of time between test 1 and test 2 varied very widely. In view of this, an additional test, Chi-Square Test, was applied to the two sets of data before Wilcoxon Signed Ranks Test and Kappa measure of agreement were used. Chi-Square Test was used to explore whether varying lengths of time between tests seemed to be influencing the results.

The Hospital Anxiety and Depression Scale (HADS) scores were explored using descriptive statistics. The association between the HADS scores and awareness scores were explored using correlation analysis (Spearman rho). For the Patient Competency Rating Scale and Social Communication Skills Questionnaire, participant and third party ratings were compared, by subtracting participant scores from third-party scores, to ascertain whether ABI participants were overrating their everyday task ability and social skills.

4.4 RESULTS

4.4.1 Task battery

Results for the 'ease' dimension relating to 'ease of task' will be dealt with first followed by the results for a 'quality' dimension.

4.4.1.1 Ease Dimension – Task Battery - Descriptive statistics

A task battery discrepancy score was calculated by subtracting each participant's post-task rating with respect to how easily they had found the task (for each of the six tasks) from the post-task ease rating assigned by the observer. Thus, if Participant 1 rated the ease with which they had undertaken the object assembly task as '4' (a score of 4 equates to 'Fairly Easily'), and the investigator/observer rated ease of performance as '2' ('Very Difficult') this would give a discrepancy score of -2. The resultant discrepancy scores for each of the six tasks were then summated for each participant, to give an 'ease awareness score'.

Group results are presented in Table 4.7. A *minus* score indicated that participants in the group were tending to overrate task battery performance. A *plus* score indicated that participants in the group were underrating task battery performance. Total agreement between participant and observer equated to zero.

Table 4.7 indicates a marked tendency for the impaired awareness group to overrate the ease with which they completed task battery tasks. This is demonstrated most strikingly when the 95% confidence intervals are compared: there is no overlap between the 95% confidence for the impaired awareness group and any of the other groups.

Table 4.7 Ease awareness scores (full task battery)

Groups	Mean	SD	95% Upper Bound	6 CI Lower Bound	Range	Inter-Quartile Range
Impaired ABI	-5.3	(5.4)	-8	-2.6	-14 to +2	10
Intact ABI	-0.6	(2.8)	-2	0.8	-0.7 to +5	2.3
SCI	2.8	(2)	-0.7	1.3	-4 to +3	2.5
Healthy	0.9	(1.4)	0.3	1.6	-1 to +4	2

95% CI = 95% Confidence Interval for the mean ABI = Acquired Brain Injury

(Possible discrepancy range: -4 to +4 for each task, and therefore -24 to +24 for the full task battery)

Mann-Whitney U comparisons were carried out comparing each group with every other group, for each individual task (within each dimension, ease and quality), and for the overall 'awareness' score for each dimension. There is a danger, with multiple comparisons, of finding significant results due to chance. To adjust for this, a P-value equal to or greater than 0.01 was taken as providing sufficient grounds for rejecting the null hypothesis, rather than the conventional P value of 0.05.

The null hypothesis: there is no difference between awareness scores in any of the four groups.

Table 4.8 indicates that awareness scores (ease dimension) for the impaired awareness differed significantly from the scores for each of the three comparison groups. Hence, the null hypothesis could be rejected. As might be expected, the most significant difference was found between the impaired awareness group and the healthy group. No significant difference was found between awareness scores for the three comparison groups.

Table 4.8 Mann-Whitney U results (P-values) across groups for the ease awareness scores (full task battery)

Impaired/ Intact ABI	Impaired ABI/SCI	Impaired ABI/ Healthy	Intact ABI/SCI	Intact ABI/ Healthy	SCI/ Healthy
0.006**	0.001**	<0.0001**	0.161	0.017	0.628

^{** =} P-value equal to or less than 0.01, two-tailed

Table 4.9 shows the descriptive statistics for each task discrepancy across groups (ease dimension). The results (see Table 4.9) showed relatively little difference in mean scores between the four groups for any of the individual tasks. The minus sign indicated a trend for the impaired awareness group to overrate ability level. Score ranges indicated that the impaired awareness group included the most extreme overrating scores. Minimum scores were lower for the impaired awareness group on every task, although the intact awareness group had the same minimum score (-2) for the kitchen task. Large differences between groups were not apparent for individual tasks, but differences between the impaired awareness group, and other groups, became more noticeable when discrepancy scores were summed for more than one task.

Table 4.9 Descriptive statistics for each task discrepancy across groups – Ease dimension

Task	Group	Mean	(SD)	Range
Timetable	Impaired	0.2	(1.5)	-4 to 2
	Intact	0.5	(0.9)	-1 to 3
	SCI	0.5	(0.8)	-1 to 2
	Healthy	0.3	(0.6)	0 to 2
Filing	Impaired	-0.9	(1.3)	-3 to 1
bills	Intact	-0.3	(0.6)	-1 to 1
	SCI	-0.2	(0.4)	-1 to 0
	Healthy	0	(0.6)	-1 to 1
Object	Impaired	-0.9	(1)	-3 to 0
assembly	Intact	-0.2	(0.7)	-1 to 1
•	SCI	0.2	(0.7)	-1 to 1
	Healthy	0.2	(0.8)	-2 to 2
Phone	Impaired	-1.2	(1.8)	-4 to 1
Enquiry	Intact	0	(0.9)	-2 to 2
	SCI	-0.2	(0.7)	-2 to 1
	Healthy	0.1	(0.3)	0 to 1
Cleaning	Impaired	-0.8	(0.9)	-3 to 0
•	Intact	-0.4	(0.9)	-2 to 1
	SCI	0.1	(0.6)	-1 to 1
	Healthy	0.3	(0.5)	0 to 1
Kitchen	Impaired	-1.2	(0.8)	-2 to 0
	Intact	-0.2	(0.7)	-2 to -2
	SCI	-0.1	(0.3)	-1 to 0
	Healthy	0	(0)	0 to 0

When individual tasks within the ease dimension were considered, significant differences were found between the healthy and the impaired awareness group for the following three tasks: kitchen (p<0.001), cleaning (p<0.001), and object assembly (p=0.002). Significant differences were found between the spinal cord injury and the impaired awareness group for the same three tasks: kitchen (p=0.001), cleaning (p=0.003) and object assembly (p=0.003). An additional significant difference was found between the impaired and the intact awareness group for the kitchen task (p=0.004).

4.4.1.2 Quality dimension Task Battery – Descriptive Statistics

A task battery discrepancy score was calculated by subtracting each participant's post-task rating with respect to how well they had performed each task (for each of the six tasks) from the post-task quality rating assigned by the observer. For example, if a participant rated the quality of the task as '5' (a score of 5 equates to 'Very Well'), and the observer assigns a score of '3' (Reasonably) this would give a discrepancy score of -2. The discrepancy scores for each of the six tasks were then summated for each participant, to give a 'quality awareness score'. Group results are presented in Table 4.10. As for the ease dimension, a minus score indicated that participants in the group were tending to overrate task battery performance. A plus score indicated that participants in the group were underrating task battery performance. Total agreement between participant and observer equated to zero.

The minimum awareness discrepancy score for the impaired awareness group was markedly greater than the minimum awareness discrepancy scores for any of the comparison groups within each of the ease and quality dimensions (Tables 4.7 and 4.10). For each dimension, the minimum score was minus 14 for the impaired awareness group. In view of this extreme minimum score, the impaired awareness mean scores of - 5.3 (ease) and - 3.4 (quality) were comparatively modest and showed that impaired awareness of task battery performance was much more marked in the case of some individuals. This variability between ABI individuals (identified as having impaired awareness) suggests the usefulness of dealing with such persons on a 'case by case' basis rather than grouping them together. This would particularly apply in the context of intervention to address impaired awareness.

Table 4.10 shows a mean quality awareness score of 2 for the healthy group (quality dimension). This indicated a trend for this group to underrate the quality of their performance compared to the observer. This tendency was in the opposite direction from the impaired awareness group, and was less apparent for the ease dimension where the healthy group mean awareness score was 0.9. Possible explanations for this are that the lead investigator, more experienced in assessing disabled rather than healthy individuals, was exercising some degree of systematic bias in relation to the healthy individuals – judging their performance more favourably than that of clinical participants. Logically, healthy individuals are likely to perform tasks more competently, but are only comparing their test performance with previous personal performances – they are unlikely to be comparing their performance to that of a disabled person.

Table 4.10 Quality awareness scores (full task battery)

Groups	Mean	SD	95% CI Upper Bound Lower Bound		Range	Inter-Quartile Range
Impaired ABI	-3.4	(5.7)	-6.3	-0.6	-14 to +4	11.5
Intact ABI	0.3	(2.3)	-0.8	1.5	-3 to +5	3.3
SCI	0.5	(2)	-0.5	1.5	-4 to +4	3
Healthy	2	(2)	1.1	3	-1 to +6	2.5

95% CI = 95% Confidence Interval for the mean

ABI = Acquired brain injury

SCI = Spinal cord injury

(Possible discrepancy range: - 4 to + 4 for each task, and therefore - 20 to + 20 for the full task battery)

The Mann Whitney U results shown in Table 4.11 indicate that the only significant difference, between groups (full task battery awareness scores), was between the impaired awareness and healthy groups. Thus, the null hypothesis can only be rejected in relation to these two groups. These results indicated that the quality dimension was less effective in discriminating between groups, than the ease dimension. In particular, it could be noted that the ease dimension discriminated between the impaired and intact awareness groups. The quality dimension was not effective in discriminating between these two groups.

Table 4.11 Mann-Whitney U Results (P-values) across groups for the quality awareness scores (full task battery)

Impaired/	Impaired	Impaired	Intact ABI/	Intact ABI/	SCI/
Intact ABI	ABI/SCI	ABI/	SCI	Healthy	Healthy
		Healthy			
0.051	0.029	0.001**	0.743	0.029	0.044

** = P-value equal to or less than 0.01, two-tailed

Table 4.12 shows the descriptive statistics for each task discrepancy across groups (quality dimension). Table 4.12 illustrates that the mean score for the impaired awareness group was lower than the mean score for any of the comparison groups. This was the case for every task within the battery. The table also shows that the impaired awareness group had the most extreme 'overrating' score for each task, and the widest range of scores for each task.

When individual tasks were considered, significant quality differences were found between the healthy and the impaired awareness groups for three tasks: object assembly (p=0.004), filing bills (p=0.007) and timetable (p=0.009). No other significant differences were found.

As for the ease dimension, three tasks (object assembly, filing bills and timetable) showed a significant difference (p<0.01) between the impaired awareness and healthy groups. The total task battery 'awareness' scores (Tables 4.7 and 4.10) indicate significant differences between impaired and intact awareness group scores.

Table 4.12 Descriptive statistics for each task discrepancy across groups – Quality dimension

Task	Group	Mean (SD)	Range
Timetable	Impaired	-0.7 (1.6)	-4 to 1
	Intact	0.3 (1)	-2 to 2
	SCI	0.7 (1)	-1 to 2
	Healthy	0.7 (0.8)	0 to 3
Filing	Impaired	-0.7 (1.4)	-3 to 2
bills	Intact	-0.2 (0.5)	-1 to 1
	SCI	-0.1 (0.6)	-2 to 1
	Healthy	0.4 (0.7)	0 to 2
Object	Impaired	-0.4 (0.9)	-3 to 1
assembly	Intact	0.3 (0.7)	-1 to 2
	SCI	0.2 (0.5)	-1 to 1
	Healthy	0.6 (0.7)	0 to 2
Phone	Impaired	-0.8 (1.6)	-4 to 2
enquiry	Intact	-0.4 (1.2)	-3 to 2
	SCI	-0.3 (0.9)	2 to 1
	Healthy	0 (0.4)	-1 to 1
Cleaning	Impaired	-0.5 (1.2)	-3 to 1
	Intact	0.1 (0.5)	-1 to 1
	SCI	0 (0.5)	-1 to 1
	Healthy	0.3 (0.6)	-1 to 1
Kitchen	Impaired	-0.3 (1.2)	-3 to 1
	Intact	0.2 (0.5)	0 to 2
	SCI	0 (0.3)	-1 to 1
	Healthy	0 (0.4)	-1 to 1

The ease awareness scores showed greater discrimination between the intact and impaired awareness groups. The fact that a different *configuration* of tasks was found to be significant, within the two different dimensions (the object assembly task was the only task common to significant configuration within both dimensions), was not surprising, as quality and ease are conceptually different. The quality dimension awareness scores did not discriminate between the impaired and intact awareness groups. The healthy group achieved an overall quality awareness mean score of 2, indicating that this dimension may be over-sensitive to healthy individuals underrating their ability level. This might be due to British people tending to be modest about their abilities. Alternatively, the observer may have been more lenient in judging the performance of healthy individuals. As the quality dimension appeared less useful than the ease dimension, it was decided to only include ease dimensions questions in future phases of the research programme.

In order to ascertain the configuration of tasks that best discriminated between the impaired and intact awareness groups, every possible combination of five, four, three and two tasks was examined and subjected to further Mann-Whitney U analysis. In Table 4.13 below, all Mann-Whitney U results (P values) are given for every combination of tasks within the battery.

Table 4.13 Mann-Whitney U results (P values) for every combination of 5, 4, 3 and 2 tasks from the task battery (ease dimension)

5 task combinations	P values
Kitchen, Object Assembly, Timetable, Phone, Bills	0.003
Kitchen, Object Assembly, Timetable, Phone, Cleaning	0.006
Kitchen, Object Assembly, Phone, Bills, Cleaning	0.006
Kitchen, Timetable, Phone, Bills, Cleaning	0.01
Object Assembly, Timetable, Phone, Bills, Cleaning	0.02
4 task combinations	P values
Kitchen, Object Assembly, Timetable, Phone	0.002
Kitchen, Object Assembly, Timetable, Bills	0.003
Kitchen, Object Assembly, Phone, Bills	0.004
Kitchen, Object Assembly, Bills, Cleaning	0.006
Kitchen, Object Assembly, Timetable, Cleaning	0.007
Kitchen, Timetable, Phone, Bills	0.008
Kitchen, Object Assembly, Phone, Cleaning	0.009
Kitchen, Timetable, Phone, Cleaning	0.01

Object Assembly, Timetable, Phone, Bills Object Assembly, Phone, Bills, Cleaning Kitchen, Phone, Bills, Cleaning Object Assembly, Timetable, Phone, Cleaning	0.01 0.01 0.02 0.02
Kitchen, Timetable, Bills, Cleaning Object Assembly, Timetable, Phone, Bills Timetable, Phone, Bills, Cleaning	0.03 0.03 0.03
3 task combinations	P-values
Kitchen, Object Assembly, Bills Kitchen, Object Assembly, Phone Kitchen, Object Assembly, Timetable Kitchen, Phone, Timetable Object Assembly, Phone, Timetable Kitchen, Object Assembly, Cleaning Kitchen, Phone, Bills Kitchen, Bills, Timetable Object Assembly, Bills, Phone Kitchen, Phone, Cleaning Kitchen, Timetable, Cleaning Timetable, Phone, Bills Object Assembly, Timetable, Bills Kitchen, Bills, Cleaning Timetable, Phone, Cleaning Object Assembly, Bills, Cleaning Object Assembly, Timetable, Cleaning Object Assembly, Timetable, Cleaning Object Assembly, Timetable, Cleaning Object Assembly, Timetable, Cleaning Object Assembly, Phone, Bills	0.002 0.003 0.003 0.006 0.008 0.01 0.01 0.01 0.02 0.02 0.02 0.02 0.02 0.03 0.03 0.03 0.03 0.04 0.11
Timetable, Bills, Cleaning 2 task combinations	0.11 P values
Kitchen, Object Assembly Kitchen, Timetable Kitchen, Phone Kitchen, Bills Kitchen, Cleaning Object Assembly, Timetable Object Assembly, Phone Phone, Timetable Object Assembly, Bills Object Assembly, Cleaning Phone, Bills Phone, Cleaning Cleaning, Timetable Bills, Timetable Bills, Cleaning	0.001 0.01 0.02 0.02 0.02 0.02 0.02 0.03 0.04 0.04 0.06 0.08 0.09 0.16

In this case, the null hypothesis was that there was no significant difference between the impaired and intact awareness groups. As reported above, for the full task battery (ease dimension), a significant difference (p=0.006) was found in awareness scores between the impaired and intact awareness groups. In view of this, it was considered desirable that the configuration of tasks in a reduced battery, reach a P-value greater than 0.006. One configuration of five tasks reached a P-value of 0.003 (kitchen, object assembly, phone, filing bills and timetable); three configurations of four tasks reached a significance of greater than p=0.006: p=0.002 (kitchen, object assembly, phone and timetable), p=0.003, (kitchen, object assembly, filing bills and timetable), p=0.004 (kitchen, object assembly, phone and filing bills). Similarly, three configurations of three tasks reached a significance level greater than p=0.006: p=0.002 (kitchen, object assembly and filing bills), p=0.003 (kitchen, object assembly and phone), p=0.003 (kitchen, object assembly and timetable). Notably, the kitchen and object assembly tasks formed part of all the configurations reaching significance.

Indeed, when these tasks were considered as a pair, they showed the greatest discrimination between the impaired and intact awareness groups: P-value = 0.001. Furthermore, this pair of tasks discriminated well between the impaired awareness and healthy groups (p<0.0001), and between the impaired awareness and spinal cord injury groups (p<0.0001). In addition, no significant difference was found comparing the healthy and spinal cord injury groups (p=0.7), or the healthy and intact awareness groups (p=0.02), with regard to this combination of tasks. This pair of tasks combines the task that all participants felt they were very conversant with (making toast and a hot drink), and the task which no participant had previously been exposed to (although some participants were more used to making up DIY packs or engaging in woodwork). The cleaning task did not figure in any of the configurations reaching significance and can therefore be deemed to have been the least useful within the battery.

4.4.2 Test-retest reliability study and measure stability study

Two different aspects related to test-retest reliability were explored, a) Reliability of observer ratings over time, b) Reliability of participant ratings over time. In addition measure stability was examined to ascertain the variability of awareness scores over time. It was intended that 18 of the 36 acquired brain injury participants would participate in the

test-retest studies. It was also intended that the time between test 1 and test 2 should be short: 1-2 weeks. In practice, only 11 cases completed test 2, and only four of the eleven cases completed test 2 within a 1-2 week time-scale. This necessitated additional statistical analysis (Chi-Square Test) to clarify whether the length of time between test 1 and test 2 may have affected the results. In view of the smaller than anticipated sample size, and the variable length of time between test 1 and test 2 for different participants, the statistical test results should be interpreted with extra caution.

4.4.2.1 Observer ratings

Eleven acquired brain injury participants (three with impaired awareness and eight with intact awareness) carried out the task battery on two occasions as part of a test-retest reliability study. These participants were a subset of participants taking part in the 'phase 2: group comparison study'. The participants were seen at differing intervals (range 7 – 126 days) according to their availability. Chi-Square Test (2 x 3 table) was performed to ascertain whether the differences in scores (assigned by the observer) between time-point 1 (T1) and time-point 2 (T2) were significantly affected by the length of interval between the two observations. In order to carry out this calculation observer ratings for T2 were subtracted from observer ratings for T1.

In the first instance, the length of difference in days (7, 7, 7, 14, 17, 24, 28, 28, 42, 91 and 126 respectively) was cross-tabulated separately for the "ease" and "quality" dimensions, but many cells had an expected count less than 5 (thus reducing the accuracy of the chisquare test). Accordingly, observer ratings for the eleven participants were grouped into one of two categories by means of a 'median split', (the median length of time between T1 and T2 was 24 days). There was an uneven number of participants, so a decision was made (arbitrarily) to put six ratings in the 'equal to and more than 24 day interval' group, and 5 into the < 24 day interval. The 'score' columns were also collapsed until no cells had an expected count less than 5. There were 3 score categories: i) -1 and -2; ii) 0; and iii) 1, 2, 3 and 4.

Chi-square Test showed no relationship between time interval between T1 and T2 and ease dimension observer ratings ($\chi^2 = 4.876$, df = 2, p = 0.09). Nor was a relationship found between T1 and T2 and quality dimension observer ratings ($\chi^2 = 5.669$, df = 2, p = 0.59).

To check that the method of dividing participants between the two groups was not causing bias, the observer ratings for the participant seen with a 24 day interval were then added to the group: 'more than 24 day interval'. No significant relationship was evident: quality dimension ($\chi^2 = 2.836$, df = 2, p = 0.24), ease dimension ($\chi^2 = 4.876$, df = 2, p = 0.09). Having ascertained that there was no evidence that the length of interval between T1 and T2 was having no effect on observer ratings, Wilcoxon Signed Ranks Test (related samples) was performed to ascertain whether or not there was a significant difference between the observer's ratings for T1 and T2. No significant difference was found: ease (z = 1.214, N-ties = 34, p = 0.23, two-tailed); quality (z = 1.091, N-ties = 31, p = 0.28, two-tailed).

Wilcoxon Signed Ranks Test was then performed to ascertain any significant difference for any *individual* task within the battery between T1 and T2 (for either the ease or quality dimension). None of the results reached significance at the 0.05 level, for either dimension. These results indicated that it can be assumed that the results were similar at T1 and T2.

To explore the results further, Kappa measure of agreement was applied to the observer ratings from T1 and T2. This yielded: $\kappa = 0.33$ (P=<0.001) for the ease dimension, and $\kappa = 0.34$ (P=0.001) for the quality dimension. Both results indicate that a fair strength of agreement between the results at T1 and T2.

4.4.2.2 Participant ratings

The above exercise was repeated for participants' ratings (raw scores) for T1 and T2 for each dimension. Once again ratings for T2 were subtracted from T1. Chi-square results for ease ($\chi^2 = 1.092$, df = 2, p = 0.569), and quality ($\chi^2 = 2.786$, df = 2, p = 0.248) indicated that length of time between T1 and T2 was not having a significant impact on participant ratings. Wilcoxon Signed Ranks Test was performed to ascertain whether or not there was a significant difference between the first and second set of participant ratings. No significant difference was found for ease (z = 1.522, N-ties = 35, p = 0.128, two-tailed), or quality (z = 1.808, N-ties = 27, p = 0.071, two-tailed).

Kappa measure of agreement was applied to the participant ratings at T1 and T2, yielding κ = 0.26 (P<0.001) for the ease scores; and κ = 0.44 (P<0.001) for the quality scores. This

indicated a fair strength of agreement between the ease scores, and a moderate strength of agreement between the quality scores.

4.4.2.3 Measure Stability: Variability in Awareness ratings

Apart from test-retest reliability, it was considered of interest to ascertain the stability or variability of the awareness score (difference between observer and participant score for each task and summed) over time. Once again, chi-square calculations were performed to ascertain whether variable length of time between observations made a significant difference to the awareness score. For both dimensions, the awareness score for T2 was subtracted from the awareness score for T1. As for the test-retest reliability study, participants were divided into one of two groups by a means of a median split (less than and including a median of 24 days' interval between T1 and T2, and more than 24 day interval between T1 and T2). For the quality dimension, awareness scores (task battery as a whole) ranged from -2 to 3. Scores in columns were collapsed to three columns, i) - 1 and -2, ii) 0, and iii) 1, 2 or 3. In this way, no cells had an expected count of less than 5, and no significant difference was found between quality 'awareness' score and interval between T1 and T2 ($\chi^2 = 2.041$, df = 2, p = 0.360).

For the ease dimension, to achieve no cells with an expected count less than 5, the scores were collapsed to 2 columns, i) - 2 and - 1, ii) 0 and 1, (overall range 1 to -2). As for the quality dimension, no significant difference was found between the ease 'awareness' score between T1 and T2 ($\chi^2 = .080$, df = 1, p = 0.777).

Wilcoxon Signed Ranks Test was used to ascertain any significant differences between the awareness score at T1 and T2. No significant difference was found for the awareness scores in the quality dimension (z = 0.211, N-ties = 40, p = 0.833, two-tailed). However, a significant difference was found for the ease awareness scores (z = 2.753, N-ties = 30, p = 0.006, two-tailed). When the raw scores were scrutinised it was apparent that at T1 six participants were overrating and five under-rating their ability (as compared to observer). At T2, three were overrating their ability, seven underrating and one score was the same as the observer's. All five participants who underrated at T1 also underrated performance at T2, so the changes were amongst those who overrated their ability on the first occasion: three continued to do so on the second occasion, and two underrated their performance on

the second occasion. Of the three patients categorised as having impaired awareness only one overrated ability on both occasions.

With so few participants, the difference between T1 and T2 ease awareness scores must have been markedly different to register as statistically significant. This may be a further indication that the ease dimension is more sensitive to awareness, than the quality dimension. This result may indicate that awareness of task performance fluctuated over time for several of the eleven participants. However, as very few impaired awareness participants were included it is felt that drawing even tentative conclusions from this could be misleading.

When Kappa measure of agreement was applied to the awareness scores at T1 and T2, this indicated a fair strength of agreement for ease: $\kappa = 0.32$ (P<0.001); and a poor strength of agreement for quality: $\kappa = 0.13$ (P<0.05).

4.4.3 <u>Inter-rater reliability study</u>

4.4.3.1 Aims of study

- i) To determine the inter-rater reliability of the task battery.
- ii) To determine the reliability of the criteria developed to guide assessment of task battery performance.

4.4.3.2 Results

Eighteen participants from across the four groups were observed, completing the task battery, by three raters. Four participants were randomly drawn from each of the healthy, spinal cord injury and impaired awareness groups respectively, six participants were drawn from the intact awareness group. Three raters observed all 18 participants (the lead investigator - an occupational therapist, a further occupational therapist, and a psychology graduate). Weighted Kappa calculations were carried out on the three sets of raw scores. This test was chosen since the data were non-parametric.

Interrater reliability - Weighted Kappa results

Scrutiny of the raw scores indicated that scores of 4 and 5 had been much more commonly used by raters. This resulted in a 'poisson' distribution – a greater preponderance of higher scores within one end of the range (possible range 1—5). To correct the scores for the uneven distribution, Weighted Kappa was applied to take account of the frequency with which a particular score was given (Tables 4.14, 4.15).

Table 4.14 Ease dimension - Weighted Kappa results

Raters	Kappa value	Significance Agreen	
1 and 2	.73	p<0.001	Good
1 and 3	.89	p<0.001	Very good
2 and 3	.82	p<0.001	Very good

Table 4.15 Quality dimension – Weighted Kappa results

Raters	Kappa value	Significance	Agreement
1 and 2	.68	p<0.001	Good
1 and 3	.71	p<0.001	Good
2 and 3	.87	p<0.001	Very good

The agreement 'interpretation' is based on that proposed by Altman (1991):

Value of Kappa	Strength of Agreement
< 0.20	Poor
0.21 - 0.40	Fair
0.41 - 0.60	Moderate
0.61 - 0.80	Good
0.81 - 1.00	Very good

The results indicated good or very good levels of agreement between raters. The test corrected for the abnormal distribution and was carried out across all pairs of scores within each dimension for each pair of raters. This strategy is a more stringent test of agreement than summing task battery scores for each participant – such a procedure evidently could potentially mask much error.

4.5 QUESTIONNAIRES

4.5.1 Hospital Anxiety and Depression Scale (HADS)

The Hospital Anxiety and Depression Scale was administered to all participants (n = 72).

Table 4.16 Hospital Anxiety and Depression Scale – Anxiety results

Group	Mean	score (SD)	Range	Inter-Quartile Range
Impaired Awareness	6.44	(3.93)	1 - 15	6.5
Intact Awareness	7.00	(4.99)	0 - 17	9.3
Spinal Cord Injury	5.78	(4.18)	0 - 17	5.3
Healthy	5.06	(3.10)	1 - 14	4.3

Score range: 0 to 21 for anxiety and 0 to 21 for depression (0 to 7 = normal range; 8 to 10 borderline range or doubtful cases; 11 to 21 abnormal range or definite cases)

The mean scores for anxiety (Table 4.16) showed quite minimal differences between groups, though the intact awareness group had the largest number of participants falling within the abnormal or borderline range. High anxiety scores in the intact awareness group and low anxiety scores in the impaired awareness group could have indicated that impaired awareness might be acting as a defence mechanism, protecting participants (in the impaired awareness group) from anxiety. This study showed no evidence to support this. It was apparent from the range of scores that each group had some participants with abnormal range anxiety scores.

Table 4.17 Hospital Anxiety and Depression Scale - Depression results

Group	Mean score (SD)	Range	Inter-Quartile Range
Impaired Awareness	5 (3)	1 - 13	5
Intact Awareness	6 (4)	0 - 14	6
Spinal Cord Injury	5 (4)	1 - 15	5.3
Healthy	2.6 (2)	0 - 7	2.3

The HADS depression scores indicated that the mean score was markedly lower for the healthy group compared with the other three groups (Table 4.17). The intact awareness group had marginally the highest mean score of depression compared to the other two clinical groups.

To explore the relationship between mood and task battery performance, HADS anxiety and HADS depression scores were correlated (Spearman rho) with task battery awareness scores (i.e. discrepancy scores for the full task battery), for the ease and quality dimensions. When these calculations were carried out for each of the four groups, none of the results approached significance. However, when all 72 participants were grouped together. One result was significant.

Ease awareness scores (full task battery)

and HADS Anxiety: rho = -0.11

Ease awareness scores (full task battery)

and HADS Depression: rho = -0.23

Quality awareness scores (full task battery)

and HADS Anxiety: rho = -0.03

Quality awareness scores (full task battery)

and HADS Depression: rho = -0.37 *

* Significant at 0.05 level

As can be seen from the above results, all task battery awareness scores are negatively correlated with HADS anxiety and depression scores. The strongest negative correlation was between quality awareness scores and HADS Depression scores. A correlation of -0.37 is not a strong correlation. According to Altman, this could be viewed as indicating no more than a 'fair' degree of negative association between these 2 variables. Nevertheless, the result may indicate a tendency for participants to describe their task battery performance in less positive terms if feeling low. For the quality dimension, participants were asked to rate 'how well' they had carried out the task. In contrast, to describe the ease with which they had carried out the task may be considered to have fewer connotations of self-praise. Therefore, ease self-ratings may be less subject to change in the face of low mood.

These results suggest that mood was unlikely to be having an impact on awareness, although summarising data within groups may have masked a pertinent relationship between mood and awareness in the case of specific individuals. Hence, the raw data were re-examined. The four impaired awareness group participants with the most extreme overrating scores, i.e. a minimum ease awareness (overrating) score of -13 indicated normal range anxiety and depression scores for three participants and one borderline score ('10') for anxiety in the fourth participant. This participant had a normal range depression score. This participant had the most extreme task battery awareness scores of any of the 72 participants (-14 for both the ease and quality dimension). This example does suggest that the interaction of mood and awareness may be highly individual, negligible in many cases but pronounced for some specific individuals.

4.5.2 Patient Competency Rating Scale (PCRS)

All thirty-six participants with acquired brain injury completed a PCRS. For each of these participants a key clinician and a significant other completed third party versions of the scale. Results were compared. Table 4.18 shows the professional backgrounds of clinicians providing third party data. Occupational therapists form the largest group of participating clinicians.

The PCRS's thirty items were examined. If a participant had underrated their performance on a majority of items, compared to the clinician, they were assigned to an 'underrating' group. Where the majority of responses were the same as the clinician's, the participant was assigned to the 'equals' group, and participants overrating their performance on the majority of items formed part of an 'overrating' group. Table 4.19 shows the proportion of acquired brain injury participants who underrated or overrated ability level when compared with clinician ratings.

Table 4.18 Professional background of clinicians who completed the Patient Competency Rating Scale and the Social Communication Skills Questionnaire

Clinician	N
Occupational Therapist	26
Psychologist	7
Physiotherapist	1
Speech and Language Therapist	2
Total	36

Table 4.19 Patient Competency Rating Scale results (participant/clinician comparisons)

ABI Group	1 (underrating)	2 (equals)	3 (overrating)	Total
Impaired awareness	n = 3	n = 0	n=15*	18
Intact awareness	n = 5	n = 9*	n = 4	18

^{1 =} underrating (participant mostly underrates performance as compared to clinician)

^{2 =} equals (participant responses are mostly the same as clinician's)

^{3 =} overrating (participant mostly overrates performance as compared to clinician)

^{*} largest group

A "significant other" version of the scale was completed for thirty-three participants. For three participants, no significant other could be identified. Table 4.20 shows the categories of significant others who provided third-party ratings for the Patient Competency Rating Scale and the Social Communication Skills Questionnaire.

The largest proportion of persons in the impaired awareness group was assigned to the 'overrating' category when participant ratings were compared with either clinician or significant other ratings (see Tables 4.19 and 4.21). However, clinicians assigned a larger number of individuals to this category.

Table 4.20 Significant others who completed the Patient Competency Rating Scale and the Social Communication Skills Questionnaire

Significant other	N=
Spouse Parent Child Sibling Other family member Friend Paid carers	15 7 1 3 2 2 2
Total	33

Table 4.21 Patient Competency Rating Scale results (participant/significant other comparisons)

Clinical Group	1 (underrating)	2 (equals)	3 (overrating)	Total
Impaired awareness	n = 2	n = 3	n = 11*	16
Intact awareness	n = 2	n = 9*	n = 6	17

^{1 =} underrating (participant mostly underrates performance as compared to significant other)

^{2 =} equals (participant responses are mostly the same as significant other's)

^{3 =} overrating (participant mostly overrates performance as compared to significant other)

^{*} largest group

4.5.3 Social Communication Skills Questionnaire (SCSQ)

The SCSQ was administered in exactly the same way as the PCRS, the same clinicians and significant others who completed a PCRS also completed a SCSQ. The scale has twenty-seven items which were examined by the method described for the PCRS.

For the Social Communication Skills Questionnaire, clinicians and significant others appeared to be scoring participants in a markedly dissimilar way (see Tables 4.22 and 4.23). As for the PCRS participant/clinician comparison scores result in the majority of the impaired awareness group being placed in the overrating category.

Table 4.22 Social Communication Skills Questionnaire results (participant/clinician comparison)

Clinical Group	1 (underrating)	2 (equals)	3 (overrating)	Total
Impaired awareness	n = 3	n = 4	n = 11*	18
Intact awareness	n = 8*	n = 7	n = 3	18

^{1 =} underrating (participant mostly underrates performance as compared to clinician)

Table 4.23 Social Communication Skills Questionnaire results (participant/significant other comparisons)

Clinical Group	1 (underrating)	2 (equals)	3 (overrating)	Total
Impaired awareness	n = 3	n = 7*	n = 6	16
Intact awareness	n = 2	n = 8*	n = 7	17

^{1 =} underrating (participant mostly underrates performance as compared to significant other)

^{2 =} equals (participant responses are mostly the same as clinician's)

^{3 =} overrating (participant mostly overrates performance as compared to clinician)

^{*} largest group

^{2 =} equals (participant responses are mostly the same as significant other's)

^{3 =} overrating (participant mostly overrates performance as compared to significant other)

^{*} largest group

However, participant/significant other results were different, with a majority of participants being placed in the 'equals' category, indicating a greater trend towards concordance between the ratings of participants and significant others.

A number of factors might account for this. The clinicians may have been overly severe, perhaps attributing what they perceived to be social skills deficits to the brain lesion but which in fact were part of the participants' social skills repertoire pre-morbidly. Alternatively, clinicians may have spent more time with some in-patients post injury, and might, therefore, have given a more accurate rating than relatives who had not been exposed to their relative behaviour for a long enough period to realise the degree of change that had occurred.

4.6 DISCUSSION

4.6.1 'Phase 2: group comparison study' – task battery

The full task battery, used in conjunction with ease awareness scores, appeared to discriminate effectively between the impaired awareness group and each of the three comparison groups. The quality awareness scores were found to have less discriminatory power with significant differences between the impaired awareness group and healthy group only. The Abreu et al. (2001) study used the quality dimension approach only and this may cast further doubt on the reliability of the Abreu et al. study. Although some individuals exhibited extreme 'awareness' (overrating) scores, the full task battery mean awareness scores did not appear to vary dramatically (despite being statistically significant) between the impaired group and the other groups. It is argued that this may be due to the selection of participants. Clinicians were asked whether the patient they were referring had intact or impaired awareness, they were not guided as to specific 'objects' of awareness. The clinicians' accounts (see Chapter 6) indicate that some of the participants had lacked awareness of everyday task ability, but that this had now resolved, although they still lacked awareness with regard to future goals or social skills deficits. This suggests that selecting participants to the impaired group on the basis of lacking awareness of everyday task ability, specifically, would have resulted in much more marked differences between groups.

It was noted in the 'phase 1: preliminary study' that one participant with a high awareness score did not vary her pre-battery and post battery ratings. Scrutiny of raw scores indicated that none of the impaired group participants in the 'phase 2: group comparison study' had this tendency.

The good level of inter-rater reliability gave some reassurance that the lead investigator was reliably rating participants' task battery performance. The good level of inter-rater reliability may be largely due to the clear and detailed criteria for judging performance. The rater (psychology graduate) who was much less experienced in clinically observing patients, was nevertheless able to use these guidelines effectively.

A short-coming of the test-retest reliability study was the few participants included, and also, the fact that participants with intact awareness out-numbered those with impaired awareness. There were difficulties carrying out the second test within a short time-frame. Many of the participants included in this study were being seen on an out-patient basis and this seemed to contribute to their lack of availability. A number of these participants were away on holiday, busy with other commitments, or sick for extended periods between assessments. Some participants may simply have been unwilling to complete the test on a second occasion (though there was no specific evidence to support this supposition). In either case, use of the abbreviated version of the battery may have facilitated continued participation.

4.6.2 <u>Implications of group differences</u>

The spinal cord injury participants included in this study did not demonstrate impaired awareness with regard to the task battery, and did not differ from the healthy participants in any tangible way. It was hypothesised that if emotion was contributing to impaired awareness in ABI participants, then this would also be apparent among spinal cord injury participants, who also have to come to terms with a considerable degree of disability. The fact that the spinal cord injury participants demonstrated no awareness impairments, showed that the study was successful in excluding participants who had sustained a concurrent brain injury at the time of traumatic spinal lesion. However, it does not rule out the possibility that emotional reaction to a brain injury may be impacting on the 'awareness

profile' of some individuals with acquired brain injury. There seems little doubt that coming to terms with cognitive dysfunction presents a very considerable threat to one's sense of self, such as may not be encountered by patients faced with marked physical impairment (and resultant activity limitation), such as permanent paraplegia. This threat to the self may be viewed as placing an additional emotional demand upon an individual with an acquired brain injury. The clinicians' accounts (considered in Chapter 6) illustrate that psychologically motivated denial was strongly suspected in the case of several individuals, though clinicians had much difficulty determining the degree to which lack of insight was due to this.

4.6.3 Questionnaires

Hospital Anxiety and Depression Scale

The second phase of the study illustrated little difference between groups in relation to mood as measured by the Hospital Anxiety and Depression Scale. However, extreme scores were apparent in some individuals. The 'phase 3: case studies' will provide an opportunity to examine the relative importance of mood as a factor contributing to impaired awareness in particular individuals.

Patient Competency Rating Scale

A question repeatedly asked by clinicians and relatives was whether they answer the question assuming that the participant has or doesn't have recourse to disability aids. Other questions which arose were whether they should answer the question assuming that the patient was having a good or a bad day. Relatives in particular explained that ability levels varied greatly according to specific circumstances, for example, relatives would comment that their relative could do the laundry – but not if distracted whilst doing so, etc. Some significant others required clarification regarding what was meant by 'doing the laundry'. These issues add to concern about the use of verbal report as a methodology of choice in determining awareness. The 'phase 1: preliminary study' indicated that asking people with acquired brain injury to predict how they will perform an everyday task may elicit random responses. Use of the Patient Competency Rating Scale may elicit such answers also.

A further issue relating to the Patient Competency Rating Scale (and the Social Communication Skills Questionnaire) was the variation in response to questions depending on whether a clinician or significant other was selected to provide collateral third party data. This might be due to the amount of time either the clinician or significant other has spent with an individual following their brain lesion. It seems probable in many cases that the third party who has spent most time with the brain injured individual may provide the most objective responses. This was explored further in the 'phase 3: cases studies' which will involve administration of these questionnaires at more than one time point.

4.7 CONCLUSIONS

In the 'phase 1: preliminary study' a task battery was developed. The task battery consisted of a greater number and wider range of tasks than other studies. Similarly, rather than leaving judgement of participant performance to the potentially biased opinion of therapists, detailed guidelines were developed to guide such assessment of task performance. The resultant battery was the main measure in a carefully designed group comparison study. In the design of the study, careful consideration was given to the choice of comparison groups – having three comparison groups allowed more detailed analysis of the task battery than had been attempted in the past. Likewise, it was noted that previous studies using task batteries had chosen different dimensions of performance to score. For the first time, within the 'phase 2: group comparison study', the discriminatory power of two different dimensions - 'ease' and 'quality' - was compared. Although both dimensions discriminated well between the impaired awareness group and the healthy group, only the ease dimension was found to discriminate effectively between the impaired and intact awareness groups. For the first time, future researchers might choose to use the ease score dimension, in preference to the quality dimension, in the knowledge that there is now some evidence to make this distinction. Consistent use of one dimension will mean that future studies in this area can be compared in a more meaningful way. In turn, this might result in quicker advancement of knowledge in this area.

The finding, that two of the tasks had better discriminatory power than the full task battery, indicates that these two tasks could be used instead of the full battery. Use of the abbreviated task battery might be an additional benefit to busy clinicians with limited time.

As this finding arose from a group study context, the abbreviated task battery will be administered to case-study participants in Chapter 5, in order to compare their results with results obtained in the group comparison study.

Furthermore, the good, or very good, levels of agreement, found between three raters within the inter-rater reliability study, give some assurance that the scoring guidelines, developed for the task battery, can be implemented by different raters in a reliable manner. This is a further improvement on the batteries developed by Abreu et al., (2001) and Hart et al. (1999), in which scoring was left to the subjective opinion of therapists.

Although it was not possible to carry out all aspects of the design as originally planned, notably, it was possible to recruit only 11 participants, rather than 18, to the test-test reliability and measure stability studies, it is argued that sufficient elements of the design were carried out as intended, so that the resultant battery was subjected to more rigorous testing than earlier studies.

It could be highlighted that score ranges within the four groups indicated that, although the impaired awareness group had the most extreme overrating scores, not all members of the impaired awareness group had overrating scores. In Chapter 6, the 36 clinicians, who had categorised the acquired brain injury participants as having either impaired or intact awareness, were interviewed. This provided an opportunity to ascertain why some patients, identified as lacking in awareness, did not lack awareness with regard to task battery performance. One possible explanation could be that individuals were categorised as lacking in awareness because of impaired awareness of a functional domain unrelated to everyday task ability.

Little relationship was found between awareness of everyday task ability and either anxiety or depression. However, this group finding masked a possible relationship between anxiety and an extreme (overrating) task battery awareness score in one individual. In Chapter 6, a qualitative approach was used to attempt to identify factors that had an impact upon awareness status in individuals with acquired brain injury. This could allow a more detailed insight into the possible impact of anxiety – or other mood disorders – on impaired awareness.

The Patient Competency Rating Scale results were as expected. When the impaired awareness group participants were categorised, the largest number of participants was categorised as overrating ability. This was true whether participant responses were compared with clinician or significant other responses. Nevertheless, it was apparent that not all impaired awareness group participants fell into this category, and there was not full concordance between clinician and significant other responses. Even more marked differences, between clinician and significant other responses, were apparent when considering the Social Communication Skills Questionnaire results. This finding begs an obvious question. If clinician and significant other responses are different, is there a means of distinguishing which set of responses is more valid? The 'phase 3: case studies', in which these questionnaires were used longitudinally, might provide some answers to this question.

CHAPTER FIVE

PHASE 3: CASE STUDIES

5.1 INTRODUCTION

Clinical presentation of impaired awareness, in persons with acquired brain injury, is very varied, with many factors potentially contributing to the impaired awareness 'profile' in any given individual. It has been suggested that single-case designs are more appropriate (than group comparison studies) for individuals whose behaviour is complex, as in the case of those with acquired brain injury (Sunderland, 1990). The single-case, experimental design methodology might have more clinical utility. If an intervention is found to be helpful in some cases, and not in others, clinicians can compare the individuals whom they are treating, with individuals for whom the intervention was either successful or not, and act accordingly (Barlow and Hersen, 1984). For these reasons, single-case designs are common in the neurological rehabilitation literature relating to clinical effectiveness. Single-case, experimental design will be used to determine the effectiveness of interventions used to attempt to increase awareness in case study participants recruited to this phase of the research programme.

The earlier research studies have, in the main, involved one off assessments. The 'phase 3: case studies' will now allow closer examination of impaired awareness phenomena in specific individuals. Cross-sectional sampling provides little opportunity to detect variability in awareness for different domains, and in relation to the present and the future. The 'phase 3: case studies' should detect such variability. The semi-structured interviews provided a means of exploring factors and critical incidents that might be impacting upon any change in awareness. Semi-structured interviews will be used once again to capture salient factors. Findings will continue to be considered in the light of the Hierarchical model, and other models outlined in Chapter 1.

Finally, the 'phase 3: case studies' will allow closer examination of measurement issues relating to the Patient Competency Rating Scale, and try to ascertain why there might be differential results, according to whether significant other or clinician report is compared with acquired brain injury participant report. The sensitivity of the abbreviated task battery will also be examined in more detail. Abbreviated task battery results, arising from the 'phase 3: case studies', will be compared and contrasted with the results obtained for the 36 group comparison participants with acquired brain injury.

5.1.1 'Phase 3: case studies' - Main aims

- i) To determine the effectiveness of interventions, to increase awareness of everyday task ability, in persons with acquired brain injury,
- ii) To determine the effectiveness of interventions, to increase awareness of social interactive abilities, in persons with acquired brain injury,
- iii) To explore the natural history of recovery in respect of impaired awareness of social skills deficits or everyday task performance, in persons with acquired brain injury,
- iv) To investigate the critical incidents impacting upon the awareness status of case study participants,
- v) To review the sensitivity of using the abbreviated version of the newly developed task battery.

5.1.2 Data collection

Demographic data for the six case study participants is shown in Table 5.1 (page 132). The measures used for each of the six case studies are summarised in Table 5.2 (page 133). Table 5.3 (page 134) shows the third parties who provided collateral data for each case study.

Table 5.1 Summary of demographic data – Acquired brain injury participants

Case	Age	Gende	r Nature of Injury	Time post injury	CT Data	Neuropsychological deficits
S	26	Male	TBI (fall)	6 years	Large bi-frontal haematomas Large occipital haemorrhage	Information processing accuracy Long-term verbal memory retention
В	68	Male	Stroke	11 months	Large left subdural haematoma	Information processing speed Delayed recall Mild executive dysfunction
R	20	Male	TBI (skiing)	6 months	Right cerebral lesion	Verbal memory New learning Executive dysfunction - planning - impulsivity - mild disinhibition
G	23	Male	TBI (cycling)	12 years	Right cerebral infarct followed surgery to remove extra-dural haematoma	Impulsivity Mild disinhibition
A	22	Male	TBI (RTA)	18 months	Subarachnoid haemorrhage	Information processing speed Verbal and visual memory
Н	61	Male	Stroke	14 months	Right posterior cerebral infarct involving posterior limb of internal capsule, occipital cortex and thalamus	Refused formal testing Left inattention was apparent

Table 5.2 Measures administered to most, or all, case study participants

	Intervention Intervention attempted		Intervention not attempted	Natur Cases	ral History
Case study participants:	S	В	R G	A	Н
Measures					
Patient Competency Rating Scale (PCRS)	J	•	•	•	•
Semi-structured Interview Schedule	•	•	•	•	•
Social Communication Skills Questionnaire (SCSQ)	•		•		•
Abbreviated Task Battery (ATB)	•	•	•	~	•
Notes		· · · · · · · · · · · · · · · · · · ·			
The SCSQ was not administered to Case B or Case A because neither was identified as lacking in awareness of social skills deficits.					
The ATB was not administered to Case G because work commitments meant he was available for testing by phone only.					

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Table 5.3 Third Parties providing Collateral Data in relation to all questionnaires used in 'phase 3: case studies'

	Intervention C	ases			Non-intervention Cases	
	Intervention attempted		Intervention not attempted			
Case Study Participants:	S	В	R	G	A	Н
Questionnaires used with most or all participants						
Patient Competency Rating Scale, Self-Awareness of Deficits Interview, Semi-Structured Interview Schedule and Social Communication Skills Questionnaire (where applicable)	Mother O.T.	Wife O.T. Physio	Mother O.T. Physio Psychology Assista	Mother O.T.	Brother O.T. Physio Psychology Assistant	Wife O.T. Physio
Intervention Questionnaires						
Eye Contact Questionnaire	Mother Receptionist					
Spontaneous Conversation Questionnaire	Mother OT					
Assistance to Stand Questionnaire		Physio				
Focus on Task Questionnaire			Physio			
Overly Personal Comment Questionnaire				Mother		
Interruption Questionnaire				Mother		

Questionnaires

It was hypothesised that a number of factors might interact to produce impaired awareness in an individual with acquired brain injury. In order to monitor the interaction of factors, the following questionnaires were used in both intervention and non-intervention case studies. In every case, the Self-Awareness of Deficits Interview, the Patient Competency Rating Scale and a semi-structured interview schedule were used. The Social Communication Skills Questionnaire was used only if lack of awareness of social skills deficits was identified. Collateral data were gathered from third parties (clinicians and significant others) in respect of the above questionnaires.

The semi-structured interview schedule was devised for the final phase of the research programme and had two versions, one relating to impaired awareness of communication or social skills deficits, and the other, relating to impaired awareness of everyday task ability (See Appendix 25, page 34, and Appendix 26, page 35). The results of the semi-structured interview will be considered briefly in this chapter, to clarify any critical incidents occurring in the life of participants that might account for a change in awareness. Tables with semi-structured interview data are included for the two intervention case studies only. These are included to illustrate how data relating to critical incidents were obtained. The tables containing semi-structured interview data are long, and in order not to distract from the flow of the text, the remaining four tables are included in the Appendix. Data arising from these questionnaires will be explored in more detail in Chapter 6 relating to the nature of impaired awareness.

Abbreviated Task Battery

The Abbreviated Task Battery was administered to provide a behavioural measure of both everyday task ability (activity level of function) and awareness of everyday task ability, in order to assess its sensitivity to awareness impairment in individuals with acquired brain injury.

5.1.3 Design

Intervention case studies

Individuals were recruited to the 'phase 3: case studies' if they lacked awareness of one or more areas of social skill or everyday task deficit. One or two areas of either social skill or everyday task deficit would be identified, after discussion with the individual with acquired brain injury, a therapist and significant other. It was deemed essential that the individual be willing to work on the areas identified. It was hypothesised that willingness to take part did not imply adequate awareness of a problem area. An individual might, for example, have only a general idea that something is amiss (a rudimentary degree of intellectual awareness).

Where two behaviours were identified, one would be chosen at random for intervention, by the sealed envelope method of randomisation. It was envisaged that, in some instances, it would not be possible to choose to intervene on a random basis, if it were more logical to work on a particular skill area initially. An example would be working on eye contact before expanding topics of conversation.

There would be a minimum of five baseline measures of target behaviour A (i.e. the first behaviour selected for intervention). At this point, the number of further measures (1 to 3) would be decided according to the sealed envelope method of randomisation. This would mean that each participant had a minimum of six baseline measures before intervention started. The baseline period would be extended by three measures if a stable baseline had not been achieved within five measures.

Having started Intervention A for target behaviour A, target behaviour B would be assessed five more times. At this stage, the number of extra measures would be decided by the sealed envelope method of randomisation (as for target behaviour A). This would mean that each participant had a minimum of six assessment measures, after the introduction of Intervention A, before starting Intervention B.

Natural History Case Studies

In the initial two phases of the research programme, it was apparent that some individuals with acquired brain injury underwent rapid changes in relation to awareness of their ability to perform everyday tasks. It is not clear which factors contributed to such improvement. It was hypothesised that following up a number of individuals on a non-intervention basis might contribute to current understanding of the factors facilitating, and inhibiting, the acquisition of awareness of everyday task performance.

Once participants were recruited to the research, they would be followed up on a single case experimental basis where possible. That is, they would be identified by third parties as having impaired awareness of at least one impairment or activity limitation. If a participant seemed unlikely to engage in active intervention, he or she was followed up as a natural history case study. For example, if a participant was refusing to engage in rehabilitation, because of their impaired awareness, it could be considered unlikely that he or she would agree to engage actively in an experimental intervention.

In order to include as many cases as possible within the 10-month timescale, a decision was made to include complex cases. Youngjohn (1989) and Chittum et al. (1996) demonstrated that an increase in awareness could be brought about by targeting intervention at those with severe acquired brain injury. Before beginning the 'phase 3: case studies', clinicians were consulted in respect of suitable participants. The clinicians indicated that a number of potential participants had more than one diagnosis. It was decided that such individuals would be included in the 'phase 3: case studies', provided that the main reason for the awareness impairment was associated with their acquired brain injury.

In the 'phase 3: case studies', an explicit aim was to ascertain critical incidents that might have an impact upon awareness level and any change in this. In order to achieve this aim, it was considered important to start data collection as soon as possible, after participant recruitment. This would provide an opportunity to obtain *concurrent* (rather than retrospective) reasons for any change in awareness level. Pilot work was therefore limited to brief sampling of questionnaires that were designed for specific individuals involved in the 'phase 3: case studies'.

5.1.4 Procedure

The investigator administered all questionnaires and the Abbreviated Task Battery to participants. The Self-Awareness of Deficits Interview and semi-structured interview schedule were administered on a fortnightly basis, as far as possible. If no change had occurred after several weeks, the frequency was reviewed and reduced to once a month. The Patient Competency Rating Scale (PCRS), Social Communication Skills Questionnaire (if applicable), and the Abbreviated Task Battery were administered at the beginning and end of each case study participant's involvement. A ten-month period was available to collect data for the 'phase 3: case studies'. During this period, participants continued to be recruited, provided that they could be followed up for a minimum of three months. A three-month period was considered an adequate period of time to pick up changes in awareness level. When possible, participants were followed up for longer than three months. Participants, who were likely to be involved in the study for six months or more (i.e. they were recruited in the early stages of the 10-month period available), the PCRS and SCSO were administered at a third (mid) time point. Data collection was carried out in the rehabilitation services to which participants were attached, and was carried out at participants' homes once they had been discharged.

5.1.5 Data management

For the intervention case studies, the principle aim of data analysis was to distinguish whether improvement in everyday task ability and social interactive ability, and awareness of these domains, could be attributed to the intervention, rather than to spontaneous recovery or other factors. This was ascertained by visual inspection of plotted data points, using Excel graphs and diagrams.

For the natural history case studies, the main aim of data analysis was to identify critical incidents that might be facilitating, or inhibiting, 'recovery' of everyday task ability. Changes in awareness were compared with intrinsic (e.g. observable changes in mood), and extrinsic factors (e.g. change in family circumstances). In keeping with the exploratory nature of this phase of the research programme, factors affecting awareness were examined for the intervention case studies as well. Results were displayed in the form of tables,

showing concurrent factors and critical incidents occurring on a month-by-month basis. These 'circumstantial' factors were then considered in relation to the other results.

5.1.6 Participant recruitment

Six participants were recruited to the study. (See Table 5.1, page 132)

Two more cases were referred initially but, subsequently, did not participate. One had no awareness at all of social skills deficits, and it became obvious that there was no means of engaging her in the research. The second individual was reported to have experienced a sudden realisation of the extent of his brain damage, two years after his traumatic brain injury. This resulted in a catastrophic reaction and severe depression. The sudden onset of awareness was believed to be triggered by a work placement. He reported to his occupational therapist that, while pricing up CDs in the back of a charity shop and talking to some old ladies, the full extent of what he had lost suddenly dawned on him. He had previously had been a successful IT systems analyst.

The case studies will be considered in pairs: firstly the two case studies for whom intervention was attempted; secondly, the two cases for whom baseline data were gathered but intervention not attempted; finally, the two cases studied on a non-intervention basis.

5.2 INTERVENTION CASE S

5.2.1 Background

S was living with his parents, his brother and his sister, when he sustained a severe head injury in a fall six years before participating in this study. He was 26 years old, had a prior diagnosis of Asperger's syndrome and experienced frequent bouts of clinical depression. He was reported as 'living in his own world' during his schooling and had difficulty relating to others socially. However, he was reported to be of above average intelligence, achieving seven GCSE passes. For the duration of his involvement in the study, he attended a community head injury service as an outpatient. He was identified as lacking awareness of impoverished social skills. More detailed discussion with S, his mother and clinicians indicated that his social skills, already compromised by the Autistic Spectrum

Disorder, had been affected to a greater degree by the head injury. Furthermore, his mother and clinicians agreed that his impaired awareness of social skills deficits was attributable mainly to his acquired brain injury.

S's mother and clinicians concurred that specific areas of deficit included very poor eye contact and failure to initiate conversation or expand beyond one-word utterances when addressed. S was very motivated to engage in the project. A single-case, experimental design methodology, incorporating multiple baselines was chosen.

5.2.2 Aims

- To evaluate the effectiveness of a social skills intervention programme, in increasing eye contact and in increasing appropriate spontaneous conversation (when addressed).
- To evaluate the effectiveness of the intervention programme in increasing S's awareness of poor eye contact and lack of spontaneous conversation (when addressed).
- To identify any critical incidents impacting upon awareness level.

5.2.3 Data collection

Questionnaires

Two questionnaires were devised to measure S's eye contact and spontaneous speech in one-to-one and group situations.

1. Eye Contact questionnaire

Respondents using the eye contact questionnaire were required to rate the duration of eye contact, according to a 4-point scale (0 = No eye contact, 3 = Normal duration of eye contact). See Appendix 27, page 36.

2. Verbal Response questionnaire

Respondents were required to rate S's verbal responses, when they addressed him, according to a 5-point scale (1 = No verbal response, 5 = S answered the question and sought view of other). See Appendix 28, page 37.

The Patient Competency Rating Scale and the Social Communication Skills Questionnaire were used to determine whether S was overrating his abilities compared with third parties. The Self-Awareness of Deficits Interview was included as an additional measure of awareness. A semi-structured interview schedule was used to identify critical incidents affecting S's awareness.

Abbreviated Task Battery

The Abbreviated Task Battery was employed to provide a behavioural measure of S's awareness of everyday task ability, and to continue to explore its sensitivity to impaired awareness.

5.2.4 Procedure

The eye contact and verbal response questionnaires were completed by personnel in the rehabilitation centre, and also by S's mother in situations away from the rehabilitation centre. Towards the beginning of the intervention phase, a further measure was added: a numerical rating scale (NRS) of S's perception of social competence in situations he engaged in regularly, outside the rehabilitation unit. An NRS score of 0 denoted feeling no social competence, and a score of 10 denoted feeling very socially competent. It was felt that the existing measures did not cover this salient dimension. The NRS was administered early in the intervention phase, and on a second occasion post intervention.

The Self-Awareness of Deficits Interview and semi-structured interview schedule (Appendix 25, page 34) were used at fortnightly, then monthly, intervals. The other questionnaires were administered at three time points: the beginning of S's involvement with the study, during the intervention phase, and following the intervention phase. Third-party data were provided by S's mother and, to a lesser extent, by S's occupational therapist, who saw S only sporadically. The Abbreviated Task Battery was administered to S on two occasions, at the beginning and end of his involvement in the study. All data collection was carried out in the brain injury unit.

The investigator devised and delivered the intervention programme. The investigator met S twice weekly (Mondays and Thursdays) over a nine week period. Each session was approximately 45 minutes long. It was felt that eye contact should be addressed before spontaneous conversation, because eye contact could be viewed as a prerequisite for engaging in spontaneous conversation.

Intervention Programme

The programme involved teaching and reviewing the rudiments of social skills. It encompassed role play of dyadic, themed conversation, video feedback, eliciting S's views of his own performance, of the investigator and, when possible, an occupational therapy student. S was encouraged to identify strengths and weaknesses on each occasion. He was always set homework tasks and these were reviewed after the first session. Further details are given in Appendix 29, page 38.

In order to reinforce learning, there was a high degree of overlap between sessions. The programme was modified over the nine week period, when S's mother or his occupational therapist gave the investigator feedback on areas of particular difficulty that occurred outside intervention sessions. For example, S had arrived very late for a session with his occupational therapist, but neither apologised nor made any reference to this. Thus, ways of dealing with this circumstance were added into the programme.

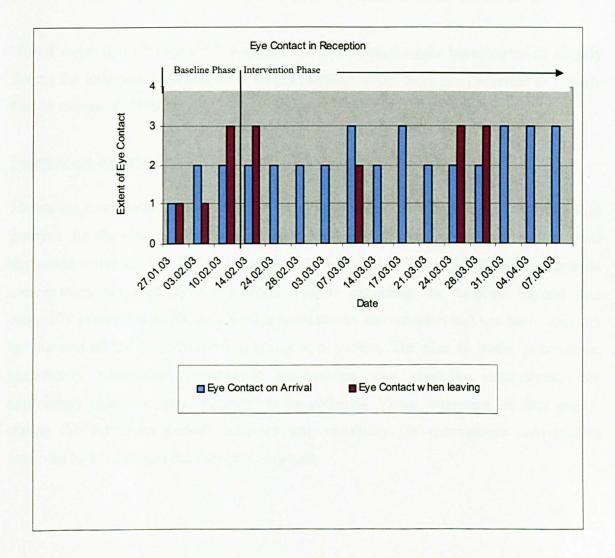
5.2.5 Results

Questionnaires

Data collection did not proceed as envisaged originally. Clinicians involved in S's care were briefed and provided with data collection forms in November 2002, and were willing to collect data. At that time S attended the unit to follow self-directed study only. In theory, S would see a clinician each time he attended (twice a week). In practice, clinicians were very busy and saw him only sporadically. It eventually became apparent that the only person who saw S regularly when he came to the rehabilitation unit was the receptionist, and so she was approached to collect eye contact data. Almost invariably, the receptionist saw S on arrival, because he needed her to open the door into the rehabilitation unit. She

saw him less commonly on the way out, since individuals could let themselves out and the reception area was usually very busy. Hence, Figure 5.1 shows more data for S's arrival in reception than departure.





Data were collected during a baseline phase and at regular intervals throughout the intervention phase. The baseline phase was shorter than envisaged, caused by a delay of two months between S consenting to take part in the study and the first measure being taken. S's clinicians, and his mother, indicated to the investigator that S was becoming discouraged at the delay in starting the intervention programme. For this reason S was given a specific start date for the intervention programme. In theory, there was still time to

collect sufficient baseline date but, in practice, data were collected only on three occasions before the start of intervention. Since S had been given a firm start date, it was considered ethically unacceptable to delay this any further.

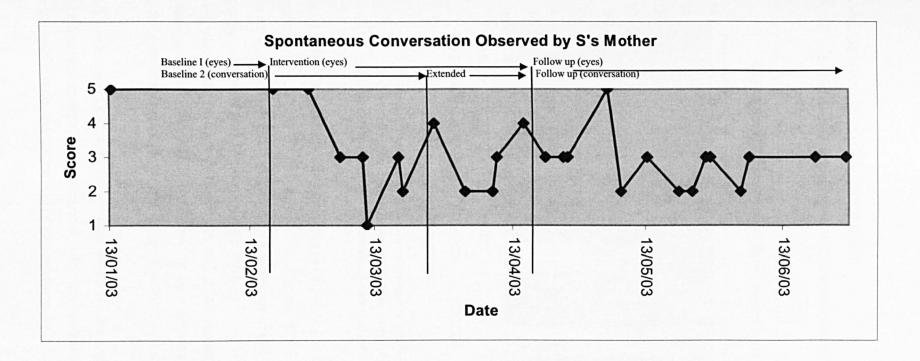
There were no data points during the last 10 days of intervention or post-intervention. Data collection on eye contact stopped when the receptionist became unwell and was away for several weeks. A replacement receptionist agreed to collect data, but did not do so.

Visual inspection of Figure 5.1 suggests that eye contact might have improved slightly during the intervention period but a longer baseline would have been required to provide clearer evidence of this.

Spontaneous conversation

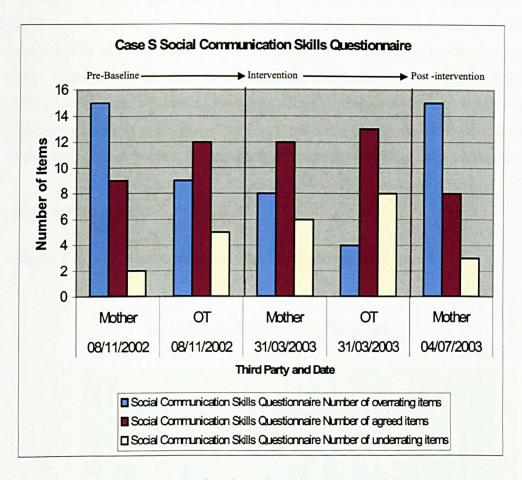
Measuring spontaneous conversation in the rehabilitation unit likewise proved difficult in practice, for the reasons already mentioned. Measures of spontaneous conversation were attempted within the unit but were too sporadic to be valid. Figure 5.2 shows spontaneous conversation observed by S's mother. Despite extending the baseline beyond that originally planned, a stable baseline for spontaneous conversation had not been achieved by the end of the intervention addressing eye contact. The plan to begin intervention specifically addressing spontaneous conversation was, therefore, abandoned. For exploratory purposes, data continued to be gathered. Visual inspection of data points, during the follow-up period, indicates that variability (in spontaneous conversation observed by S's mother) did decrease eventually.

Figure 5.2 Verbal Response questionnaire results - Spontaneous conversation observed by S's mother



Score on y axis refers to Verbal Response Questionnaire ratings (A score of 5 = normal response; 1 = no response)

Figure 5.3 Social Communication Skills Questionnaire results – Case S



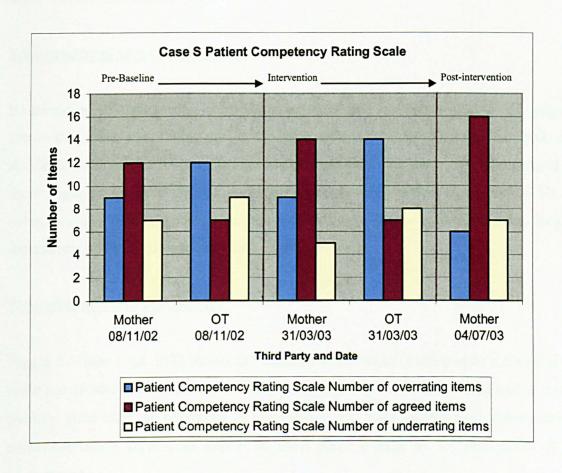
The Social Skills Communication Questionnaire was scored in the same way as the Patient Competency Rating Scale. By this method, the 27 items of the scale were assigned to one of three categories: i) overrating (participant overrates ability for item compared with a third party); ii) concordant (participant and third party agree on participant ability for item); iii) underrating (participant underrates ability for item according to third party). At a single time point, a participant is considered to be overrating ability if, the investigator having categorised all items, the largest category is for overrating items.

Figure 5.3 demonstrated that, in the pre-baseline phase, S overrated social communication ability, when his ratings were compared with his mother's. When the occupational therapist's ratings were considered, the largest category is for 'agreed (concordant) items'.

Since the occupational therapist rarely saw S over the study period, it is perhaps of greater interest to consider the data arising from comparison of S's ratings and his mother's ratings. The second time point was towards the end of the intervention period. The data collected then demonstrated a change from the pre-baseline data. By the second time point, the majority of S's and his mother's responses are concordant. Strikingly, three months after intervention, the data spread was almost identical to the pre-intervention data, showing that S had returned to overrating social interaction abilities on a majority of items. This would appear to indicate some improvement in *awareness* of social skills during the intervention phase but that the improvement was not maintained once intervention ceased.

The Patient Competency Rating Scale

Figure 5.4 Patient Competency Rating Scale results – Case S



The PCRS addresses awareness across a broader range of abilities, rather than focusing on social interaction alone. Again, looking at the third-party comparison (Figure 5.4) involving S's mother, at each time point the largest category of S's responses were concordant with his mother's. The number of concordant responses appeared to increase steadily over the three time points, suggestive of some gradual improvement in self-awareness – of activity limitations - over this period.

Self-Awareness of Deficits Interview (SADI)

S achieved a score of '1' for each level of the SADI, on each occasion that data was gathered. This suggests some, but not full, awareness of deficits, nor awareness of the implications of deficits, and some, but not full, realism regarding goals that would be achievable in six months.

Semi-structured interview schedule

Examination of data arising from the semi-structured interviews (Table 5.4, page 150) shows that, other than taking part in the intervention, there were very few notable critical incidents occurring in S's life during his participation in the study. By March/April 2003, there began to be some change, and some increase in awareness in aspects of S's social behaviour. His mother's comments indicated that, this change in behaviour was lacking in naturalness and thus did not constitute an improvement.

Perception of Social Competence

Figure 5.5 (see page 153) shows the Perception of Social Competence numerical rating scale scores across four settings in which S engaged in social interaction and at two time points – soon after the beginning of intervention and three months post-intervention. The numerical rating scale does appear to show some change in S's perception of social competence.

The results suggest improvement in S's subjective impression of social competence. This might be an artifact of the multiplicity of measures, because there was no evidence at all of

improvement in social competence, nor was there any identifiable improvement in self-esteem. An increase in self-esteem might be expected when people feel that their social competence has improved.

The Abbreviated Task Battery

S achieved an awareness score of -1 at time point one (overrating by one point on the tea and toast task); and an awareness score of -2 at time point two (overrating performance by two points on the tea and toast task) for the Abbreviated Task Battery. At time point two, three additional tasks (rail enquiry task, filing task and timetable task) were included from the original battery for exploratory purposes. The cleaning task was excluded, as it had been shown to be the weakest task in the 'phase 2: group comparison study'. Administration of the further three tasks from the original battery showed that S overrated performance by one point on the time-table task. Thus, S's awareness score for the Abbreviated Task Battery indicated that he overrated performance slightly more at time point two.

To put this result into context, data were re-examined for the groups who had participated in the 'phase 2: group comparison study'. The Abbreviated Task Battery (i.e. tea and toast task and object assembly task only) score range for the impaired awareness group was -5 to 0. The score range for the three comparison groups: intact awareness group: -2 to 0; spinal cord injury group: -1 to 1; healthy group: -2 to 0. S's awareness scores were not extreme, indicating that he did not have marked awareness deficits in relation to everyday task ability, or the 'activity level' of function.

Table 5.4 Semi-structured interview data – Case S

Month	Nov/Dec 02	Jan/Feb 03	Mar/Apr 03	May 0	3 Jun 03	July 03
Rehab phase	Outpatient follow-up					
Contact with therapy staff	Minimal (brief contact about once a week attending rehab unit, mostly for self-directed study)					
Notable events	None	Baseline data collected from S's mother, O.T. and rehab unit receptionist. Intervention phase begins mid Feb	Intervention phase continues until mid-April S's mother agrees to S entering reception alone		Post-intervention phase Receptionist has extended sick leave. S told that OT in rehab unit will follow up social skills work. Change of O.T. S told that person he dislikes might attend Headway	Insulted by passerby in street

Month	Nov/Dec 02	Jan/Feb 03	Mar/Apr 03	May/Jun 03	July 03
Rehab phase	Outpatient follow-up				
Change in behaviour	None apparent	No change	Some improvement		
- eye contact			Some improvement in reception		
- spontaneous conversation			Some improvement in reception		
- other			Some change at home – active effort to improve posture; to smile when entering a room, and to change the subject smoothly (but efforts appear 'affected') (mother)	Efforts to correct posture and to smile when entering a room are maintained (but still lacking in naturalness).	
Change in awareness	None apparent	More aware of what he should do but no change in practice (mother)	Some change		
- eye contact			More aware in reception		
- other			Claims to have realised through video feedback that hunched posture made him 'look vulnerable' to assault		

Month	Nov/Dec 02	Jan/Feb 03	Mar/Apr 03	May/Jun 03	July 03
Rehab phase	Outpatient follow-up				
Emotional status	Fluctuating very long- standing tendency to dwell on negative thoughts – about himself and state of the world in general	No change		Low and therefore more aware of tinnitus	
Other	Motivated to engage in social skills programme	No change but expressing concern about delay in starting the intervention phase	Concern that social skills input will cease at end of intervention phase	Preoccupied and angry about possibly seeing person he dislikes in Headway (holds the person responsible for his head injury)	Very low after insult. Anger at perceived injustice

Perception of Social Competence Intervention 10 Score (Range (0-10) 8 6 4 Retab Unitary Tosco Reseated Date Tosco Renab Unit 24/02/03
Tesco Reseauran 24/02/03 2 0

Date and Setting

Figure 5.5 Perception of Social Competence results - Case S

5.2.6 Discussion

Eye contact

The receptionist's subjective impression was that S's eye contact in reception did appear to increase noticeably. The short baseline failed to provide evidence to support this. From initial recruitment to the research, S had stated that he wished to work on his eye contact. However, during intervention he reported feeling more aware of the need to maintain eye contact, and stated that he was making an effort to give eye contact in reception. This would appear to indicate some degree of improvement in emergent awareness. Components of the intervention, which appeared to be contributing specifically to this improvement in awareness, were setting as a specific 'homework' goal that S should make eye contact with the receptionist upon entering and leaving the reception area; manipulation of the environment, i.e. asking S's mother to let him enter reception on his own (she usually accompanied him, and he reported that, habitually, he left social interaction to her).

There was no evidence that S's eye contact, or awareness of eye contact, improved in other contexts. In addition, there is no evidence that the improvement in eye contact, or the awareness of the need for this, was maintained beyond intervention, since the receptionist who had taken the measures so diligently had an extended period of leave. Semi-structured interview data indicated that S was very bothered by some circumstances occurring in the follow-up period. The absence of the receptionist meant that it was not possible to assess the impact of these circumstances on S's eye contact.

The clinical realities of minimal staff contact with S, sick leave and other factors, meant that application of the single-case, experimental design was difficult in practice. Furthermore, it was difficult to evaluate the reliability of the receptionist's verbal report. Every time she gave in completed data sheets, she commented that S's eye contact had been much better but the data collection sheets did not reflect this. Possible explanations might be that the receptionist was keen to please the investigator, or that she was not completing the data collection sheet correctly.

Spontaneous conversation

Baseline data were gathered but visual inspection indicated that these data were very variable. There was no evidence that spontaneous conversation improved during the intervention or post-intervention periods, although variability did decrease to some extent in the follow-up period. It is possible that this more stable pattern reflected S's habitual behavioural pattern. As mentioned above, there was a delay before data collection stated. Since S knew, in broad terms, what was being measured, this delay in starting may have had a 'priming' effect on his behaviour, leading it to fluctuate between extremes more than usual.

S was a challenging case within an intervention context, particularly in view of his premorbid diagnosis of Asperger's syndrome. Nevertheless, since his clinicians and his mother agreed that his head injury had exacerbated his social skills deficits (and, crucially, the impaired awareness of social skills was largely attributable to this), it was considered worthwhile to include S in the study. It is common for clinicians to be faced with patients who have more than one diagnosis, and it was considered that excluding individuals, on the basis of additional diagnoses, could lessen the clinical relevance of the research. The dislike of change and rigid behavioural patterns associated with Asperger's syndrome might have contributed to the limited difference in S's behaviour, despite his motivation to participate in the research. The impact of other factors is difficult to ascertain: other than the intervention, little altered in his life, or usual routine, during the time of his involvement with the research study.

In conclusion, S's social skills deficits were marked and long-standing. A relatively short intervention (twice weekly for nine weeks) did bring about some slight change. During the intervention phase, this included some apparent improvement in eye contact in a specific environment. There was no evidence that the improvement generalised to other areas, or that it was maintained post-intervention. The Social Communication Skills Questionnaire results indicated that S's awareness of his social skills deficits improved modestly during the intervention period but returned to pre-morbid levels post-intervention. As some change was effected, it is felt that a longer, more intensive, social skills programme might have been of benefit to S. Specifically, such a programme would need to include practice of adequate social skills in each situation S encountered regularly – to promote generalisation of skills.

5.3 INTERVENTION CASE B

5.3.1 Background

B was a self-employed professional, living with his wife, when he sustained a stroke resulting in left hemiplegia and reduced range of motion in both hips. He was 68 years old.

B was referred to the research because his clinicians noted that he consistently underrated the amount of assistance he required to complete tasks or activities in both physiotherapy and occupational therapy. After discussion with therapists, one such task was selected for intervention: standing in a Powered Oswestry Standing Frame (POSF). This task was

selected since he engaged in it regularly – two or three times per week in normal circumstances.

Creation of the intervention

Prior to designing the intervention, the investigator observed the process of B getting into the powered frame. With B's consent, the subsequent session was videoed. Finally, B was shown the video, to see whether this additional evidence would modify his opinion. He maintained that he required only a little assistance with the task.

The videotape provided strong evidence regarding the considerable assistance B required to get into the powered standing frame. Using the videotape as a basis, an intervention was devised. See Appendix 30, page 40.

5.3.2 Aims

- To evaluate the effectiveness of an intervention programme, devised to make B more aware of the assistance he required when getting into a powered standing frame (through use of single-case, experimental design methodology).
- To identify critical incidents impacting upon awareness level.

5.3.3 Data collection

Questionnaires

The Assistance-to-Stand Questionnaire (ATSQ)

The ATSQ (Appendix 31, page 42) was devised by the investigator to elicit a rating from B, regarding the amount of assistance B judged that he required when getting into the standing frame. A rating of the actual amount of assistance he required was recorded concurrently by his physiotherapist.

In addition to the Self-Awareness of Deficits Interview, the everyday task version of the semi-structured interview schedule was used (See Appendix 26, page 35), to identify any critical incidents likely to be affecting B's awareness.

The Patient Competency Rating Scale (PCRS) was used to determine whether B was overrating his abilities compared with third parties. The Social Communication Skills Questionnaire was not indicated; B was not identified as lacking awareness of the social skills domain of function.

Abbreviated Task Battery

The Abbreviated Task Battery was used to provide a behavioural measure of awareness of everyday task ability, and to continue to examine the battery's sensitivity to impaired awareness at the activity level of function. Specifically, B's results were compared with the 'phase 2: group comparison study' results described in Chapter 4.

5.3.4 Procedure

The Assistance-to-Stand Questionnaire (ATSQ) was administered every time B attended physiotherapy to stand in the powered standing frame. B was shown video footage of himself getting into standing frame. The physiotherapist obtained ATSQ scores from B, and gave ATSQ scores on the basis of B's observed performance. Once a sufficient number of baseline ATSQ measures had been taken to establish a stable baseline, the intervention was initiated. B, his wife, his physiotherapist and occupational therapist were interviewed with the assistance of the semi-structured interview schedule and Self-Awareness of Deficits Interview at fortnightly intervals, and then monthly intervals. The other questionnaires and the task battery were administered at the beginning and end of the data collection period – a six-month period.

5.3.5 Results

Questionnaires

Assistance to stand Questionnaire

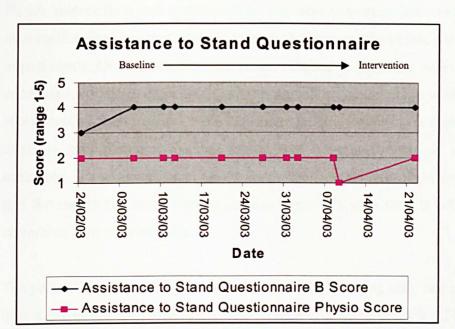


Figure 5.6 Assistance to Stand Questionnaire results - Case B

Scoring: 5=No assistance required, 1=Full assistance required.

Figure 5.6 shows that, throughout the data collection period, the physiotherapist judged that B required 'A lot of assistance'. (On one occasion she judged that he had required maximal assistance). Conversely, at the initial data point, B judged that he had required a moderate degree of assistance, thereafter he claimed consistently that he had required minimal assistance.

Due to the practical clinical circumstances explained below, it was not possible to start the intervention part of the study at the proposed time. It had been agreed that the investigator would collect the completed ATSQ measures at frequent intervals. The first three measures were collected as planned. After this the physiotherapist had intermittent periods of unplanned leave. This meant that, although the physiotherapist continued to collect measures, she (the physiotherapist) was away when the investigator went to fetch the data collection sheets. By the time the investigator next made contact with the physiotherapist, seven additional measures had been taken. This resulted in 10 baseline measures being taken, before a decision was made about the start date for intervention. Examination of baseline measures at this juncture, indicated that a stable baseline had, in fact, become apparent after five measures had been taken.

At the point when the baseline measures had been reviewed, and the decision made to proceed with intervention, B's discharge had been set for just over two weeks' later. Hence, intervention was condensed: an intensive two-week intervention phase, with eight intervention sessions, was planned over the last two weeks before discharge. B was willing to participate. Once again, practical issues resulted in only four intervention sessions being completed. Although eight sessions were agreed and times set in with B and his clinicians, subsequently, four sessions were cancelled for the following reasons: B was required to attend a goal planning meeting which was brought forward at short notice; on two occasions, B's wife was upset (at the discharge date being brought forward), and requested that the researcher come back at another time; B's wife took B off the ward before the researcher arrived to see him.

The prioritising of discharge arrangements led to B having only one physiotherapy session during the two-week period prior to discharge and, therefore, the ATSQ was administered once only during the intervention period. Post-intervention measures were not possible: B was not followed up on an outpatient basis by the discharging hospital.

The Patient Competency Rating Scale (PCRS)

Figure 5.7 shows PCRS results for B. At time point one, B could be categorised as overrating, underrating, or neither overrating nor underrating ability, according to which third party data were used. By time point two (four months later), B was tending to overrate his abilities, no matter which third party data were used for comparison. At time point two, B had been at home for five weeks and the data would appear to indicate that his wife was giving more accurate ratings, as she had greater exposure to his real ability level, than whilst B was in hospital.

Figure 5.7 Patient Competency Rating Scale results - Case B

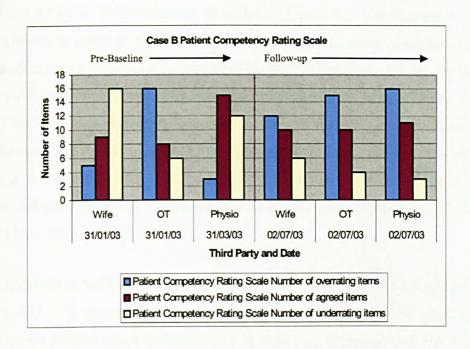
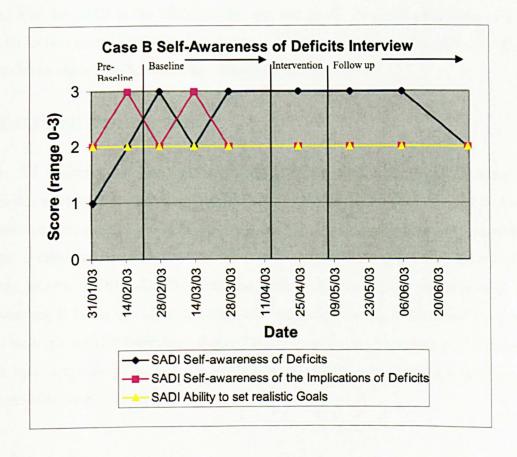


Figure 5.8 Self-Awareness of Deficits Interview results - Case B



Self-Awareness of Deficits Interview (SADI)

Level 1 of the SADI is 'self-awareness of deficits'. Figure 5.8 demonstrates that, at the outset, B achieved a score of 1, indicating some acknowledgement of cognitive deficits, though a tendency to focus on minor physical changes. Thereafter, B's scores fluctuated between 2 and 3. A score of 2 indicates that only physical deficits were acknowledged, and a score of 3 indicates that no acknowledgement of deficits could be obtained, other than an acknowledgement that problems were being imposed upon him from outside. Of note, is that B had a stable score of 3 (lowest score) some weeks before intervention, during intervention and post-intervention, indicating consistently poor self-awareness of deficits (impairment level of function).

Level 2 of the SADI is 'self-awareness of the implications of deficits'. Throughout the data collection period, B's scores fluctuated between 2 and 3, a score of 2 showing some acknowledgement of functional deficits, but a tendency to minimise them. A score of 3 indicated that little acknowledgement of functional deficits could be obtained, with the participant admitting problems only in so far as 'not being allowed' to do things.

Level 3 of the SADI is the 'ability to set realistic goals'. B achieved a score of 2 at each data collection point, indicating that he set unrealistic goals for six months' time, but did not claim to know how he would be functioning by that time.

Semi-structured interview schedule

Table 5.5 summarised data, gathered from B, his wife, occupational therapist and physiotherapist, over the six-month period of B's involvement with the study. A number of critical incidents might have affected B's awareness, or self-disclosure, of awareness. Key events, related to aspects of the rehabilitation process, included: first home visit; the treating team's decision that B would not walk again; discharge. An incidental event – interviewing B for an induction video for staff suggested that he had been trying to come to terms with his activity limitations during his in-patient stay. B commented (in the context of the induction video) that staff should understand that it takes people a long time to come to terms with losses.

Key themes arising indicated that B lacked awareness mainly in relation to his ability to walk again and drive.

The Abbreviated Task Battery (ATB)

At time point one, B achieved an awareness score of -3 for the ATB; i.e. he overrated performance on the tea and toast task by two points and on the object assembly task by one point. At time point two, B achieved an awareness score of -4. He was overrating performance in relation to the kitchen task by three points, and the object assembly task by one point. B did not overrate ability on the rail enquiry task, filing task or time-table task, when these were included at time point two, for exploratory purposes.

Considering that the score range, for the impaired awareness group in the 'phase 2: group comparison study', was - 5 to 0 for the ATB, B's scores suggested that he could be placed at the extreme end of the overrating spectrum by time point two. The results also indicate that the abbreviated task battery was sensitive to B's impaired awareness of the activity level of function.

5.3.6 Discussion

The intervention aiming to address B's lack of awareness of the assistance he required with tasks and activities was not carried out according to the strict single-case, experimental design envisaged at the outset. This was caused by difficulty in gaining access to measures at a pertinent time, which, in turn, meant a delay starting the intervention programme. Furthermore, the clinical decision to hasten discharge resulted in only one measurement being taken during the short intervention period. It was clear, however, that B claimed he required only a little assistance with tasks, when third parties claimed that he required considerable assistance. B's view of his abilities remained fixed, before and during the intervention phase, as borne out by his Self-Awareness of Deficits scores.

Table 5.5 Semi-structured interview data – Case B

Month	January 03	February 03	March 03	April 03	May 03	June/July03
Rehabilitation Phase	Early assessment Initial home visit just completed	Assessment nearing completion Team considers functional improvement unlikely and therefore begins to plan discharge	Discharge date set for April	Completion of home adaptations (e.g. throughfloor lift) Home visit 4-day stay at home over weekend preceding discharge Discharge	Post-discharge Outpatient follow-up for physiotherapy at local neurology unit	
Relevant events			Team sorts out discharge arrangements Interview for staff Induction Programme		Outpatient physio- therapist tells B (in jest) that he will walk again	
Couple's relations with Team Team's approach to couple	Neutral Neutral	Growing tension Team decision not	Very tense	Fluctuating between tense/neutral		
		to collude with unrealistic expectations of recovery – despite pressure from B's wife			•	
Emotional status of wife	High expectation of recovery especially with regard to walking	Growing concern that team giving up too soon	Disbelief/anger in face of team's judgement that B will not walk again	Anger giving way to daily bouts of tearfulness on the ward; becoming resigned to discharge	Calmer but intermittent anger/sadness	Intermittent anger/ sadness

1 B 3 awareness				1	
Driving	Acknowledges current inability to drive	Claims currently able to drive (given the opportunity)			
Leg function	Claims it is improving	Claims it is improving	Claims it is improving	Claims it is improving	
Walking Current status	Acknowledges inability to walk	Acknowledges inability to walk	Revising short-term goal (to leave rehab unit walking)	Claims would be able to walk (given the opportunity)	
Future status	Hopes to walk but is uncertain	Claims he will walk	Claims he will walk		Claims with certainty that he will walk

Comments that never imagined

would not be able

to kick a ball on

beach with his

grandchildren

Closed

February 03

Passive/tearful

when speaking of

limited role with

his grandchildren

March 03

Passive resignation

In interview for

staff Induction video,

it takes time to come to

comments that staff

need to realise that

terms with losses

Closed

April 03

Closed

Real excitement about

returning home;

could return to normality without walking (OT)

realisation that life

May 03

Euphoria

Open

June/July03

Euphoria

Open

Month

Emotional status of B

PB's awareness

Other

Disclosure of awareness

Open

January 03

Tearful after

home visit

The intervention was very brief and appeared to have no effect – perhaps because of its brevity. B's view of his abilities apparently remained unchanged, in the face of: video evidence to the contrary; the open ridicule of his wife, who was present at one of standing frame sessions; being taught explicitly how a therapist might arrive at a judgement regarding the assistance he required with a task.

The investigator noted that, when B was questioned about the assistance he required with individual steps making up the task, he reported doing things independently - in clear contradiction to visual evidence on the video. One explanation could be psychologically motivated denial - B was very focused on walking again, and appeared to accept thirdparty information supportive of this goal. An example of this occurred after his discharge. B was seen in a local neurological outpatient unit, where the physiotherapist stood him in a ceiling track hoist. She remarked, in jest, that they would soon have him walking. This was reported to the investigator by B's wife, who said the comment was very obviously made in jest. (The clinician in question was approached and acknowledged that this was so: she did not believe that B had potential to walk again.) However, B seemed to take the comment literally, and as proof that he would walk again. During the final interview with the investigator, two months post-discharge, B's wife expressed amazement at what she described as B's extreme lack of awareness. For example, she reported that he became euphoric (after discharge) and began planning weekends away as a surprise for his wife, which was clearly impracticable. One explanation for this could be that B was still lacking in 'intellectual' awareness. Results from the SADI support this explanation. Specifically, he could be said to lack intellectual awareness of the implication of deficits. This might have been exacerbated by use of a well-rehearsed, pre-morbid coping strategy: determination to be positive. B's wife explained that B had always displayed a tendency to be somewhat unrealistic about obstacles.

Both the occupational therapist and the physiotherapist reported occasions when B said things that indicated that he was trying to come to terms with his physical losses. For instance, he became tearful one day, whilst standing in the standing frame, and commented that he had always imagined having a full grandfather role with his grandchildren, including playing football with them on the beach. This appears to be an example of what Clare (2003) described as spending 'time in the depths' - trying to make sense of what has happened and come to terms with it. B's comment was made soon after his admission and

showed a willingness to reflect on his losses. The comment was made before the decision to plan for discharge because the team believed that walking again was impossible. The couple felt this course of action to be unreasonable and, from that time to discharge, no further reflection about loss was witnessed. This is not to say that further reflection did not take place. The Self-Awareness of Deficits Interview and semi-structured interview schedule results coincided, and suggested that B entrenched himself in a position of impaired awareness from the time the decision about discharge was communicated to him.

5.4 CASE R – INTERVENTION CASE WHICH BECAME NATURAL HISTORY CASE STUDY

5.4.1 Background

R, a 20-year-old student, was at university, when he sustained a severe traumatic brain injury in a skiing accident. He had been very gregarious with many friends. He had enjoyed numerous sports, particularly football, and he had a black belt in Karate.

R's occupational therapist and his physiotherapist noted that he was easily distracted in therapy and was unable to complete tasks or exercises without frequent prompting. Typically, he would stop to ask the clinician a question unrelated to the session in progress. He was referred to the research because his clinicians reported that he was oblivious to the fact that he became distracted in this way.

Initially, it was felt that R might be suitable for an intervention study, using single-case, experimental design methodology. It was anticipated that the intervention would focus on his awareness of distractibility during therapeutic sessions. A questionnaire was therefore devised to measure this.

5.4.2 Aims

- To evaluate the effectiveness of an intervention, designed to increase R's awareness
 of distractibility during task performance.
- To identify any critical incidents affecting awareness level.

5.4.3 Data collection

Questionnaires

Focus on Task Questionnaire (FOTQ)

A questionnaire was devised by the investigator to capture R's awareness of distractibility. The purpose of the questionnaire was to gain baseline measures of R's perception of the percentage of time he spent focusing on his tasks or exercises, during therapeutic sessions:

Please state the type of activity involved (therapist to complete): Prior to the task/exercise: Ask R how long he thinks he can stay focused on the task/exercise before getting distracted, bored or tired.

100% 75% 50% 25% less than 25%

Comments:

Repeat question after the task, exercise or session.

This time the therapist should give a percentage rating, though he or she should not divulge this to R.

The Patient Competency Rating Scale and Social Communication Skills Questionnaire were administered, to determine whether R was overrating his everyday task and social interaction abilities. As for the cases S and B, the Self-Awareness of Deficits Interview and semi-structured interview schedule were used, to identify critical incidents and factors impacting upon R's awareness level. Third-party information was gathered from R's mother and from his occupational therapist, physiotherapist and psychology assistant.

The Abbreviated Task Battery

The Abbreviated Task Battery was used to provide a behavioural measure of awareness of everyday task performance, and to assess its sensitivity to impaired awareness.

5.4.4 Procedure

R's physiotherapist completed an FOTQ, when engaged in sessions in which R was required to carry out a task or activity.

R, his mother, physiotherapist, occupational therapist and psychology assistant, were interviewed with the assistance of the Self-Awareness of Deficits Interview and semi-structured interview schedule (everyday task version, Appendix 26, page 35) on a fortnightly basis. The Patient Competency Rating Scale, Social Communication Skills Questionnaire and the Abbreviated Task Battery were administered twice to R, at the beginning and end of his involvement in the study.

5.4.5 Results

Ouestionnaires

Focus on Task Questionnaire (FOTQ)

Figure 5.9 Focus on Task Questionnaire results – Case R

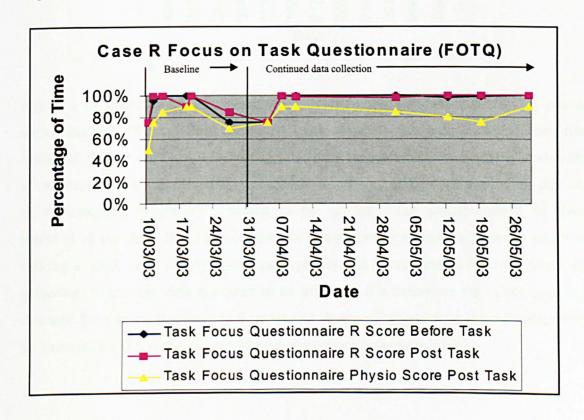


Figure 5.9 indicates little variation between R's pre- and post-task estimates of the percentage of time he spent focused on each task or activity within physiotherapy. Within the baseline phase, some of R's post-task scores are the same as the physiotherapist's scores.

Figure 5.10 Focus on Task Questionnaire results – Discrepancy between Case R's scores and physiotherapist's scores

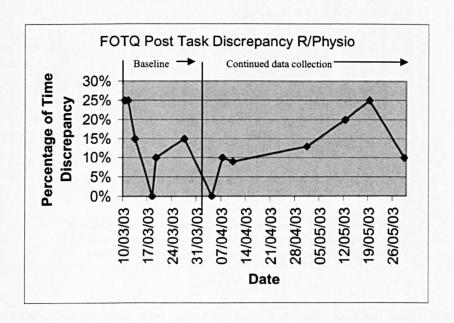


Figure 5.10 indicates that the discrepancy between the post-task distractibility scores varied between 0% and 25%. Since no stable baseline had been achieved after five measures, further measures were taken. After eight data points, there was still no stability in measures, and the discrepancy between R's judgement of distractibility and his physiotherapist's judgement appeared to be reducing. The physiotherapist involved reported, at the time, that administering the questionnaire seemed to have the effect of making R think more clearly about his responses and focus more in sessions. Since the gathering of baseline data appeared to be affecting R's behaviour (in effect, reducing distractibility), it was decided that there was no longer a clear rationale for proceeding with an intervention. R was thereafter followed up on a non-intervention basis.

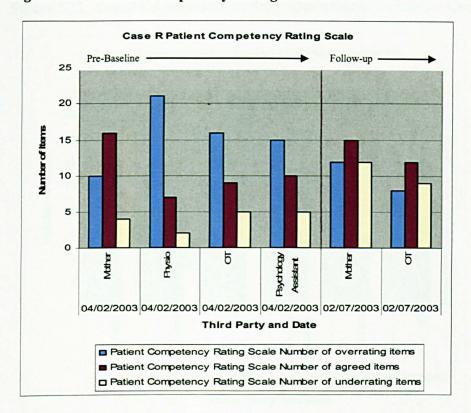


Figure 5.11 Patient Competency Rating Scale results - Case R

The PCRS results (see Figure 5.11) indicated that, at time point one there was a discrepancy between clinician scores and family member scores. R had overrated performance in comparison with each clinician but the majority of his ratings was in keeping with his mother's. In contrast, at time point two, the available data indicated that both the clinician and family member scores follow a more concordant pattern. The majority of R's responses fell into the 'concordant' category in accord with those of his mother and occupational therapist. Ratings at time point two were taken when R had been discharged: he had been at home for two weeks. It seems likely that, as for B, R's significant other did not appreciate the full extent of R's lack of awareness at time point one. At time point two, the concordance between R's responses and third-party responses suggests that R's awareness had improved in respect of abilities measured by the PCRS.

There was no third-party input from the psychology assistant or physiotherapist at time point two because these clinicians were no longer involved.

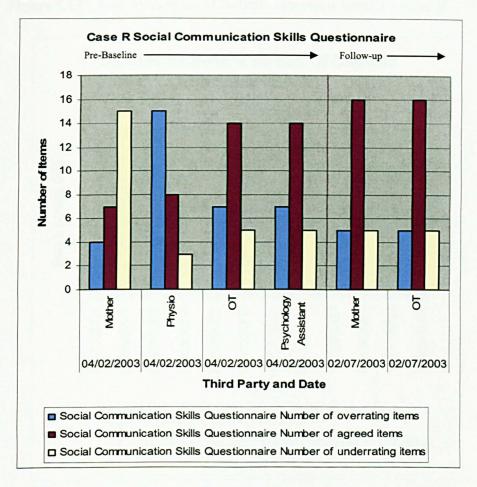


Figure 5.12 Social Communication Skills Questionnaire results - Case R

The SCSQ results (see Figure 5.12) show that there is disagreement between third parties with regard to R's social communication skills. At time point one R was underrating his social interaction skills, compared with his mother, overrating skill when compared with his physiotherapist, and mostly in agreement with his occupational therapist and psychology assistant. At this stage, the occupational therapist and psychology assistant had spent more time with R than his mother or physiotherapist which may account for the difference.

By time point two, the occupational therapist and R's mother appeared to be judging R's social communication skill, in a similar way, the majority of their responses in accord with R's. This might reflect an improvement in R's awareness at time point two or his mother might have had better first-hand knowledge of R at time point two, since R had been home on a full-time basis for two weeks by then.

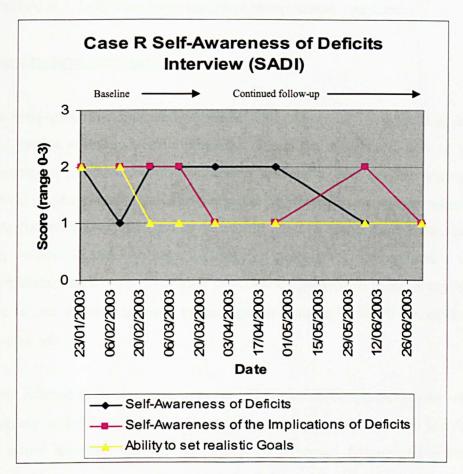


Figure 5.13 Self-Awareness of Deficits Interview results - Case R

SADI results (see Figure 5.13) indicated that, for level 1 of the SADI, R's scores fluctuated between 1 and 2 (possible score range 0 to 3). His initial score, for example, was 2, indicating that he acknowledged physical problems only and either denied cognitive/psychological problems or stated that other people thought there were problems, but that he did not agree. At the second data point his score was 1, indicating an acknowledgement of some cognitive problems, but a minimising of these, and a tendency to focus on minor physical problems. R reverted to a score of two for the next four consecutive data points before returning to a score of 1.

For level 2 of the SADI, the self-awareness of the implications of deficits, R's scores likewise oscillated between a score of 1 and 2. As for the other levels of the SADI, the

lower the score, the better the level of self-awareness. A score of 2 at level 2 indicated the admission of some functional deficits, but the minimising of these and denial of others.

For level 3 of the SADI, the ability to set realistic goals, scores started at 2 for R, then stabilised at 1, indicating some moderate improvement over time.

Semi-structured interview data

The semi-structured interview schedule data (Appendix 32, page 43), indicated that the third parties noted awareness problems in relation to certain areas of R's life: driving, returning to his Saturday job, resuming university, and dealing with girls of his age. Critical incidents were related to goals that he wished to achieve in respect of these areas. In particular, the realisation that he would need to moderate the way he communicated with women, in order to have a chance of getting a girlfriend, and a work trial in the rehabilitation tuck shop. The latter experience appeared to make R realise that he would have to use a perching stool to manage his fatigue levels, if he were to return to his Saturday job.

R was referred to the research because of his unrealistic timescales for returning to work, university and driving; that is, he lacked awareness with regard to the future. Clinicians also noted impaired 'on-line' awareness of increased fatigue and distractibility during tasks.

The Abbreviated Task Battery

At time point one, R had an awareness score of 0 for the ATB, indicating no discrepancy between his view of his performance and the investigator's view. At time point two, five months later, R had an awareness score of -1, overrating by this margin on the tea and toast task. When the further three tasks (filing task, rail enquiry task and timetable task) from the original battery were included (time point two only), R achieved an awareness score of -1 for the timetable task and an awareness score of -2 on the rail enquiry task.

These results indicated that, in R's case, the task that involved using the phone (rail enquiry task) was the most sensitive to his lack of awareness. In view of this, raw data for

the impaired awareness group ('phase 2: group comparison study'), were re-examined. The most extreme (overrating) awareness score (ease dimension) possible for a single task was - 4. This score was reached only three times during the 'phase 2: group comparison study' once in relation to the timetable task and twice in relation to the phone task. This indicates that, for a small minority of people with impaired awareness, the phone task could well be particularly sensitive. Although the task battery, in its full and abbreviated form, appears to be a valid measure of everyday task performance, it might be that the task requiring use of the phone is also sensitive to the social skills domain.

5.4.6 Discussion

In R's case, the actual measurement of awareness, during the proposed baseline phase of the study, appeared to influence his behaviour, which begs the question whether inviting individuals to rate behaviour, of which they lack awareness, might be an effective intervention for some.

The reason R was referred to the research was his unrealistic expectations about timescales for returning to his Saturday job and to university. To some extent he proved his clinicians wrong. 'Proving others wrong' had been identified by R's mother as a pre-morbid coping strategy. It was partially effective because, against their initial expectations, he did return to his Saturday job within a relatively short period, albeit in a somewhat more limited capacity. Use of this coping strategy also was apparent whilst collecting data about R's ability to focus on tasks. He appeared to view the situation competitively and to show that, when he wanted, he was able to focus fully on tasks.

Although the abbreviated task battery excluded the rail enquiry (phone) task, this was the task on which R most overrated his performance when it was included at time point two. This illustrates that different people might have impaired awareness for different tasks.

5.5 CASE G – INTERVENTION CASE WHICH BECAME NATURAL HISTORY CASE STUDY

5.5.1 Background

G lived with his parents and one younger brother, and was attending a community head injury service when he was referred to the study. G was 23 years old. Clinicians reported that G had notable social skills deficits but impaired awareness of these. It was noted that G tended to be 'over familiar', particularly with women; frequently asked very personal questions of people whom he hardly knew, and often arrived late at group sessions and interrupted people. At home, these behaviours were manifested when his parents' friends were present.

5.5.2 Aims

- To evaluate the effectiveness of an intervention devised to increase G's awareness
 of social skills deficits: interrupting and over familiar behaviours (using singlecase, experimental design).
- To identify any critical incidents that impacted upon G's awareness level.

5.5.3 Data Collection

Questionnaires

Two questionnaires were devised by the investigator, to capture the behaviours and social skills deficits mentioned above.

Over-personal question/comment questionnaire

Day of the week: Date: Comments:

Number of different times you (or other person) were with G:

1st occasion

Annual of time (approx) you (or other person) were with G

Amount of time (approx) you (or other person) were with G Was this continuous or intermittent?

Number of overly personal questions: comments:

Number of people present at the time (apart from G):

2nd occasion

Amount of time (approx) you (or other person) were with G Was this continuous or intermittent?

Number of overly personal questions: comments:

Number of people present at the time (apart from G):

Interruption questionnaire

The content of the 'interruption' questionnaire was the same as the above questionnaire but the line *Number of overly personal questions: comments:* was replaced by *Number of interruptions:*

For both behaviours, the intention was to count the number of interruptions and overly personal questions. Other circumstantial data were sought to guide potential interventions.

The semi-structured interview schedule, Self-Awareness of Deficits Interview, Patient Competency Rating Scale and Social Communication Skills Questionnaire, were used to determine G's level of awareness and to identify the factors and critical incidents impacting upon his awareness level.

5.5.4 Procedure

G's clinicians and his mother felt that G might benefit from intervention but shortly after being recruited to the research, G obtained employment at his father's place of work. This entailed working away from Monday to Friday, returning home at weekends. G had begun work against the advice of his clinicians. Initially, during the working week, he lodged with his father. Later, his father was seconded abroad, so G lived on his own during the week. Follow-up data from clinicians ceased (this became impracticable) but his mother agreed to take measures of the identified behaviours at weekends. For the reasons given above, it was not possible to administer the Abbreviated Task Battery.

The PCRS, SCSQ and the SADI were administered to G on three occasions: November 2002, March and July 2003 (by telephone). Third-party versions of these questionnaires were administered to G's mother and his occupational therapist. G's mother was interviewed using the semi-structured interview schedule fortnightly and then monthly (by telephone). For the reasons explained above, the occupational therapist provided third-party data at the first time point only.

5.5.5 Results

Questionnaires

Overly personal questions/comments questionnaire and Interruptions questionnaire

Measures were taken by G's mother for six consecutive weekends from 24 January 2003. During this period, his mother reported that there were no episodes of inappropriate interactions with others. Frequency of measures was, subsequently, reduced to once per month, with further measures taken at the beginning of April, May, June and July 2003. His mother continued to report that there were no episodes of inappropriate social interaction.

As G had apparently ceased to exhibit the inappropriate social behaviours identified at the outset of the study, there were no grounds for pursuing an intervention study. In order to understand the factors that might have contributed to this apparent change in behaviour, G was followed up as a non-intervention case study until the beginning of July 2003.

Patient Competency Rating Scale (PCRS)

Figure 5.14 Patient Competency Rating Scale results - Case G

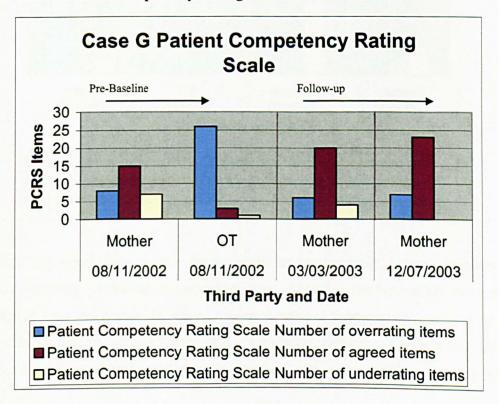
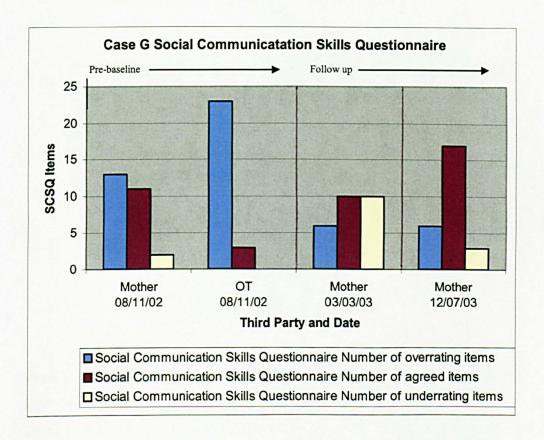


Figure 5.14 shows (PCRS) results at three time points. There is a very marked difference in perception demonstrated by G's mother and his occupational therapist at time point 1. G overrated performance for 26 of 30 items, when his ratings were compared with the occupational therapist's ratings, but eight of 30 items, when his ratings were compared with his mother's. It was apparent (over the 3 time points) that, gradually, even more item ratings given by G and his mother became concordant. Possible interpretations could be that G's awareness of his abilities had improved slowly over the eight-month period, that only his behaviour improved, or that both improved.

Social Communication Skills Questionnaire

Figure 5.15 Social Communication Skills Questionnaire results - Case G

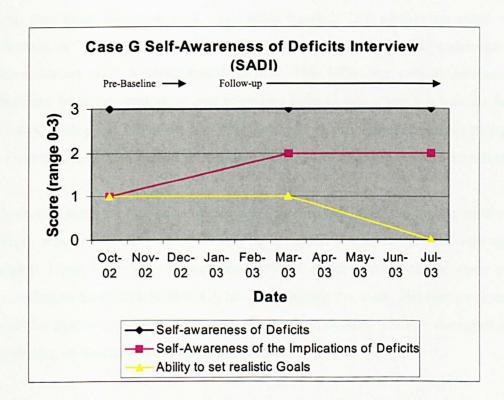


For the SCSQ, which focuses on everyday social interaction skills, Figure 5.15 shows that G was overrating performance compared with either his mother or his occupational therapist at time point one. However, the occupational therapist was seen to be more 'severe' in her judgements. As for the PCRS, looking at the mother's ratings over the three time points, there was some variation. By time point two, the smallest category was for

overrating items; on this occasion, G appeared to underrate performance on considerably more items than at time point one. By time point three, the largest category is for agreed items. Once again, this provides evidence of some improvement in awareness over this time period. Other measures used indicate that G experienced no increase in awareness. The increasing concordance in ratings could be attributed to an improvement in behaviour, without any corresponding improvement in awareness.

Self Awareness of Deficits Interview





Over the three data collection points, Figure 5.16 shows that G consistently demonstrated least awareness in relation to 'deficits', achieving a score of 3 (lowest possible score) for Level 1 of the SADI. G would acknowledge only the most obvious of physical deficits.

For Level 2 of the SADI: self-awareness of the implications of deficits, initially, G achieved a score of 1, as he reported some functional consequences of deficits, though was uncertain of other functional consequences. Thereafter, his score deteriorated to 2, he

reported some functional consequences, but minimised their importance, and actively denied other functional consequences.

For level 3 of the SADI: the ability to set realistic goals, G scored 1 for the first two time points, indicating that he had set somewhat unrealistic goals but acknowledged that his brain injury would still be affecting him in six months' time. By the final time point, G has achieved the minimum score of 0 because he sets reasonably realistic goals and identified that the brain injury would still be having an effect in six months' time.

Semi-structured interview data

Semi-structured interview data were quite limited: G's mother provided most of the information. The results (Appendix 33, page 46) summarised G's domestic and work circumstances over a seven-month period. The following critical incidents could be identified from the semi-structured interview data: G was given a job at his father's place of work; losing this job at the end of a three month probationary period; going on holiday to Greece with money he had saved; being offered another job on his return from holiday.

His mother reported that he managed well. Even when, after the three-month probationary period, when G became unemployed, he appeared unconcerned and went to Greece on holiday. Upon his return, he was soon offered another job with the same organisation. According to his mother (and to G), he was enjoying the work. His mother reported that his social behaviour was much improved. G remained equally positive throughout, seemingly registering no awareness of this improvement.

5.5.6 Discussion

Such a sudden change in G's behaviour could appear implausible. However, when challenged to give specific examples of improvements in behaviour, G's mother was able to do so. On one occasion, she explained how she was speaking to two friends in the conservatory, when G came in to smoke a cigarette. She reported that when G saw them there, he said that he would come back later. His mother said that this was a change: previously he would have interrupted them and stayed to smoke.

In relation to the implausible sudden improvement in G's social skills, another factor might be pertinent. It could be that G's mother (before his employment) felt worn down by his behaviour, which she found irritating, and which might have led her to exaggerate his social skills deficits, or the frequency with which they occurred, when data were first collected.

However, there seems some grounds at least for believing that G's social skills improved during the time he was followed up. It is less clear whether he was aware of this improvement. The last time the investigator spoke to him, he acknowledged no change in his social skills, stating that he was outgoing and had never had a problem with social skills. He stated this in an open manner – suggestive of an organic-based lack of awareness, rather than the defensive manner apparent in individuals with a psychologically motivated awareness deficit, described by Prigatano and Klonoff, (1998).

If, indeed, he were unaware of the improvement, then this is one further example of improvement in behaviour occurring in the absence of a corresponding improvement in awareness of behaviour. As mentioned in the literature review, Sohlberg et al. (1998) reported a case of an individual who was trained successfully to decrease interrupting behaviour, without a corresponding increase in awareness. This finding refutes a basic assumption of the Hierarchical model of awareness (Crosson et al., 1989), namely, that people with brain injury need to have intellectual awareness of their deficits (impairments) before they modify their behaviour.

If G did not experience any increase in awareness, it is difficult to account for the Social Communication Skills Questionnaire results, which indicated that, over the nine-month period of follow up, an increasing number of items fell into the category of participant/significant other agreement. These results could be explained, in part, by an initial exaggeration of G's social skills deficits by third parties.

5.6 CASE H – NATURAL HISTORY CASE STUDY

5.6.1 Background

H was semi-retired from his job as maintenance man at a local power station, when he sustained a stroke. This resulted in left-sided hemiparesis, inattention and homonymous hemianopia. At the time, he was living at home with his wife who worked full time. H was socially very active and played golf on a weekly basis. H was 68 years old.

No neuropsychological data were available because H consistently refused to be tested, stating that he knew that his memory was impaired and that he tended not to notice things on his left side. He stated too, that he compensated for these deficits by, for example, turning his plate around at mealtimes, so that he didn't miss food on the left side of his plate.

H was referred to the research five months after his stroke because frequently he made implausible excuses for the inability to move his left side, when encouraged to do so in the course of therapy. His clinicians were unclear whether H believed, or did not believe, what he was saying. They reported that he gave the excuses with great naturalness and appeared to be convinced by what he was saying. Typically, H would claim that he never (premorbidly) used his left side. For clarity, the investigator asked H's wife about this and she confirmed that he had used his left side normally before the infarct. It was decided to examine H's awareness, on a non-intervention basis, for the duration of his admission. Specifically, it was of interest to track the occurrence of apparent confabulation, and the critical incidents impacting upon confabulation.

5.6.2 Aims

To observe H's self-awareness over time, identifying critical incidents that might be inhibiting or facilitating his self-awareness. Since the main manifestation of H's lack of awareness was confabulation, it was of interest to observe changes in confabulation over time.

5.6.3 Data collection

Questionnaires

The Patient Competency Rating Scale and the Social Communication Skills Questionnaire were administered, to determine the degree to which H was overrating everyday task ability and social skills. The Self-Awareness of Deficits Interview and semi-structured interview schedule were used to identify the critical incidents that might be impacting on H's level of awareness.

The Abbreviated Task Battery was administered to provide a behavioural measure of awareness of everyday task ability, and to continue to assess its sensitivity to impaired awareness.

5.6.4 Procedure

H, his wife, his occupational therapist and physiotherapist were interviewed at fortnightly intervals with the assistance of the semi-structured interview schedule and the Self-Awareness of Deficits Interview. The other questionnaires were administered to H and third parties at the beginning and end of his involvement with the study. The Abbreviated Task Battery was administered to H on two occasions, at the beginning and end of the study.

5.6.5 Results

Questionnaires

Patient Competency Rating Scale (PCRS)

The usual way of reporting PCRS results is to report whether the majority of items fall into the overrating, concordant or underrating category. The brain injured individual is then considered to be overrating, underrating, or neither overrating nor underrating, performance on items of the scale. PCRS data for H (see Figure 5.17) indicated that assigning someone to a particular category is not always straightforward.

The views of H' wife, his physiotherapist and his occupational therapist showed little similarity at time point one. H was clearly overrating performance compared with his wife's views. In contrast, when his ratings are compared with the occupational therapist's, the largest category is the 'agreed' or concordant category. There was no clear majority category when H's ratings were compared with ratings assigned by his physiotherapist. At time point two the greater number of responses fell into the overrating category, no matter which third party was used for comparison.

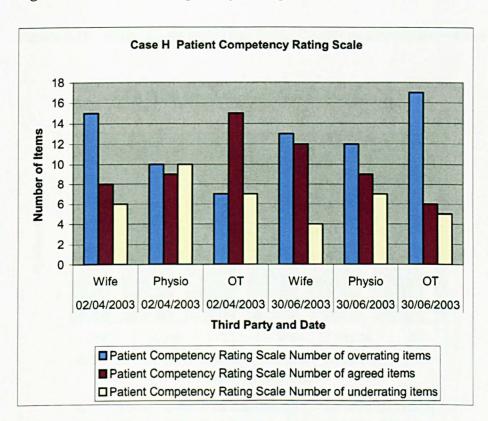


Figure 5.17 Patient Competency Rating Scale results - Case H

Social Communication Skills Questionnaire (SCSQ)

As for the PCRS, there was no agreement between third parties at time point one (see Figure 5.18) but good agreement at time point two, when the largest category of responses fell into the overrating category compared with each third party.

Self-Awareness of Deficits Interview (SADI)

The SADI results showed very little change or variation at any of four data collection points. At each data collection point, H achieved a score of 1 for levels 2 and 3 of the SADI; i.e. self-awareness of the implications of deficits (Level 2), and the ability to set realistic goals (Level 3), indicating that he was falling short to some extent in relation to full awareness in these areas. His self-awareness of deficits score (level 1) showed relatively intact awareness but with a distinctly different score of 3 at the last data collection point.

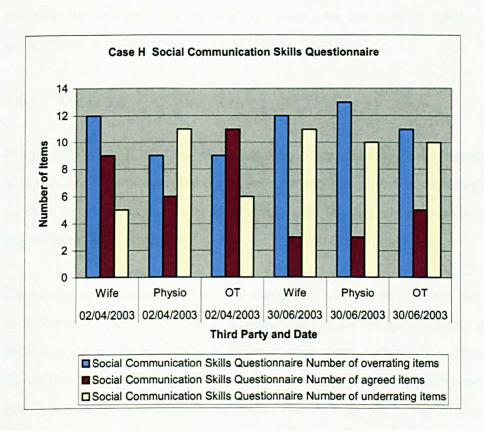


Figure 5.18 Social Communication Skills Questionnaire results - Case H

Semi-structured interview data

Semi-structured interview data (Appendix 34, page 49) indicated marked confabulation just before H's involvement with the research. Confabulation then declined but peaked again just before H was to have a change of physiotherapist. The change of physiotherapist

appeared to be the main critical incident affecting H's awareness level. However, other critical incidents could be identified: situations in which H appeared to feel threatened, for example, when practising his golf swing in physiotherapy.

The Abbreviated Task Battery

At time point one, H achieved an (overrating) awareness score of -3 for the ATB (combining a score of -2 on the tea and toast task and -1 on the object assembly task). At time point two, his awareness score was -4 (-3 for the tea and toast task and -1 on the object assembly task). Of the additional three tasks included at time point two, B had a score (i.e. overrating score) of -2 on the filing task and -1 on the rail enquiry (phone) task. Considering that the ATB score range for the 18 impaired awareness participants in the 'phase 2: group comparison study was 0 to -5, H's second ATB score of -4 appears to be towards the extreme end of the spectrum. As for case B, there was an apparent deterioration in awareness of everyday tasks, over time.

5.6.6 Discussion

H was followed up with the main intention of monitoring the incidence of confabulation and possible factors contributing to the increase/decrease in confabulation. Confabulation seemed to increase or decrease according to the degree of confidence H felt in the physiotherapist treating him.

Corroborating evidence for this view was provided when H was informed that there would be a change of physiotherapist. H appeared to experience great anxiety at the prospect. In particular, he admitted fearing that the change from a male physiotherapist to a female therapist would result in his being at greater risk of falling. Coincidentally, H was very tall and the male physiotherapist in question was a county-level rugby player. Having being informed of this imminent change of physiotherapist, confabulated responses peaked to their original high levels. Yet again, he claimed never to have used his left side before his stroke. Once he had gained confidence in the new physiotherapist, confabulation reduced.

5.7 CASE A – NATURAL HISTORY CASE STUDY

5.7.1 Background

Case A was working as a taxi driver when he sustained a severe traumatic brain injury in a road traffic accident. He was 22 years old. At the time of the injury, he was living with his three brothers and his mother. Although A was born in the UK, English was his second language (his first language was Punjabi). His past medical history indicated that he had sustained a fractured base of skull at age 12 years, when he was hit by a car. He was sent home after overnight observation without further follow-up. This injury might have been more serious than it appeared at the time; his brother noted that A's personality changed after this accident. From being fun-loving, spontaneous and cheerful he became serious, 'dulled' and lacking in initiative and spontaneity.

Neurological examination on admission to the rehabilitation unit indicated mild motor weakness and ataxia in both arms and both legs, mild visual disturbance (difficulty focusing whilst reading) and moderate dysarthria (hyper-nasal slurring).

Case A was referred to the research as clinicians reported unusual health beliefs. Repeatedly A expressed the belief that he would recover merely by being in the rehabilitation unit. He appeared not to understand that he needed to engage in therapy and, initially, refused occupational therapy and, sometimes, physiotherapy. He appeared to have poor awareness of risk as well.

It was decided to follow-up A as a non-intervention case study – his therapists felt that he would not engage with active intervention.

5.7.2 Aims

 To explore the critical incidents impacting upon A's awareness status over time. 5.7.3 Data collection

Questionnaires

The Patient Competency Rating Scale was administered to determine awareness of

everyday task ability generally. The Self-Awareness of Deficits Interview and semi-

structured interview schedule were used to elucidate the factors that might be impacting on

awareness status.

Abbreviated Task Battery

The Abbreviated Task Battery was administered to provide a behavioural measure of

awareness of everyday task ability.

5.7.4 Procedure

A, his brother, and A's occupational therapist and physiotherapist were interviewed using

the semi-structured interview schedule and Self-Awareness of Deficits Interview at

fortnightly intervals. A psychology assistant became involved with A during this period

and was interviewed on two occasions. The Patient Competency Rating Scale and

Abbreviated Task Battery were administered at the beginning and end of A's involvement

with the study. All measures were administered by the investigator in the rehabilitation unit

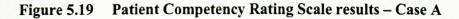
to which A was attached.

5.7.5 Results

Questionnaires

Patient Competency Rating Scale (PCRS)

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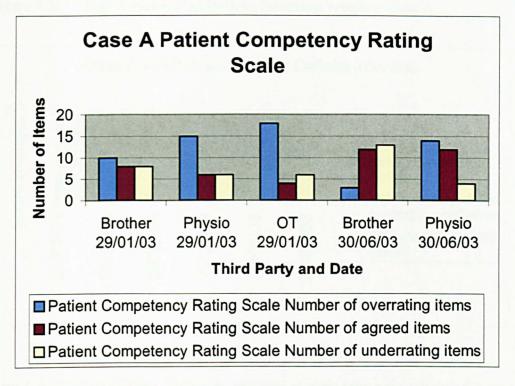


Figure 5.19 shows that three third-party comparisons were available at time point one: provided by A's brother, physiotherapist and occupational therapist. At time point two, five months later, the occupational therapist was no longer involved.

At time point one, A was overrating abilities on the majority of items on the PCRS, no matter which third-party comparison was used. At time point two, the results suggest that 'A' was underrating abilities when his ratings were compared with his brother's, but still overrating ability compared with his physiotherapist. Although A had been living at home for some weeks by time point two (he lived with this brother amongst other family members), the brother admitted that, because of severe pressure at work, they had had little contact. Conversely, the physiotherapist had continued to see A on a weekly basis and, for this reason, there are grounds for considering the physiotherapist's ratings more reliable.

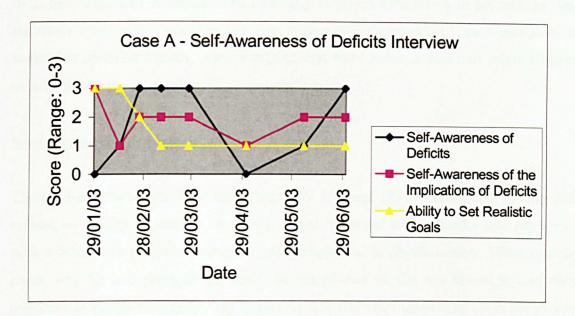


Figure 5.20 Self-Awareness of Deficits Interview results - Case A

In total, SADI data (Figure 5.20) were gathered at eight time points during the case study period. For level 1 of the SADI (self-awareness of deficits), A's scores varied considerably over the study period. Case A readily acknowledged cognitive and psychological problems at time point one, achieving a score of 0. However, by time point two he was uncertain of cognitive problems and was tending to minimise these, hence a score of 1. At the following three time points, A scored 3 – indicating no acknowledgement of deficits, other than the most obvious of physical deficits. Thereafter, scores for self-awareness of deficits continued to vary widely.

Scores for level 2 of the SADI (self-awareness of the implications of deficits) also fluctuated but in a less extreme way; i.e. apart from the initial score of 3 (indicating that little acknowledgement of functional consequences can be obtained), scores fluctuated between 1 and 2. A achieved a score of 1 on occasions when he admitted to some functional consequences but was unsure of others, and a score of 2 when he admitted to some functional consequences but minimised their importance and denied some functional consequences of deficits.

Level 3 of the SADI relates to the ability to set realistic goals (for six months' time). A's scores indicated some improvement over time in the ability to set realistic goals. A started by achieving scores of 3 (indicating that he believed with certainty that he would be operating at pre-morbid levels within six months). These scores were followed by a score of 2, indicating that A hoped to be operating at pre-morbid levels in six months but was uncertain whether this would be the case. Scores then stabilised at 1, as A continued to set somewhat unrealistic goals, acknowledging that some areas of function might continue to be affected by the head injury in six months' time.

Semi-structured interview data

The semi-structured interview data (Appendix 35, page 52) indicated that, having initially refused to engage in therapy, A then changed his mind within weeks and engaged well with a woodwork project in occupational therapy, and in physiotherapy. When questioned about why he had changed his mind, he stated that he did not know. It was difficult therefore to gauge how much key events in A's life were impacting upon his awareness level. However, the change coincided with his wife being allowed to come and stay in England, a change of medication and becoming less low in mood, so there may have been different contributory factors. A's brother claimed that the change had come about because A was more aware of what he was able to do and, so was more motivated to participate in therapy.

In terms of 'objects' of awareness, the semi-structured interview results indicated that A had relatively good intellectual awareness of difficulty controlling inappropriate laughter and cognitive difficulties. He seemed less aware of the difficulties with walking and driving/working. Driving and working amounted to the same thing for A who was a taxi driver. In broad terms, he became more realistic about the likely extent and time frames associated with recovery. He was, initially, certain of full recovery but gradually modified this view. In relation to driving, his awareness remained apparently unchanged over the five and a half month period during which he was followed up. He maintained consistently that he could drive if given the chance, but was not allowed. The team discovered that some family members might have been encouraging him to start driving again because of financial pressures. This could have hindered his acquisition of awareness in relation to driving.

A's intermittent risk taking behaviour remained a concern to the team throughout this period, as for case H.

The Abbreviated Task Battery (ATB)

A achieved an awareness score of 0 on both occasions that the ATB was administered to him, indicating no discrepancy between his judgement regarding his performance and the investigator's judgement regarding his performance. When the three additional tasks (rail enquiry task, filing task and timetable task) were included at time point two, there continued to be no discrepancy between participant and investigator scores. This implied that A had intact awareness of ability to perform tasks immediately after their execution. This, in turn, would appear to indicate that A had good emergent awareness, or good awareness of errors being made 'in the stream of action'.

5.7.6 Discussion

A's Abbreviated Task Battery results were in marked contrast to H's results. H also exhibited risk-taking behaviour but his ATB score indicated poor emergent awareness. Thus, it would appear that emergent awareness does not protect individuals from engaging in high-risk behaviour. This fits well with the Crosson et al. (1989) Hierarchical Model of Awareness. On the basis of the Crosson et al. model, it could be argued that only the highest level of awareness (anticipatory awareness) could protect an individual from engaging in risk-taking behaviour.

It was judged that A had an adequate level of English to take part in the research. Nevertheless, English was his second language, and this impeded conclusive neuropsychological assessment. Initially, A was referred to the research because of his unusual health beliefs. For example, believing, at first, that he would recover merely by being in the rehabilitation unit and therefore apparently not understanding why he needed to attend therapy. Although he did comply later with therapy, he expanded little on what had led to the change. It was unclear whether he did not expand further by reason of cognitive deficits, inadequate English, not wanting to or a combination of these and, possibly, other factors.

A did express other isolated unusual health beliefs. On one occasion he asked the psychology assistant to give him medication to stop the hair growing on his face.

The psychology assistant was the person on the team with whom A spent most time talking. The psychology assistant felt initially that A's insight was improving because A commented to him that he was benefiting from therapy. However, a few weeks later the psychology assistant revised this judgement: A had asked him for the same information week after week. The psychology assistant stated that this might have been to seek reassurance, or due to cognitive deficits. A could not retain information.

5.8 DISCUSSION

In practice, it was not possible to carry out the interventions with the rigour required for single-case, experimental design. Attempts to apply this design proved to be fraught with difficulties in the busy clinical settings used. This may have contributed to the use of video feedback apparently making no impression on B's awareness of deficits. However, video feedback did appear to contribute to some change in S's behaviour – though not in relation to the specific areas targeted for intervention. It appears, then, that video feedback might be a useful adjunct to intervention for some individuals.

As regards critical incidents, a recurring theme was the effectiveness of direct comparison of past and present performance in a domain that is meaningful to the individual. R was very motivated to return to his Saturday job but was adamant that he would not use a perching stool. Some work trials in the hospital tuck-shop made him realise that he would need to sit down when tired, and subsequently, he agreed to use the perching stool. As mentioned above, one prospective participant was withdrawn from the study when he experienced a very forceful adverse reaction to being placed on a work trial, during which the extent of his losses suddenly dawned on him. He became very depressed after this. This adverse reaction shows that a lack of awareness might help protect individuals from a reality which is too painful to acknowledge. It also provides evidence that putting a person in a situation which allows them to compare present and past performance could have a strong impact on an individual. This demonstrates the need to have adequate psychological support available for individuals undergoing rehabilitation.

Two measures used in this phase of the study involved comparing the brain injured person's view of their ability with the view of third parties. As can be seen from the results, third-party views were frequently divergent. Although this was due in part to third parties having different levels of involvement with particular individuals, it raises concerns about the validity and reliability of such measures.

With regard to intervention to increase awareness, it is noteworthy that one prospective participant was so lacking in awareness that it was not possible to engage her in the study at all. This had not been anticipated. Although it would not be ethical to try to address this individual's awareness in the context of research (she did not consent to take part), a clinician might try to begin work on this individual's 'intellectual' awareness, considered the lowest level of awareness in the Hierarchical Model of Awareness (Crosson et al., 1989).

5.9 CONCLUSIONS

On the evidence provided by the 'phase 3: case studies', the effectiveness of attempting to increase awareness in individuals with acquired brain injury remains inconclusive. A nine-week intervention programme showed some slight improvement in awareness of social skills in one individual. Although there was also evidence of change in behaviour, this appeared to fall short of a clinically significant improvement in social skills. In a second case, a very short intervention programme appeared to make no impact at all on the individual's awareness status.

Attempts to carry out the single-case design protocol with the anticipated rigour were thwarted in a number of different ways by circumstances beyond the researcher's control. There were unforeseen absences on the part of individuals who had agreed to collect data, in one case a physiotherapist and, in another, a receptionist. In a third case – Case R - attempts to determine level of awareness appeared to increase the individual's awareness and, thus, the rationale for an intervention to increase awareness was lost. In a fourth case, an individual started a job against the advice of his clinicians. This resulted in two difficulties from the point of view of data collection: loss of any clinicians who could provide data, and loss of physical access to a participant, who worked a long way from home during the week.

Despite these problems, the longitudinal follow-up of the six case-study participants allowed further clarification of questions, raised earlier in the research programme, relating to the measurement and nature of impaired awareness.

It was noted in Chapter 4 that there were differences in Patient Competency Rating Scale and Social Communication Skill Questionnaire results, depending on whether a clinician or significant other provided ratings (which were then compared with acquired brain injury participants' ratings). However, the cross-sectional nature of data collection in the 'phase 2: group comparison study' made it difficult to know which third party ratings were the more valid. The 'phase 3: case studies' suggested that the third-party who had had the most contact with the brain injury participant, would give the most valid ratings. For example, early in his admission, PCRS results indicated that case B was overrating ability, compared with his occupational therapist, and underrating ability, compared with his wife. After his discharge, PCRS results indicated that case B was overrating ability, no matter which set of third-party ratings were used for comparison. A likely explanation for this is that, after discharge, B's wife spent more time with him and, because of this increased 'exposure', was better placed to judge his awareness level. That is, competency to make a judgement appeared to be related to the amount of direct observation, of those with impaired awareness.

A number of different measures was used to look at changes in awareness over time in the case-study participants. Fluctuations in awareness were apparent in some participants. The abbreviated task battery was administered twice to five of the case-study participants. In four of the five cases, participants overrated ability more at time point two. This could indicate a slight deterioration in awareness – of activity limitation - over time.

It has also been noted in Chapter 4 that the study of individual cases, over time, might provide some additional insight into the nature of impaired awareness. Indeed, the findings from the 'phase 3: case studies' suggested that manifestations of impaired awareness varied widely, and that different factors appeared to be impacting on individuals' awareness status, to varying degrees. For instance, the fact that case R's awareness appeared to improve, when measures of awareness started to be taken, suggests that he was reacting to data collection in a 'comparative' way. This reaction might have been enhanced

by R's pre-morbid personality traits, such as a tendency to 'prove others wrong' when faced with obstacles.

Whereas case S appeared to increase awareness, without a corresponding increase in improved social skills, case G appeared to improve in social skills without any corresponding increase in awareness. In the 'phase 2: group comparison study', anxiety had appeared associated with impaired awareness in only one case, one who was noted to have an extreme (overrating) task battery awareness score, and a borderline anxiety score on the Hospital Anxiety and Depression Scale. In the 'phase 3: case studies', case H's manifestation of impaired awareness (i.e. confabulation) appeared to be related closely to high anxiety levels.

In Chapter 6, further exploration of the semi-structured interview data, collected from multiple informants, will provide greater opportunity to consider the nature, manifestations and objects of impaired awareness, in individual people with acquired brain injury, as well as factors impacting upon changes in awareness level.

CHAPTER 6

PHASE 4: THE NATURE OF IMPAIRED AWARENESS

6.1 INTRODUCTION

6.1.1 Clinician respondents

Mainly quantitative methods and measures have been used in earlier phases of the research programme. However, attempts to determine the presence of impaired awareness might be misleading, if based on an assumption that impaired awareness is a clear, definable entity that can be determined by a 'one-off' assessment such as a demonstrable loss of a proportion of field of vision. One of the participants in the 'phase 3: case studies' was identified as having impaired awareness of social skills deficits. Perplexingly, there was evidence to suggest that these social skills deficits disappeared when he started a job.

The emphasis in this chapter will be on exploring the nature of impaired awareness, mostly by means of qualitative methods. Firstly, clinicians' understanding of impaired awareness will be explored. In order to give greater perspective to this exploration, clinicians' descriptions will be compared with severity ratings of awareness level in acquired brain injury participants. A large part of the rationale for undertaking research in this area was the presumed obstacle that impaired awareness poses clinically. Indeed, clinicians' views have been taken very seriously within awareness research following acquired brain injury. Many methods of determining awareness level involve comparing patients' views of their abilities with clinicians' views. In these cases, the clinicians' opinions are considered to be correct. If clinicians are wrong in their judgements, this could result in individuals being assumed incorrectly to have impaired awareness. Considering the importance attached to clinicians' views, it seems imperative to explore these in more detail. Very little attention has been paid to this area within the existing literature.

Access to the descriptions of 18 individuals with impaired awareness, and 18 with intact awareness (recruited to the 'phase 2: group comparison study'), provided an opportunity to ascertain whether these descriptions are clear enough to indicate where the acquired brain

injured participants should be placed on the hierarchical model of awareness (Crosson et al., 1989).

6.1.2 <u>Case-study respondents</u>

The clinicians' descriptions of individuals with impaired and intact awareness are cross-sectional, necessarily shedding little light on factors affecting, for example, fluctuation in awareness level. However, the semi-structured interview schedules used in the 'phase 3: case studies' were administered longitudinally with multiple informants – including the individuals presumed to have impaired awareness. The semi-structured interview schedule data will be considered, in more detail, later in the present chapter, to draw out differing 'objects' of awareness intrinsic and extrinsic factors that appeared to be influencing awareness in the single-case-study participants – over time.

6.2 MAIN AIMS – NATURE OF IMPAIRED AWARENESS

- To explore what clinicians understand by self-awareness, and to explore the factors that they believe to have an impact upon self-awareness in participants with acquired brain injury. Interview scripts were subjected to thematic analysis.
- ii) To explore the relationship between numerical rating scale scores of awareness and placement within the hierarchical model of awareness.
- To attempt to use clinicians' descriptions to align 36 acquired brain injury participants to specific levels of the Hierarchical Model of Awareness. An interrater reliability study was conducted, to ascertain the degree to which two different raters classified acquired brain injury participants.
- iv) To explore the longitudinal data arising from the qualitative interviews conducted in the 'phase 3: case studies'. Data were compared and contrasted with the themes arising from the study, to explore clinicians' understanding of awareness following acquired brain injury.

All of the studies within 'phase 4: the nature of impaired awareness' were initiated as described in the procedure sections of this chapter. The initial administration of measures was considered on a pilot basis. Had any of the measures been found to be unfit for purpose, they would have been amended or discarded. For instance, had clinicians found it impossible to give a severity rating of awareness using a 10 point numerical rating scale, alternative strategies would have been attempted. In practice, however, no obvious difficulties were encountered with the measures or procedures employed during 'phase 4: the nature of impaired awareness'.

6.3 EXPLORATION OF CLINICIANS' UNDERSTANDING OF AWARENESS FOLLOWING ACQUIRED BRAIN INJURY

In exploring what the clinicians understand by self-awareness, it was important to be open to any new themes arising from their accounts. In addition, it was anticipated that obtaining 36 accounts might help identify the following:

- Similarities between different clinicians' accounts of manifestations of either intact or impaired awareness.
- Similarities between different clinicians' perceptions of particularly problematic manifestations of impaired awareness.
- Whether clinicians have difficulty pinpointing the relative contribution of organic and psychologically motivated impaired awareness to an individual's selfawareness.
- Whether mood (anxiety and depression) appears to be associated with severity of impaired awareness (numerical rating scale scores).

6.3.1 Design

A primarily qualitative design was chosen to explore how clinicians were conceptualising awareness. Clinicians' perceptions were gathered using the following brief, open questions.

'On balance, would you describe the patient as having impaired or intact awareness?'

'What are your main reasons for describing the patient as having impaired/intact awareness?'

The open question format allowed the investigator to seek clarification and illustrative examples as required.

In addition, a quantitative measure of awareness (numerical rating scale score) was elicited, to ascertain the severity of the awareness impairment. Specifically, clinicians were asked:

'On a scale of 0 to 10, with 0 representing no awareness, and 10 representing full awareness, how would you rate the patient?'

6.3.2 Participants

The participants were the thirty-six clinicians providing third-party data for the acquired brain injury participants taking part in the 'phase 2: group comparison study'. Twenty-six interviews were conducted with occupational therapists, seven interviews with psychologists, two interviews with speech and language therapists, and one interview with a physiotherapist.

6.3.3 Procedure

Clinicians were interviewed at their place of work by the lead investigator. If clinicians gave general responses, they were invited to provide examples to illustrate. Their comments were noted down and later word-processed by the lead investigator. A decision was made not to audio-tape the interviews for two reasons. Firstly, the lead investigator was trained and experienced in the use of shorthand. Secondly, it was felt that some prospective clinical participants might find the use of audio tape overly invasive, and be deterred from taking part (it was anticipated that some clinicians might be interviewed in relation to a number of different people with acquired brain injury). In order to check the

accuracy of notes made, these were read to the informant, at the time of the interview, and corrected as necessary. It is acknowledged that recording the interviews and having them transcribed by an independent person might have reduced investigator bias.

6.3.4 Data analysis

Box plots were used to examine the Numerical Rating Scale scores.

Thematic analysis was conducted in the following way (Edwards and Talbot, 1999). Each interview script was assigned a numerical identifier according the order in which the interviews were conducted, so that the interview script arising from the first interview was assigned number 1, and so on. Apart from the numerical identifier, an 'A' or 'B' was added to denote whether the patient had been assigned to the intact (A) or impaired (B) awareness group. For example, in the second interview, the clinician described their patient as having impaired awareness so this interview script was coded 2B. Within each interview script, statements were recorded chronologically. To facilitate the identification and categorisation of themes, statements relating to a new theme or example were separated out by bullet points. The scripts were read several times by the lead investigator, who drew up overarching and subordinate themes emerging from the data. To minimise bias at this stage, two collaborators (from a psychology and a nursing background respectively) went through this process with the coded scripts independently. Subsequently, a meeting was held and a final list of overarching and subordinate themes agreed by consensus. The lead investigator then categorised the statements again under the agreed themes. Six of the original interviewees were approached to verify that the statements they had made (in relation to a total of nine ABI participants) matched the categories to which they had been assigned. As a consequence, one of the statements was moved from one category to another.

Note was also made of the number of times a particular theme was mentioned in order to provide a quantitative assessment of themes.

To enable exploration of the inter-rater reliability of the Crosson et al. Hierarchical Model of Awareness, the scripts arising from clinician interviews were examined. Participants were assigned to the intellectual, emergent or anticipatory level of the model by the investigator and, independently, by a second rater. The second rater was blind to participants' awareness status (impaired or intact), and to Numerical Rating Scale scores. Degree of agreement between raters was explored using Kappa measure of agreement.

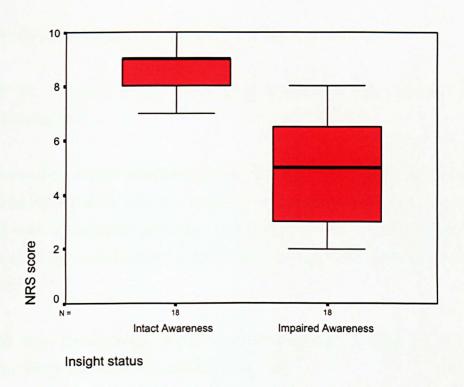
6.3.5 Results

Numerical Rating Scale scores

The box plot shown in Figure 6.1 illustrates the degree of difference between the impaired and intact awareness groups. The median score for the intact awareness group is 9 (score range 7 to 10), which is much higher than the median score of 5 (range 2 to 8) for the impaired awareness group. As can be seen from the raw scores for each group (Tables 6.2 and 6.3), there is some overlap in scores 7 and 8. The clinician who gave a score of 8 for the participant in the impaired awareness group explained that the participant had good awareness but this fluctuated and, sometimes, her awareness could not be described as good. Several clinicians who gave a rating of 7 or 8 had struggled to decide in which group to place their patient, but eventually felt that they were 'unaware' because of the variable nature of their awareness.

Potential associations between the numerical rating scale scores and HADS anxiety and HADS depression scores were examined using correlation analysis (Spearman rho). No significant correlations were found. Re-examination of the raw scores confirmed considerable variability between numerical rating scale (NRS) scores and depression and anxiety scores. For instance, four participants were assigned a very low NRS score of 2, indicating very impaired awareness. All four participants had depression scores within the normal range. Two of these participants had exceptionally low anxiety scores (1), the two remaining participants had anxiety scores of 10 (borderline range).

Figure 6.1 Numerical rating scale scores for the impaired and intact acquired brain injury groups



Thematic Analysis of clinicians' accounts of participant awareness

Differential awareness in relation to time: the present and future

Table 6.1 (page 205) shows the six overarching categories and the subordinate categories that were identified from the interview scripts. 'Differential awareness' over time, and across behaviours and impairments, was a prominent category: differential awareness in relation to time was the largest subordinate category. Some patients lacked awareness of their impairments, activity limitations and participation restrictions, in the present and future; others had become aware of impairments and activity limitations in the present, but held on to unrealistic expectations with regard to the future. A continuum between the present and future was apparent: patients in the earlier stages of rehabilitation tended to lack awareness of their impairments and activity limitations in the present, whilst other patients were described as no longer lacking awareness with regard to their present

abilities, but having limited awareness of how their impairments and activity limitations might affect them in the future.

Patient 3B was on a stroke unit and was in the early stages of rehabilitation.

3B 'He has no insight into his poor performance with tasks.'

3B 'He has poor insight: there is no carry over with tasks and no progress with rehabilitation.'

Patient 32B was an exception in that, despite several months of in-patient therapy on a neuro-rehabilitation unit, he continued to demonstrate severely impaired awareness of physical impairments and their implications in the 'present' (Statements relating to physical impairments were grouped within the subordinate category 'motor function'. See Table 6.1):

32B 'Very limited insight. He is aware minimally of some physical impairments and that some things take longer [to do] than they used to.'

Others patients were described as having gained insight into physical impairments and how these might impact on everyday activities. However, awareness of cognitive and perceptual impairments tended to lag behind, as illustrated by the following example.

17B 'It [insight] is better than it was. It is OK in terms of the physical limitations on occupational performance; but insight, into the cognitive and perceptual deficits on function, is reduced.'

Similarly, several patients who were described as having had a global lack of awareness, had gradually begun to have awareness of impairments and activity limitations in the 'here and now', but were not yet able to anticipate that problems would occur and so did not initiate compensatory strategies.

Table 6.1 Impaired or intact awareness: Overarching and subordinate categories emerging from the clinician interviews

Overarching category	Subordinate category	Number of statements made within each subordinate category
Differential awareness	In relation to time (present, future) Variable across behaviours/impairments	28 11
Awareness of specific behaviours/impairments	Social skills/speech Cognitive function Emotional control Motor function Perceptuo-sensory function	16 11 4 4 3
Other mediating factors (i.e. affecting the presence of impaired/intact awareness)	Degree of psychological/emotional adjustment Impact of cognitive impairment Impact of mood	23 11 4
Consistency of behaviour	Use of initiative In relation to risk/caution Expressed in terms of optimism/pessimism Coherence of verbal output and behaviour	10 7 6 3
Culture	Personality of the ABI participant Culture of the treatment unit	8 2
Speed/stability of learning	Needing to be shown/told more than once	7

7B 'She gives an accurate summary when she has done something but doesn't anticipate difficulties before the task.'

Differential awareness: Impaired awareness in relation to future plans

Many patients who were undergoing in-patient or outpatient rehabilitation were described as lacking in awareness with regard to future plans, and this was given frequently as the main reason for categorising them as having impaired awareness.

4B 'On everyday things, he can verbalise what he needs to do (and what he can do) but he thinks that all this is temporary and will resolve within 18 months from the TBI (this would be in six months' time). He has insight into his present limitations, but not his medium/long-term plans.'

Frequently, unrealistic hopes or expectations for the future revolved around resuming work roles – an example of the participation level of function.

2B 'He'd think he was capable of doing what he was doing before, without real understanding of what he could do; for example, going back to being a car mechanic, not realising the implications of cognitive deficits, especially memory deficits.'

32B 'His insight into his physical state is limited; he has weakness, shortness of breath, limited endurance – but thinks he can go back to work as before on an assembly line; feels he can operate heavy machinery – doesn't see there's any task he couldn't do at work.'

Other patients, who were described as having unrealistic expectations relating to work roles, were found to moderate their expectations as the self-imposed 'deadline' approached.

11B 'She thinks she could return to nursing; although she is now qualifying this by saying it is too soon to return to nursing full-time.'

Environmental factors

Environmental factors tended to be categorised under differential awareness in relation to time (present, future), and was not identified as a separate category in the course of thematic analysis. Nevertheless, there was evidence that being in an unfamiliar environment – such as a hospital - might be contributing to an apparent lack of awareness of how present impairments might limit future function:

11B 'She claims that she could live at home independently (been an in-patient for one year) but has never attempted to do anything to make this happen.'

And:

18A 'He has no insight into how he is going to get home and the problems he'd have to face there. His way of shutting down; emotionally saying: "It'll be OK when I get home."

Conversely, some patients who had spent more time at home, were demonstrating improved awareness, and this was attributed to experiencing the effects of impairments in a familiar environment.

17B 'She is more receptive to feedback lately – facilitation by therapist with husband present. She's been at home (recently discharged as in-patient, still an outpatient) – her difficulties have been more apparent there, where she has more exposure to daily activities.'

This fits with Dirette's (2002) findings that patients mentioned gaining more awareness by experiencing the effects of impairments in familiar environments, such as their home, rather than being given this information by therapists.

Awareness of specific behaviours/impairments

After 'differential awareness', 'awareness of specific behaviours/impairments' was the seconded largest overarching category. Clinicians tended to name specific 'objects' of awareness – all of which could be categorised as an impairment, activity limitation or participation restriction, rather than speak of awareness of a level of function. Apart from

level of function, clinicians mentioned different domains of function. The social skill/communication domain was the most frequently cited as an example. The second most commonly cited was the cognitive domain. Impaired awareness of emotion, motor, and perceptuo-sensory function was less commonly mentioned. This pattern fits with observations made in Chapter 1, that impaired awareness of motor impairments tend to resolve more quickly than impaired awareness of cognitive and social skills deficits.

Awareness of social skills deficits

As for risk-taking behaviour, a range of severity was apparent, and social skills deficits were less severe in some cases. An example is given below of a more severe problem.

21B 'His insight has improved a bit. He picks up problems in others, not himself. He can't monitor self in relation to communication problems. He's verbose, tangential, disorganised, misses the point a lot, has social skills problems.'

And a less severe problem:

31A 'He tends to dominate the conversation and is not so aware of this. It's not extreme.'

Psychologically based impaired awareness and adjustment

Psychological/emotional adjustment was one of the three subcategories grouped under the overarching theme of 'other mediating factors'. Clinicians appeared to feel on firmer ground when explaining why they felt patients had intact awareness. In contrast, they tended to adopt a cautious approach to describing patients who appeared to have impaired awareness. Several clinicians mentioned their uncertainty in understanding, or having a clear picture of, what they were seeing. They mentioned that different factors might be contributing. This is not surprising as they were speaking of patients whose awareness varied across domains of function, levels of function, and varied across time. Clinicians mentioned the probable impact of psychological/emotional adjustment 23 times. This finding is in keeping with Prigatano and Klonoff's (1996) observations that there is an interaction, between organically based lack of awareness (i.e. damage to the brain per se) and psychologically based lack of awareness, in most individuals who present with lack of

awareness. Clinicians tended to make a distinction between impaired insight and psychological adjustment. However, some clinicians implied that poor psychological/emotional adjustment prevented individuals from having intact awareness.

17B 'Emotional adjustment has been inhibiting insight. Protection. All too much or too painful. Is this more denial rather than lack of insight?' [Rhetorical question]

And:

28A 'Good understanding of limitations. Full insight means accepting limitations – there are emotional issues around this – not full acceptance, and therefore a score of 8 rather than 9 or 10. Very good insight considering his executive dysfunction.'

31A 'Insight is variable: last session, I would have given him a lower score; it is very difficult to know the impact of the emotional side. He doesn't have a full picture of what therapy can offer.'

Impact of mood

The impact of mood formed a further subordinate category under the overarching category of 'other mediating factors' (see Table 6.1). References to anxiety and depression were rare but, when present, mood seemingly had a strong impact on awareness.

13A 'He is depressed and has had suicidal ideation since the stroke. He had a reactive depression following the stroke. Anti-depressants had effect but there were still underlying adjustment issues. His mood is variable.'

And:

22A 'Very anxious. Anxiety causes her sometimes to be under confident about her abilities. She has low self-esteem.'

A further mood disorder – hypomania was mentioned as affecting level of awareness in this patient.

20B 'He'd say he was close to being completely recovered: "Probably better than before the injury." He means close to how he was before, and now has a whole new range of experiences (life experiences; meeting new people; finding new strategies: "I'm smoking again, which is brilliant." (A little hypomanic).

Fluctuations in awareness

Statements relating to fluctuations in awareness were mostly grouped within the category 'Consistency of behaviour – expressed in terms of optimism/pessimism.' (See Table 6.1). Examples were given of patients who had progressed, from having little or no awareness of a particular level or domain of function, to having *fluctuating* awareness of that level or domain of function.

16B 'His insight fluctuates. Generally, it has improved overall over the past few months. It fluctuates in the sense that he sometimes says resuming a 40-hour week [as a tool setter] is not a problem. At other times he says his working life is over.'

For other cases, who were described as having fluctuating or variable awareness, clinicians emphasised a tendency to dwell on the side of not being able to do things.

31B 'Sometimes he feels he's more impaired than he is; he's more capable than he is aware. It is arguable whether this is an insight thing or depression related.'

And:

14B 'She sometimes wants to be overly dependent on people – fears not being able to express herself adequately – which is unlikely (this seems to be the other end of the insight spectrum).'

Consistency of behaviour in relation to risk/caution

Those described as holding an unrealistically negative view of their abilities tended to be categorised as having intact awareness.

22A 'I often associate lack of insight with an incautious approach to life – she has the reverse problem – she's overcautious. For example, she went to MMC and, when a driving assessment was mentioned, she felt she wouldn't be able to do it. She was persuaded and it was successful.'

And a further example:

23A 'His disinhibition is not as much as he thinks; says he swears, is abrupt.'

This tendency to describe individuals with an unrealistically negative view of themselves as aware might be related to these patients causing less concern, as cautious individuals are less likely to engage in risk-taking behaviour.

In contrast, when the interview scripts of those with the lowest numerical ratings scale scores of awareness were compared, the patients with the lowest scores gave concern because of risk-taking behaviour. In the earlier stages of in-patient rehabilitation, some patients caused concern by attempting to stand from their wheelchair, when not physically capable of doing so.

8B 'He lacks insight thinking he could walk at home – even though this is not realistic. He is impulsive, for example, getting up from his wheelchair.'

And:

13A 'He lacks insight at times into his level of disability: this seems to be to do with psychological adjustment. For example, thinking he can walk (when he is wheelchair dependent). He is impulsive and has fallen, a few times, for this reason.'

The most extreme example of risk-taking behaviour was a patient who had recently become an outpatient. He was described in the following terms.

32B 'He does rifle shooting against advice. He is arranging a driving assessment against advice (he may be driving). There have been several crisis meetings about driving/rifle shooting.'

Delusions and desire to 'save face'

Some of the more extreme examples grouped under the category 'consistency of behaviour – expressed in terms of optimism' (see Table 6.1, page 205) included patients were noted to display a lack of awareness that was bordering on delusion.:

14A 'If you asked me whether to put her in a deluded or not deluded group, I would put her the self-deluding group; for example, having private therapy for her hemiplegic hand; she is unable to formulate a sentence (dysphasic) but grabs on to hope and talks about finishing her Master's; publishing some archeology work. This is not realistic (she is having alternative therapy for her hand, which is still not functional). It is a 'trying to convince herself' rather than 'not seeing it', but there is a thin border between the two.'

And:

9N 'He doesn't ask about how he'll be – he protects his own views on this (very set views) that he will get better: "Leave me alone for one day and I'll be better tomorrow"; "My stroke's reversing, and if I come to therapy that couldn't happen.""

There is a danger that using a patient quotation – without hearing the patient's explanation for a particular view might make the individual's awareness appear more impaired that it is. For example, a patient was described as saying:

20B "I know I have problems with memory and attention but these are not important cognitive functions and I don't need them."

This could appear to be bordering on delusional. However, the clinician went on to give the patient's rationale for saying this: 20B 'His phone is his memory – this is his rationale for saying that he doesn't need a memory.'

Before his brain injury, this patient had worked in IT and was very keen to use gadgets to make up for cognitive losses.

Desire to 'save face'

Other manifestations of unrealistic optimism could be seen as attempts to 'save face'. It is apparent from the interview scripts that frequently clinicians gave what patients had said about themselves as evidence for having impaired awareness. Patients might say things in an attempt to maintain their dignity. Clare (2002) suggested that this was often the case in relation to Alzheimer's patients suspected of having impaired awareness. The following three examples could fall into this category.

16B 'He manages quite well unilaterally. He tends to say about most things, "Oh yes, I can manage that." He gives the impression that he manages better than he actually does.'

20B 'Lack of insight is reflected in types of things he'd say: "I know I have problems with memory and attention but these are not important cognitive functions and I don't need them."

24B 'She needs mistakes pointed out to her, for example, difficulty with heavy saucepans – the grip. When asked about tasks she's just completed she says "That's fine." – doesn't expand a lot. I'm unsure whether she thinks it's fine or perhaps is concealing how much she's taken on board.'

Awareness 'severity continuum'

In relation to impaired awareness, a severity continuum was apparent from the interview scripts. Amongst the patients described as having intact awareness, few were described as being 100% aware. For example:

26A 'I wouldn't give her a 10/10 because she seems quite focused on a speech problem trying to tell her that it's more related to fatigue. She has difficulty making the connection

between fatigue and speech. The problem is very slight.'

And:

27A 'Not 10/10 as not fully there yet. Difficult to say, may be due to less exposure to

friends, work, etcetera.'

Extreme cases

Extreme cases were rare, so there was limited opportunity to explore similarities in

manifestations of impaired awareness in such cases. The most extreme case did cause

concern, because the lack of awareness appeared to be profound and to result in risk-taking

behaviour that was potentially very dangerous to himself and others: driving and shooting

against advice. Risk taking behaviour tended to result in greater concern. Failure to learn

also appeared to cause concern and frustration.

Stability of learning

Four of the seven statements in this overarching category of 'speed/stability of learning'

(see Table 6.1) related to participants with impaired awareness, and reflected therapists'

frustration at the lack of treatment progress. Examples included:

3N 'He has poor insight: there is no carry over with tasks and no progress with

rehabilitation.'

And:

32N 'Therapy is not going anywhere: he doesn't carry over.'

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Stability of learning and impact of cognitive deficits

The impact of cognitive impairments formed a separate subordinate category within the overarching category of 'other mediating factors' (see Table 6.1). However, there was considerable overlap between categories and cognitive impairments appeared to be compounding the problem of needing to be shown or told something more than once – as mentioned in Chapter One.

24B 'Her attention is questionable – it may be having an impact.'

32B 'He is very impaired following instructions – basic ones (2/3 step commands), for example, to get things out of a drawer. When I tried to relate this to work he said: "We don't have these drawers at work."

Conversely, awareness of cognitive deficits was given frequently as evidence of intact awareness for other participants with acquired brain injury.

34A 'He talks about his difficulties and is able to report them spontaneously. Once he understood the concept, he would recognise he had a problem or not and was accurate; e.g. slow processing.'

36A 'He reports his cognitive problems and how they're going and is accurate and related them to everyday life. Today, he reported that, when stressed, he's having problems with thinking speed, planning and organising.'

The above examples suggest that intact awareness is compatible with moderately severe cognitive deficits. This is in keeping with observations made in Chapter One.

Use of initiative

Use of initiative identified as a subordinate category under the overarching category of 'consistency of behaviour' (see Table 6.1, page 205) in those identified as having intact awareness. This was the only category in which all the examples given were in relation to participants perceived as having intact awareness.

30A 'She is very clear about what she wants out of therapy; for example, she requested to go to the workshop.'

37A 'She has lots of initiative. She calls the therapist to set up specific things – how to get advice from Dialability. When given information, she can go ahead and sort things out herself; for example, information on a computer course: she is attending the course now.'

Impact of cultural and personality factors on awareness

Eight statements related to the possible impact of a person's culture or personality, in support of Weinstein and Kahn's (1955) contention that pre-morbid personality was important in the genesis and manifestation of impaired awareness. For example:

19B 'He has no insight into how he is going to get home and the problems he'd have to face there. It's his way of shutting down, emotionally saying: "It'll be OK when I get home." I suspect his pre-morbid personality was the same.'

The following observation is an example of culture having a possible impact on social skills deficits.

20B 'Cultural influence (afro-caribbean). The mother is similar – doesn't turn take, tangential. The socialness may be cultural.'

The majority of statements made by clinicians could be grouped under one or other of the agreed categories. Despite this, it would be misleading to conclude that statements about different participants under a given category reflected similarity between these participants. This was rarely the case.

6.3.7 Discussion

Clinicians were asked to provide reasons for describing each ABI participant as having either impaired or intact awareness. Methodologically, this entailed constraints which could impact on the validity of the data. In effect, clinicians were providing a 'snapshot' in time. The information recorded reflected examples they remembered and, perhaps, feelings they had about their patient at that moment. Other salient points might have been forgotten.

Many of the clinicians' accounts supported the contention that awareness (or *insight*) recovers first for physical disability and simple activities of daily living. In respect of the eight patients identified as lacking awareness with regard to their future plans, clinicians mentioned that they were now improving, or had improved, in relation to their awareness of 'the here and now', whereas previously they had lacked awareness of difficulties with everyday tasks.

Notably, none of the intact awareness participants was reported to have (or to have had) any lack of insight with regard to their future plans. These findings support the inclusion of the element of 'temporality' in any model of awareness in the context of acquired brain injury. A number of clinicians noted that awareness seemed to fluctuate in patients, even within a short space of time. Once again, the case study design involving repeated measures will provide a means of exploring fluctuations in awareness.

Clinicians had, at times, great difficulty in deciding the contribution of emotional adjustment to impaired awareness. Indeed, the clinicians' accounts of attempting to decide between impaired awareness and emotional adjustment mirror the theoretical grappling between these elements within the literature, and, the likely contribution of both factors in most individuals. This serves to underline the highly individual nature of impaired awareness and the need to consider each person separately, especially with regard to potential interventions.

The 'phase 1: preliminary study' supported the view that impaired awareness lies on a continuum, and this was very much confirmed by clinicians' reports. Some patients were described in quite 'cut and dried terms' as having fully intact awareness, or very impaired awareness but this was a small minority. In most cases, patients were reported to exhibit aspects of both intact and impaired awareness, even though their clinicians frequently were clear that they belonged *primarily* to the intact or the impaired group. Interestingly, having an unrealistically negative view of ability was associated more with intact than impaired awareness. It might be that clinicians consider this part of the normal process of adjusting to disability, or that patients with unrealistically negative views are unlikely to take risks. Risk-taking behaviour, and apparent inability to learn over time, caused particular concern to clinicians. In addition, a large number of factors emerged that might have been impacting upon awareness status at the level of the individual. The qualitative study below

allowed further examination of such factors and how they might interact at an individual level.

Relationship between clinicians' accounts of patient awareness and the hierarchical model of awareness

The clinicians' reasons for assigning an acquired brain injury participant to the aware group or the unaware group were examined, to see whether it was possible to identify where the participant should be placed within Crosson et al. (1989) Hierarchical Model of Awareness. Level 1 corresponds to Intellectual awareness (the most basic level of the hierarchy), level 2 corresponds to Emergent awareness and Level 3 corresponds to the highest level of awareness: Anticipatory awareness.

Table 6.2 Intact awareness group - Numerical rating scale scores (NRS) and placement within the Hierarchical Model of Awareness

Patient no.	Level of Hierarchy	NRS score
5	3	10
22		10
36	3	10
10	3 3 3 3 3	10
30	3	9.5
12	3	9
18	3	9
26	2/3	9
34	3	9
33	3	9
35	2/3	8
23	2/3	8
25	3	8
27	2/3	8
28	3	8
31	2/3	8
37	3	8.5
13	2/3	7

For the intact awareness group, there was full agreement between rater 1 and rater 2 – regarding where acquired brain injury participants should be place on the hierarchical model. The second rater was blind to the numerical rating scale scores assigned by clinicians. Table 6.2 shows that, in several cases, raters placed participants between Level 2 and Level 3 of the hierarchy (expressed as '2/3' in Table 6.2).

For the impaired awareness group raters differed in scores given to five participants. This represents $\kappa = 0.73$ (P=<0.001), a good level of agreement for the impaired awareness group. Table 6.3 shows that, where there was disagreement, the second rater tended to give slightly lower scores (four out of five cases). When the verbal scripts for these five participants were re-examined, it appeared that the second rater tended to give a lower score where clinicians stated that participants were unrealistic about future plans. Rater 1 was inclined to consider awareness of skills in the future to be part of anticipatory awareness and, in this instance, did not assign a score of 3.

All participants in the 'aware' group had some degree of 'anticipatory' awareness, whereas only one of the participants in the 'unaware' group was deemed to have anticipatory awareness – albeit not consistently. The results support the validity of the Hierarchical Model because the clinicians involved in the study were naïve to the model.

Implications of the inter-rater reliability study results

Two independent raters were able to assign the thirty-six acquired brain injury participants to specific levels of the Hierarchical Model of Awareness, based on the scripts arising from the interviews with participants' clinicians. This supports the use of the model as a practical tool for classifying awareness deficits. In several instances, participants were noted to have intact awareness of everyday task ability but impaired awareness of social skills deficits. Impaired awareness of social skills deficits had been highlighted as an important domain to consider during the 'phase 1: preliminary study', and continued to be a prominent theme during the 'phase 2: group comparison study'.

Table 6.3 Impaired awareness group – Numerical Rating Scale (NRS) scores and placement within the Hierarchical Model of Awareness

Patient no.	Level of Hierarchy	Comment	NRS score
14	3	but not always	8
19	1/2	variable	7
8	1/2	variable	7
6	2	tasks/personal care	
	0/1	perceptual	7
*7	2	tasks	
	0	communication problems [1/0]	6.5
1	2	personal care and domestic	6
16	1/2	fluctuates	
	0	cognitive and communication	5 5
*24	1/2	sometimes 1/sometimes 2 [1/3]	5
17	2	physical	
	0	cognitive	5 5
*4	1/2	[1]	
2	0/1		4.5
21	0		4
*15	0/1	[0]	4
9	2	tasks	_
	0	visual problems	3 2 2 2 2
20	1		2
32	1		2
*11	2	[1]	2
3	0/1		

^{* =} Variation in score between Rater 1 and Rater 2

6.4 EXPLORATION OF FACTORS AFFECTING AWARENESS LEVEL IN SIX INDIVIDUALS IDENTIFIED AS HAVING IMPAIRED AWARENESS

6.4.1 Main aim

To explore the intrinsic and extrinsic factors affecting awareness level.

^{[] =} Score given by Rater 2

6.4.2 Design

A qualitative design was chosen, using semi-structured interview schedules, with individuals identified as having impaired awareness (recruited to the 'phase 3: case studies), a close relative and at least one clinician.

6.4.3 Participants

The six individuals with acquired brain injury and third parties, participating in the 'phase 3: case studies'.

6.4.4 Procedure

Participants were interviewed with the assistance of semi-structured interview schedules on a fortnightly basis, reducing to a monthly basis, if little change were noted. Participants were followed up for a minimum of three months.

6.4.5 Results

Semi-structured interview data were condensed into tables: Case S – Table 5.4, page 150; Case B – Table 5.5, page 163; Case R – Appendix 32, page 43; Case G – Appendix 33, page 46; Case H – Appendix 34, page 49; Case A – Appendix 35, page 52.

Impaired awareness of social skills deficits

When exploring clinicians' understanding of awareness, impaired awareness of social skills was mentioned as a commonly occurring phenomenon in a sample of 36 individuals with acquired brain injury. Two of the six participants in the 'phase 3: case studies' were identified as having marked impairments in this domain: Case S and Case G. They were similar in age and both had supportive mothers. Yet, comparison of the interview data for S and G indicated far more differences than similarities between them. Although they were both identified as having social skills deficits, G could be described as being very extrovert and chatty, whereas S was quite withdrawn, and rarely engaged in conversation with anyone except his mother.

Semi-structured interview data (Table 5.4, page 150) indicated that some aspects of an intensive social skills intervention programme did appear to have some impact on S's awareness that he should increase eye contact and spontaneous conversation. However, this awareness did not appear to translate into significant behavioural improvements in these areas. There was some evidence that the intervention increased his awareness of his appearance and this did translate into some behavioural change. He reported for example that, seeing himself on video, made him realise that he looked 'shifty' around the eyes and his tense, hunched posture could 'make him look like a victim'. Both he and his mother reported that, during intervention, he made concerted and sustained efforts to correct his posture and to look relaxed when walking in the street or around shops. (He was always accompanied by his mother.)

Two further areas appeared to resonate with S and resulted in attempts to effect a change. Firstly, he and his mother agreed that S had tried, on a number of occasions, to 'make an entrance' when going into rooms (at home), including smiling upon entering. Although this constituted a change in behaviour, it appeared to fall short of a clinically significant improvement in social skills since S's mother stated that these attempts were lacking in naturalness and, in her view, quite 'off-putting'.

Secondly, S appeared to realise that he needed to take more care when changing the subject; e.g. when speaking to family members. His mother reported that, when other family members were speaking, S would interrupt frequently and abruptly change the topic of conversation. Once again, S's mother felt his attempts were 'affected' and no improvement on the earlier state of affairs.

In contrast, G's interrupting behaviour and asking overly personal questions appeared to decrease completely, when he started a job. Unlike S, there is no evidence from the interview data that G registered any change or improvement in his social skills: he consistently claimed that he had no social skills deficits.

The need for acceptable alternatives prior to relinquishing unrealistic goals

Amongst the case studies, there was a number of examples that, when presented with an acceptable alternative, the acquired brain injury participants appeared to show more

willingness to relinquish unrealistic goals. R was very motivated to return to his Saturday job. Initially, he refused to admit to difficulties with fatigue but, when it was explained to him that he would not be able to go back to his Saturday job, unless he made allowances for fatigue, he began to acknowledge the problem. This coincided with doing some work experience in the rehabilitation tuck shop which appeared to demonstrate to him that he would need to sit on a perching stool should he become tired. It seems likely that the tuck shop experience enabled him to compare his current ability level with that of his premorbid, shop-work experience. This direct comparison apparently enabled him to experience an 'Aha' moment, in the way suggested by Dirette (2002). This change was not mentioned by R himself, highlighting the need to obtain collateral data from third parties.

Similarly, B appeared to be fixated on the need to be walking before his discharge from the rehabilitation unit. B's occupational therapist reported that, having resisted discharge, at a certain moment B became excited at the prospect, and realised that life could continue with housing adaptations and other aids. As observed by Ellis-Hill and Horn (2000), any change in self-concept is slow, and people need to be offered acceptable alternatives before being prepared to relinquish pre-morbid self-concept for a new self-concept.

The impact of close family relationships on awareness level

For some of the acquired brain injury participants, close family relationships appeared to exert a strong influence on awareness. Early friction between B's wife and the team could have been caused by B being selective in what he told her regarding his everyday abilities. Early in his admission, B told his wife that he was able to shower and dress (not so) and she believed him. The dynamics of the marital relationship were such that the team suggested he might have exaggerated his abilities to 'protect' her from the truth. This could have delayed her acquiring an accurate perception of the full extent of B's deficits, and might also have prevented any attempt by her to challenge his inaccurate claims regarding his functional ability. Yeates (2003) spoke of inter-familial relationships being a major part of the 'sense-making resources' available to individuals with acquired brain injury. Yeates (2003) also spoke of couples attempting to come to shared understanding of the aftermath of brain injury. This was apparent with B and his wife, who, together, resisted the team's view that B had no potential to walk again. Only later did B's wife realise that the team's view was correct.

R admitted that he trusted his mother more than anyone else. The strong influence she exerted enabled him to trust her when she told him that he was being overly direct and overly familiar with girls of his age – even though he appeared not to see this for himself. He not only accepted his mother's feedback on this, but he even began to work hard on behaving more normally with girls. Gradually, he was able to notice mistakes – evidence of emergent awareness, and eventually to think before speaking – anticipatory awareness. He was very motivated to appear attractive to girls, and this provided a strong drive to work on this area. He listened readily to advice from others (especially his mother) regarding mistakes he was making socially.

Cursory consideration of case G might suggest that, simply obtaining and carrying out full-time work effected a change, whereby marked social skills deficits disappeared from one week to the next. This might be true but other factors may have contributed to this apparent improvement. The attitude of G's mother towards him seemed to undergo considerable change once he started his job. Semi-structured interview data (Appendix 33, page 46) showed that prior to his getting the job, she talked about him using mostly negative terms. Once he had obtained the job, she spoke about him on every occasion (whilst being interviewed by researcher) in unequivocally positive terms. Hence, two quite marked changes occurred in G's life – getting a job, a socially desirable achievement for a young adult male, and a huge increase in support and positive encouragement from his mother.

Similarly, the treating team suspected that A's family might have been encouraging him to return to driving, and this might have delayed his acquisition of awareness of his ability to undertake this activity. In contrast, there was no evidence, at all, that H's wife had any influence on this awareness level.

Anxiety and impaired awareness

For the 36 acquired brain injury participants included in study 1, anxiety appeared to have an influence on awareness in some. In H (see Appendix 34, page 49), confabulated reasons for being unable to use his left side appeared to increase as a direct result of heightened anxiety levels. Having being referred to the research for confabulating reasons for being unable to move his left side, episodes of confabulation reduced markedly. However,

immediately before a change in physiotherapist, anxiety levels and episodes of confabulation peaked once again – but waned once H was confident that the new physiotherapist was unlikely to 'drop' him. To a less extreme degree, H resorted to confabulation when he felt threatened, for example, when practising his golf swing in physiotherapy. R was also reported to experience anxiety when offered the opportunity to have an on-road driving assessment. Up until this point he had consistently claimed to be able to drive – apparently secure in the belief that the rehabilitation team would prevent him from doing so.

Pre-morbid personality and coping strategies

Pre-morbid personality and coping strategies were also mentioned in the interview data and could have been affecting awareness level and manifestations of awareness. B's wife commented that her husband had always been a bit unrealistic about plans. R's mother stated that R coped with difficulties by proving others wrong. There was little evidence that B's lack of realism assisted him to get closer to the goals that he claimed were the most important to him: walking and driving. However, R's determination to resume his Saturday job, relate well to girls and return to university, did appear to enable him achieve his goals more quickly. For example, he returned to his Saturday job sooner than his clinicians predicted. Pre-morbidly, R had been a high achiever and a single-minded individual. These traits have been associated with psychologically motivated lack of awareness or denial (Weinstein and Kahn, 1955). These characteristics could be conceptualised as intrinsic factors contributing to R's awareness profile.

Optimism, rather than determination, appeared to result in G's holding down a job – against the advice of his clinicians. The interview data indicated that he was unperturbed when he lost the job after the three-month probationary period. It would seem that G had good grounds for being unperturbed; he was soon offered a further post in the same organisation. This could be an example of Herbert and Powell's (1989) finding that optimism and motivation are more predictive of successful outcome than 'insight'.

Being selective in verbal report

The interview data indicated that some of the acquired brain injury participants were selective regarding how much they said about their abilities. Six weeks after discharge, B admitted that he had resented being told what to do by everyone in the rehabilitation unit because he had been used to working things out for himself. He admitted (again retrospectively) that he tended to cope with this by 'switching off' when clinicians were giving him instructions or feedback.

B's occupational therapist and physiotherapist mentioned a number of times how B might have been more aware of his situation than he revealed. They both suggested that B was used to being in control of things in his work and at home. Similarly, R had claimed that he could go back to work by a particular date but, as this date approached, he appeared to rationalise, stating that he was too busy with therapy to go back to work so soon. Indeed, asking questions unrelated to the therapy sessions in progress could have been his way of managing his fatigue, or even concealing it. Krefting (1989) demonstrated that individuals with traumatic brain injury can go to extreme lengths to appear 'normal'.

Evidence that individuals are selective in verbal report makes awareness level difficult to determine accurately – especially on the basis of a 'one-off' assessment.

Fluctuation between extremes

Before getting the right measure, R fluctuated between two extremes: on the one hand being overly frank and familiar with girls he had just met, on the other hand, taking constructive criticism too far, on one occasion telling the investigator that he realised that he was having 'dodgy' thoughts; i.e. that he 'found women attractive'.

Impact of cognitive deficits and risk-taking behaviour

Other factors seemed to have influenced H's awareness profile including cognitive deficits. Poor short-term memory (immediate recall) and difficulty with abstract reasoning appeared to be compromising his 'sense-making' resources. In H, it was noted that there was a

failure to carry over information from one treatment session to the next, so that a manifestation of his lack of awareness was his risk-taking behaviour. H appeared to foresee risk only intermittently. An example was failing to adjust the foot-plates on his wheelchair safely before transferring. The cognitive deficits seemed to be preventing him from developing stable intellectual awareness and, in the absence of this awareness 'base', he was not able to acquire compensatory strategies that would enable him to be left safely on his own. At discharge, the treatment team judged that H could only be left alone for short periods because of his risk-taking behaviour.

Impact of discharge on awareness

Curiously, upon returning home, there was evidence that B's lack of awareness reached almost delusional levels. It was unclear whether B had lacked awareness to this degree whilst in rehabilitation. There was evidence that B was guarded in his self-report whilst in hospital. Alternatively, the team's clarity about his likely prognosis could have had a moderating effect on awareness level whilst he was an in-patient (despite his claim – after discharge – that he had consciously 'switched off' when clinicians were giving him feedback).

Likely interplay of different factors in the same individual

For Case B, it is difficult to untangle the factors potentially contributing to his awareness profile. Contributory factors appeared to include: cognitive deficits, i.e. slowed information processing; pre-morbid personality and coping mechanisms; B's relationship with his wife and the couple's relationship with the treatment team.

6.4.6 Discussion

Extrinsic factors

With the exception of A, all the cases were English. Prigatano (1989) mentioned how Japanese people with brain injury tended to overrate self-care abilities, whereas people with brain injury in Western societies tend to overrate performance in domains considered

very important within those cultures, for example, driving. Three of the cases, B, R and A all fluctuated in relation to their awareness of their ability to drive. It is worth stating that all the single case study participants were male. Different objects of awareness might have been apparent in female participants.

Relationships within the family did appear to be an important factor affecting awareness for most of the case studies, reinforcing Yeates' (2003) claim that intercommunication within the family is an important 'sense-making' resource available to the individual with acquired brain injury. In the case of B, this was seen very much to be a two-way process. His clinicians claimed that early in his rehabilitation, he might have exaggerated his abilities in discussion with his wife. Since B and his wife both appeared to trust each other's opinion more than the team's, this appeared to delay her 'awareness' of the extent of B's deficits.

Rapport with the treatment team also seemed to be having an impact on awareness. When B was first admitted, he did show signs of trying to come to terms with loss of role as a grandfather. Once the team announced they did not believe he would walk again, no further signs of his coming to terms with his situation were witnessed. It seemed that when B felt that the team was no longer working with him to pursue his goal of walking again, he became much more selective in what he was prepared to say. This caution seemed to extend to what he was prepared to say to the investigator, whom he might have perceived to be colluding with the treatment team. There is some reason to think that B was more aware of his inability to walk than he acknowledged verbally. On a number of occasions, B stated that he felt able to walk, yet he never ventured to do so. This selective verbal expression of awareness clearly underlines the difficulty of measuring the impaired awareness phenomena accurately. As mentioned in Chapter 1, determination of awareness level is problematic because accurate measurement would require access to an individual's mental states. This is not possible at the present time.

Intrinsic Factors

Pre-morbid coping strategies clearly were being used in a number of cases. There was evidence that B and R were using well-rehearsed strategies to keep 'control'. For example,

R did appear to try to prove the investigator and treatment team wrong – by being able to focus on tasks when measured. It is worth saying here that the treatment teams were not infallible and there were occasions when the treatment team 'got it wrong'. For example, the team believed that G was not ready to get a job, yet, when he did so, he appeared to be able to stay in employment. The fact that experienced clinicians can misjudge a patient's potential is relevant to research in impaired awareness. In many instances, the rationale for identifying a patient as having impaired awareness, is that the view of the individual's clinicians is at odds with that individual's view.

Fear and anxiety were important factors affecting H's awareness of deficits. When told that there would be a change of physiotherapist, his confabulation became much worse. He also tended to confabulate in the face of threats to self-esteem; for example, when prompted to move his left arm during treatment session, he claimed that, pre-morbidly, he never used the left side of his body. Although the 'phase 2: group comparison study' indicated that mood was not significantly associated with awareness, case H illustrated that mood can have considerable impact on awareness in some individuals.

No single model of awareness was able to capture all salient awareness phenomena that came to light in phase 3 or phase 4 of the research programme. The factors included in the theoretical model of awareness proposed in Chapter 1 (pre-morbid personality, emotional status, cultural background, social support, therapeutic alliances and cognitive deficits) were all shown to be important. Nevertheless, the case study data indicated that the relative importance of different factors did appear to vary considerably in particular individuals. The Halligan and Oakley (2000) model of consciousness was helpful in identifying an underlying mechanism that could account for fluctuations in awareness of impairment, and/or activity limitation, in some individuals. The Hierarchical Model of awareness assisted in categorising awareness deficits, the domains affected, and the degree of awareness (intellectual, emergent, and/or anticipatory), regardless of the underlying cause or causes. Nevertheless, case G provided an example of improvement in behaviour. without any apparent corresponding increase in awareness - in contradiction to an underlying assumption of the Hierarchical model. It is also argued that the Hierarchical model should have a further level: to account for individuals with no awareness of a particular domain. Already, within this chapter, individuals have been identified who

appeared to have no awareness at all of some impairments. The additional level could be entitled 'No Awareness', and placed beneath 'Intellectual Awareness' (the most basic level of the model). It is argued that this would make the model would make the model more comprehensive, and could be used to demonstrate how individuals progress from no awareness of a particular domain, to partial awareness – or vice versa.

Many of the examples given above illustrate that the use of multiple informants helped to validate that a particular factor was impacting upon awareness. The use of multiple informants also pointed to a factor that could delay brain injured people gaining awareness: being given mixed, or even diametrically opposed, 'messages' from others. This was apparent in three of the case studies. In case B, clinicians decided early on that B had no potential to walk again; a decision was taken that no one on the clinical team should say anything that could give the impression that B had potential to walk again. However, B's wife believed initially that B had potential to walk again. The couple was very close and took up a stance of being together against the team. This could be interpreted as B's wife lacking in awareness, as well, initially. It is not unreasonable to assume that, since his wife's view was more in keeping with what he wanted to hear, B was more influenced by what his wife was saying, than what the team was saying to him. B's wife later acknowledged that B would not be able to walk – which, perhaps, validates that the team was correct in its judgement.

In contrast, case G returned to work against the advice of his entire clinical team. G's parents, however, were strongly supportive of this course of action. In G's case, the team was apparently proved wrong. G not only held down the job for the three-month probationary period, his social skills apparently improved during this period. G's case is interesting from several perspectives. Firstly, although there was a change in problem behaviour – impaired social skills – interview data provided no evidence that there was any change in his awareness of his social skills. This contradicts one of the principles of the Crosson et al.'s Hierarchical Model of Awareness. There are only two other documented cases of an improvement in function, without a corresponding increase in awareness, those mentioned by Sohlberg (2000). See Chapter One.

Secondly, G's case indicates that a positive change in life circumstances can have a strong impact on behaviour. In Chapter 1, it was noted that self-concept changes slowly, and that brain injured people may be more able to relinquish pre-morbid life expectations, if they can replace these by something positive. Similarly, in case R, there were examples that R became more aware when this was likely to take him closer to achieving goals that were important to him, such as being attractive to girls and resuming his Saturday job.

6.5 CONCLUSIONS

This chapter helped to clarify a number of issues raised in earlier phases of the research programme. The 'phase 2: group comparison study' indicated that participants, categorised as having impaired awareness, were more likely to overrate their performance on the task battery. Similarly, a larger number of impaired awareness participants was categorised as overrating ability on the Patient Competency Rating Scale; but some impaired awareness group participants did *not* overrate ability on the task battery. Amongst those who *did* overrate ability, there was wide variation in overrating scores. Conversely, some of the *intact* awareness group were categorised as overrating ability on the Patient Competency Rating Scale.

The findings in Chapter 5 suggested some answers to these apparent inconsistencies. Exploration of the qualitative data in Chapter 6 assisted in shedding further light on these questions and other issues.

The clinician accounts indicated that most acquired brain injury participants could be categorised, as having either 'impaired' or 'intact' awareness, with relative ease. Despite this, clinicians found that some participants were more difficult to classify in this way; hence, some overlap between groups was apparent. Indeed, the numerical rating scale scores indicated that awareness lies on a severity continuum. The clinician accounts supported this: very few intact awareness group participants were described as having completely intact awareness. This was an unexpected and novel finding.

The clinician accounts clearly indicated that some participants were categorised as having impaired awareness because they had unrealistic expectations for the future. In several

cases, clinicians added, such participants had regained awareness for performance of basic everyday tasks (in the 'present'). This might explain why some impaired awareness group participants did not overrate performance on the task battery or the Patient Competency Rating Scale in the 'phase 2: group comparison study'. Furthermore, the accounts indicated that several patients lacked awareness of social skills deficits, rather than everyday task ability 'in the here and now'. This might provide another reason why some 'phase 2: group comparison study' participants did not have overrating scores on these measures. This adds support to the contention that impaired awareness may be domain specific in some individuals.

In relation to clinician judgements, exploration of the semi-structured interview data, provided by multiple informants, indicated some examples of clinicians being 'wrong'. As an illustration, clinicians assumed, apparently wrongly, that two of the case study participants were not yet ready to return to work. It is not surprising that clinicians, asked to give opinions when they, in fact, lack the information on which to make predictions, are sometimes wrong in their judgements. However, this has implications for measures based on the assumption that the clinician judgement is the correct one. This suggests that care should be taken when determining awareness level in individuals with acquired brain injury.

Detailed study of the clinician accounts and the semi-structured interview data indicated that, for some individuals, awareness level fluctuated considerably from day to day. Furthermore, the data indicated that some participants were selective in what they said about their abilities; that is, they might have known more about their ability level than they were prepared to say. Taking all these elements into account, the use of single, one-off measures could give an erroneous view of an individual's awareness level. Deciding whether an individual has awareness, or has impaired awareness, is not a stable dichotomous decision. Rather, it is a fluctuating, multi-dimensional decision.

The clinician accounts corroborated the Hospital Anxiety and Depression Scale results, indicating that mood has an impact on awareness in some cases only. However, the numerical rating scale scores showed that two of the four participants with the lowest awareness score of 2 (indicating very impaired awareness), had a borderline score for anxiety. The qualitative data, arising from the semi-structured interview schedules used

with the case-study participants, pointed to a very direct relationship between anxiety and awareness in one case. That is, when case H was experiencing high anxiety levels, his confabulating behaviour also peaked. Data provided by H and his physiotherapist demonstrated this to be so.

Regarding the nature of awareness, the 'phase 4' qualitative studies indicated that many factors might be impacting upon awareness but, the specific factors - and relative impact of each factor - appeared to vary considerably from individual to individual. It is argued, therefore, that different measures and models should be considered when attempting to ascertain awareness level.

CHAPTER SEVEN

DISCUSSION

7.1 INTRODUCTION

The discussion will revisit the main aims of the thesis, highlighting what the constituent studies have added to the knowledge base in relation to the nature of the impaired awareness following acquired brain injury, its measurement and clinical management. Limitations of the three studies will then be considered. The chapter will conclude by looking towards the future, and summarising the main recommendations arising from the findings of the thesis and the questions that remain to be answered.

Motivation for this thesis arose from the clinical experience that individuals with acquired brain injury frequently lacked awareness of their deficits. In many cases, this was manifested by individuals claiming the ability to do things that they are observed as unable to do. Liaison with colleagues in other neurological rehabilitation services confirmed similar experiences and uncertainty regarding how to address such deficits.

Hence, a dominant initial motivation for undertaking the thesis was to ascertain whether individuals' awareness of their abilities could be measured and altered, and to clarify the means by which this could be achieved.

The literature search indicated that a number of factors might be associated with impaired awareness, but that no single methodology had yet been identified as the 'gold standard', in relation to the measurement of awareness level. In view of this, it seemed fitting to explore the measurement of the phenomenon – using different methodologies - before attempting to change, or increase, awareness level. Indeed, the different methodological approaches appeared to highlight different facets. Mindful that these findings might shed new light on the nature of awareness, factors arising from the various phases of the research programme were considered in relation to two models of awareness: the Hierarchical Model of

Awareness, Crosson et al. (1989), and the theoretical model of awareness (presented in Chapter 2). Throughout, the investigator's thinking was challenged and developed through discussion with the supervisory team and fellow researchers.

7.2 PHASE 1: PRELIMINARY STUDY

In the course of the 'phase 1: preliminary study', a task battery was developed with care. one that could be used to ascertain the awareness of everyday task ability in individuals with acquired brain injury. Up to the present, determining awareness, by comparison of verbal report provided by an individual with acquired brain injury and a third-party, has been the method of choice. The Patient Competency Rating Scale (Prigatano et al. 1986) is the tool most commonly used for ascertaining awareness and employs this third-party comparison method. Potential problems with the reliability and validity of this method were outlined in Chapter 1, and provided the rationale for developing a measure that could be used to determine behaviour as well as verbal report. The 'phase 1: preliminary study' findings raised some further doubts about the validity of relying on verbal report alone. For the most part, acquired brain injury participants, included in the 'phase 1: preliminary study', had not attempted any of the tasks making up the battery since their brain lesion. All participants were asked to give predictive pre-task ratings, as well as post-task ratings of performance. It became apparent during data collection that, when participants were asked to give pre-task ratings for tasks they had not completed since their brain lesion, many of them stated that they were 'guessing', and frequently altered their rating after the experience of carrying out the task. This casts further doubt on the verbal report comparison method, which requires individuals to rate their performance on tasks which they might not have attempted post brain injury. Because there were relatively few participants in the 'phase 1: preliminary study', the Patient Competency Rating Scale was retained for further examination in subsequent stages of the study. To explore this issue further, future studies could ask participants to state their level of confidence in their predictive rating.

The 'phase 1: preliminary study' demonstrated that the Hart et al. (1998) criteria for judging emergent or on-line awareness of error during task performance might not be relevant to English people. At a theoretical level, the 'phase 1: preliminary study' finding

(that the Hart et al. criteria might not apply within an English context) was surprising and suggests, for the first time, that the possibility of determining on-line or emergent awareness can vary according to culture. It is hypothesised that emergent awareness of error during task performance is more feasible with a North American sample than an English sample, due to North Americans being more behaviourally expressive. Since both English and North American cultures are Western, and to some degree similar, it is hypothesised that even greater differences would be found when comparing North Americans with individuals from less similar cultures, such as some parts of Asia. Social etiquette associated with the expression of emotion or shame is much more strict in Malaysia or Japan, for example, than in England. A relatively small number of individuals from different ethnic backgrounds was included, so the results might not be generalisable.

Additionally, the Hart et al. (1998) criteria for judging error were found to be too narrow in focus. This resulted in the careful development of written criteria to judge participant task performance. These criteria were generated from the detailed notes made by the investigator in the first two of the three trials making up the 'phase 1: preliminary study'. High levels of inter-rater reliability between three raters highlighted the potential future usefulness of these guidelines.

The 'phase 1: preliminary study' resulted in a task battery that could be used to help determine awareness of the activity level of function in individuals with acquired brain injury. The detailed guidelines to assist in rating performance would enhance replication of the study within a research context. The guidelines also make the battery more accessible to clinicians who would not be left wondering whether their 'expert' judgement will correspond to the investigator's 'expert' judgement.

7.3 PHASE 2: GROUP COMPARISON STUDY

This study represents a first attempt in impaired awareness research to use a spinal injury and acquired brain injury comparison groups, in addition to a healthy comparison group. The Hart et al. (1998) and Abreu et al. (2001) studies had used healthy comparison groups only. The impaired awareness group was found to overrate significantly task performance ability, compared with any of the other three groups. This indicates that the task battery is a

valid tool, for ascertaining awareness of everyday task performance, in individuals identified as lacking awareness. The literature review in Chapter 1 indicated that it is difficult to assess the extent to which impaired awareness results from damage to the brain, psychological reaction to brain damage and associated losses, or a combination of these and, perhaps, other factors. It was of theoretical interest that the spinal injury group exhibited no sign of impaired awareness of everyday task performance. This could indicate that impaired self-awareness does not result from difficulty in coming to terms with permanent, and considerable, physical disability and associated lifestyle restrictions; individuals who become permanently paraplegic as a result of spinal cord injury are faced with such restrictions. It suggests, instead, that cognitive impairment could be impacting on awareness, either by disturbing the information processing mechanisms, used in making judgements about the self, or that cognitive impairment is so threatening to the sense of self that psychological defence mechanisms intervene to preserve a pre-morbid self-image, thus protecting the integrity of the 'self'.

Further analysis of the group data indicated that an abbreviated version of the battery was more effective at discriminating between the impaired and intact acquired brain injury groups than use of the full six-part battery. This suggests that the object assembly task and kitchen task were more sensitive discriminators. One possible reason is that these tasks created a 'level playing field', in the sense that all participants were equally conversant with making a hot drink and toast and were equally unfamiliar with the object assembly task. This removed confounding factors; for example, varying expectations about task performance amongst different individuals. Use of an effective, but brief, battery would offer advantages in terms of efficient use of time in research and clinical contexts, and could also be less onerous for the brain injured individuals to whom it would be administered.

The study was also original in examining whether particular questions might be more sensitive to impaired awareness of task performance, than other questions. This was found to be the case. During the 'phase 1: preliminary study', many questions were posed to elicit participant judgement about performance. Questions relating to two dimensions of awareness of everyday task performance seemed the most promising: the ease and quality of performance. Further analysis indicated that ease questions were more sensitive to awareness. Abreu et al. (2001) used quality questions, which casts further doubt on the

outcomes of their study. Conversely, ease dimension questions are used for the Patient Competency Rating Scale, which could support its use.

The investigator's judgement was, in effect, selected as a gold standard of task performance. It was, therefore, important to address inter-rater reliability. High levels of inter-rater reliability were found between the lead investigator and two raters, who used the guidelines developed during the 'phase 1: preliminary study'. As one of these raters was inexperienced in observing participants perform everyday tasks, this supports the contention that the guidelines are reliable when used by different people.

7.4 PHASE 3: CASE STUDIES

Dirette (2002) conducted retrospective interviews with three individuals, with acquired brain injury, who were deemed to have good self-awareness at the end of a cognitive rehabilitation programme. Dirette sought to identify and examine 'critical incidents' that the participants noted as helping them increase self-awareness of abilities. A shortcoming of the study was that the primary cognitive impairment for each participant was memory loss. Hence, retrospective questioning some time after their cognitive rehabilitation might have resulted in loss of pertinent information and, possibly, recourse to confabulation to fill in some of the gaps. In the 'phase 3: case studies', individual cases were followed up on an experimental or non-experimental basis but, in either case, brain injured participants, together with a significant other and clinician, were interviewed several times over a period of at least three months. In all cases, participants were still undergoing rehabilitation when data collection began, and this provided a more timely opportunity to capture the factors that might be contributing to impaired awareness, as well as any critical incidents apparently bringing about a change in awareness.

Outcomes from the earlier phases of the research programme indicated that awareness was variable in particular individuals: for example, the clinicians' accounts and numerical rating scale scores suggested that awareness not only lies on a continuum of severity but that its genesis and manifestations are very variable when considered in relation to specific people. The case study phase provided further evidence of this. The case study participants were very different from each other. At a general level, some similarities were noted; for

example, the desire to drive and to work was pronounced in four of the case study participants whose lack of awareness centred around these themes or 'objects' of awareness. A pre-morbid need to be in control seemed to affect two participants' verbal report when questioned – third-party data suggested that these participants were more aware of their abilities than they were prepared to say.

However, there appeared to be a far greater number of differences than similarities between case study participants. Anxiety and depression did not appear to be associated with impaired awareness in earlier phases of the research programme, but the longitudinal nature of data collection in the case study phase indicated that case H was an exception to this. His tendency to confabulate about his physical deficits was found to peak when he became very anxious. In H's case, his lack of awareness (manifested as confabulation) could be explained within the context of Halligan and Oakley's (2000) two-level model of consciousness mentioned in Chapter One. In H, the effective relaying of information from level 2 (unconscious) to level 1 (conscious self-awareness) might have been blocked by strong emotion: anxiety. Halligan and Oakley hypothesised that different mechanisms, such as a strong emotion, could block the effective relaying of information from the unconscious to the conscious mind. Within the model, the conscious mind is considered to be highly dependent upon information provided by the unconscious mind. If the flow of information is interrupted, this could account for confabulation as the conscious mind struggles to 'save face', and to give a coherent explanation for situations that are not fully understood in that moment.

If, as the 'phase 3: case studies' illustrate, the mechanisms underpinning awareness deficit are variable, one possible explanation is that the global term 'impaired awareness' is misleading. The balance of evidence in this thesis would suggest that impaired awareness is not a unitary concept, but rather 'objects' of awareness vary over time and between different individuals. It is suggested that, by close observation of many more single cases, it might, in future, be possible to identify different profiles of awareness, which, in turn, could facilitate the generation of specifically focused interventions. Within the context of psychiatry, 'schizophrenia' was once used as a global term to encompass any psychotic type behaviour. Over time, with closer examination of cases, definitions have become more refined and new syndromes, such as Asperger's syndrome, have been differentiated from schizophrenia. The variation in underlying mechanisms, objects and manifestations of

awareness suggests that it would be premature and misleading to attempt to produce a single model of awareness that can capture all these elements adequately.

Sohlberg (2000) mentioned two case study participants in whom improvement in function occurred without any apparent corresponding improvement in awareness. No other cases have been reported; however, Case G provided another example of this. There was evidence that G's social skills improved when he got a job, but at no point during data collection did he show any awareness of an improvement. This lack of awareness appeared to be primarily organic in origin, since G expressed himself in an open, non-defensive manner during data collection. This finding is of theoretical interest, because the Crosson Model assumes that awareness of a domain of function is necessary before any improvement in function can occur. These cases might be rare, yet have clinical relevance. indicating that clinicians should not give up too soon with people who appear to have no awareness, or even no potential to develop awareness, of a particular domain. Prigatano (1999) indicated that individuals with severe brain injury, who have impaired awareness, clearly arising from organic damage to the brain, have very little rehabilitation potential. In time, as our knowledge of this area grows, it might be possible to develop profiles of people who are likely to improve in functional domains, without a corresponding increase in awareness. Herbert and Powell (1989) provided a clue, when they suggested that optimism was found to be more important than insight in the successful achievement of rehabilitation outcomes. Case G was irrepressibly optimistic.

Consideration of what Dirette (2002) termed critical incidents is warranted for its potential applicability within clinical contexts. The clearest example of a 'critical incident' was apparent with case R. He wished to return to a Saturday job in a shop, but refused to accept advice that he would need to use a perching stool because of problems with fatigue. A trial run in the rehabilitation tuck shop apparently triggered what Dirette (2002) described as an 'aha' moment. Dirette found that 'aha' moments (moments of realisation about the implications of brain damage) were most likely to occur when individuals had an opportunity to compare current performance with pre-morbid performance of a task relevant to them. This highlights not only the importance of assessing behaviour, as well as verbal report, when determining awareness status, but also the relevance of individuals experiencing the aftermath of brain injury behaviourally, in practical, familiar, situations. Dirette's study indicated that undertaking tasks that had particular relevance to participants

was more likely to bring about improvements in awareness. This has evident face validity as a potential intervention approach within clinical contexts. Occupational therapists would be well placed to use this intervention. Yeates (2003) also found that individuals with acquired brain injury were more likely to accept feedback corresponding to context-relevant experiences.

Two of the case study participants had particularly close relationships with their significant other (a spouse and a mother respectively). In these two cases inter-family communication did appear particularly to influence the case study participants' understanding of their situation and capabilities. Yeates (2003) noted the importance of inter-family communication as an important sense-making resource open to individuals with brain injury. Clinically, this influence could be taken further into account: ensuring relatives are clear about the aftermath of brain injury could result in better understanding amongst patients. This appears to be unchartered territory: significant others interviewed by Yeates (2003) stated that they were rarely given information about brain injury by clinicians, and resorted to any means at their disposal to gather information, such as self-help books and the Internet.

7.5 PHASE 4: NATURE OF IMPAIRED AWARENESS

Clinicians' constructs of awareness were elicited by asking them give reasons for categorising patients as having either intact or impaired awareness. This represents a novel attempt to examine how clinicians in this field are conceptualising awareness. Clinicians were required also to give a severity rating of awareness. This provided a means of cross-referencing clinicians' verbal reports and severity ratings. For example, examination of clinicians' verbal reports indicated that four participants who received the lowest numerical rating scale score of '2' caused particular concern for one, or both, of the following reasons: an inability to live independently, by not foreseeing risks; failure to benefit from rehabilitation attempts, i.e. no evidence of learning from one treatment session to the next.

Four of the case study participants were young males in their 20s. Although this could be coincidental, it is well documented that young adult males most commonly sustain

traumatic brain injury, largely owing to a tendency to engage in high-risk behaviours. In different phases of the research programme, clinicians expressed particular concern about risk-taking behaviour, which they attributed to poor insight. Future studies could identify whether individuals who have a pre-morbid tendency to engage in high-risk behaviour, are more likely to do so following brain injury. Pre-morbid personality factors were seen to contribute to impaired awareness in some of the case studies, but a pre-morbid inclination to risk was not mentioned by any of the significant others providing collateral data for these individuals. This could have been because engaging in such behaviour is considered normal, and even condoned, within Western culture.

Of particular note was that clinicians expressed great difficulty in teasing out the relative contribution of psychological factors versus organic factors in respect of participants with impaired awareness. This mirrors Prigatano and Klonoff's (1998) difficulty in classifying patients, known to them both for several years, as having a primarily organic, or primarily psychologically motivated, awareness deficit. The current study adds to the body of knowledge, suggesting that organic and psychological factors combine in most people with impaired awareness following acquired brain injury. Notes, made by the investigator shortly after the interviews, indicated that therapists were apologetic for being unable to distinguish between organic and psychological factors. They could be reassured by knowing that disentangling the relative contribution of these two aspects is virtually impossible at the present time.

Analysis of the themes arising from the clinicians' accounts indicated that a number of participants with acquired brain injury were classified as having impaired awareness because of reduced awareness of social skills and/or communication problems. This supports the indications from the literature review that impaired awareness of social skills deficits could be an enduring and common problem. Impaired awareness of social skills deficits was found to be compatible with intact awareness of everyday tasks that do not involve communication. This supports the inclusion of social skills as an important domain to address in awareness research.

An attempt was made to use Crosson et al.'s (1989) Hierarchical Model of Awareness to classify each of the 36 acquired brain injury participants, on the basis of clinicians' verbal report. None of the clinicians interviewed used the terms intellectual, emergent or

anticipatory awareness and, since these terms are common currency in the literature, it was likely that these clinicians had no knowledge of the model. In view of this, the results indicate that the Crosson et al. model could provide a robust means of classifying participants. This points to the potential usefulness of the model in clinical contexts, to assist therapists in making sense of the differing patterns of awareness found in individuals with acquired brain injury. Its usefulness compared with other models may lie precisely in its simplicity. The model does not attempt to address the mechanisms that could be underpinning impaired awareness.

7.6 LIMITATIONS OF THE STUDIES

The four studies forming the main body of the thesis have been subject to critique in their respective chapters. Despite this, the main flaws in these studies, and in the research process as a whole are summarised below.

Throughout the four phases of the research programme, the researcher asked individuals with acquired brain injury about their abilities, spoke to their clinicians, observed participants and made judgements about their performance. Clearly, the overall design would have gained by separating the tasks of observation and questionnaire enquiry, so that the researcher was blind either to awareness status or to participants' judgments about their performance. This preferable approach was not possible to realise within the limited resources of a PhD study, and inter-rater reliability checks were conducted to redress this flaw in methodology.

Since an important part of the rationale for undertaking the thesis was the clinical experience of persons with poor awareness, the study involving a thematic analysis of clinicians' accounts of their patients' awareness status had particular importance. Clinicians' views and understanding of the phenomenon had not previously been explored. In this instance, the design would have been strengthened by recording these interviews and transcribing them verbatim, rather than noting down clinicians' key statements. However, recording the interviews could have been perceived as invasive by some, perhaps resulting in fewer clinicians agreeing to take part. To enhance the trustworthiness

of the data, clinicians' statements were read to them during the interview, so, they could correct any ambiguities in what they had said.

Examining the research process from a more global perspective, the initial attempts at determining awareness level or status focused on daily living activities. However, throughout the thesis a strongly exploratory approach was adopted. As a number of significant others commented that lack of awareness of social skills deficits - rather than everyday task deficits - was causing familial tension, this domain of function was given closer attention. Further examination of the literature revealed that social skills deficits, and lack of insight into these, were often cited as having a corrosive impact on family relationships, frequently implicated in marital breakdown, but, typically, two years or more after discharge from rehabilitative services (Mazaux and Richer, 1999). This point was illustrated by a number of 'phase 1: preliminary study' participants for whom no significant other could be identified.

As the research process evolved, it became clearer that social skills deficits might have been a more critical area on which to focus attention, having more specific relevance to the well being of the individual. In retrospect, the social skills questionnaire could have been administered to spinal injury participants, healthy participants and their significant others. Differences were found between groups, relating to their judgement of their ADL performance. It remains to be shown whether there would be such marked differences in awareness between the groups in relation to the social skills domain.

Taken in isolation from the rest of the thesis, the intervention case studies appeared to produce little in terms of tangible conclusive results. After scrutiny of the literature and painstaking selection of suitable measures, the intervention phase results did not provide clear evidence to answer a primary research question, namely, 'Is it possible to increase awareness following acquired brain injury?' Six prospective participants were referred for intervention case studies. Of these, intervention could be attempted only in two instances, and no significant changes in awareness could be identified in either case.

However, when reflected upon in the context of the thesis as a whole, the interview data from several informants, obtained in the 'phase 3: case studies', demonstrated how a number of different factors could indeed be contributing to an individual's awareness

profile, and that the constellation of relevant factors appeared to differ widely from individual to individual. Further, the design of the 'phase 3: case studies', with its flexible 'catch all' approach to data collection, suggested that contributory factors are not static entities but change and interact dynamically over time, and in response to changing circumstances. The earlier study designs had mostly entailed a one-off assessment and, as such, provided much less scope for observing these synergies.

7.7 PROCESS FOR IDENTIFYING THE PRESENCE OF IMPAIRED AWARENESS

The findings of the thesis support the contention that impaired self-awareness is a multi-dimensional entity. Moreover, by using a number of data collection strategies over time - observation, self report, third-party report - it is possible to draw up a profile of factors that might be impacting on an individual's awareness. As mentioned above, these factors appeared to be dynamic and waxed and waned over time, in specific individuals. Individuals seen during the course of the research programme frequently demonstrated differential awareness with respect to different domains of function.

The findings of the thesis suggest that identifying the presence of impaired awareness in an individual cannot be ascertained reliably by means of one test or one informant alone. It is suggested that the identification of the impairment should be ascertained by a number of steps; that is, a process, rather than a one-off assessment. The proposed steps are given below.

- 1. Observing the individual in a variety of different settings over a time-period of more than one day.
- 2. Requesting that an individual carry out some tasks (of relevance to him or her) and asking the individual to comment on their task performance.
- 3. Evidence of an apparent mismatch between the individual's verbal report and their behaviour.

Examples:

The individual might claim to be able to perform tasks in the present/immediate future but which he or she clearly cannot perform in view of current physical and/or cognitive impairments.

The individual might acknowledge his or her limitations in respect of the present/immediate future but have unrealistic expectations regarding the recovery time-scale of present impairments.

The individual's verbal report regarding present/future abilities can seem plausible, but he or she is observed attempting tasks beyond his or her current ability level which jeopardises his or her safety.

- 4. Obtaining verbal report about the individual's pre-morbid physical and cognitive abilities, main interests, coping style and prominent personality traits.
- 5. Obtaining verbal reports about the individual's current (including very recent) ability level from the clinicians or significant others who have spent most time with the individual in the preceding days, weeks or months, post brain lesion.
- 6. Third-party verbal report should cover (at a minimum) current physical ability, everyday task ability, and social skills.
- 7. If there is a discrepancy in opinion between two clinicians, greater weight could be given to the verbal report of the clinician who has spent more time with the individual, and/or has observed the individual in the widest range of situations.
- 8. If there is a discrepancy in opinion between a clinician and significant other, greater weight could be given to the clinician's view, if the individual has been receiving inpatient care since their acquired brain injury. Conversely, greater weight could be given to the significant other, if he or she has had prolonged exposure to the brain injured individual. For example, if significant other has been living with them for two or more weeks since discharge from in-patient care (even if the individual is still being followed up on an out-patient basis).

Practicality, resource restrictions, and the variability of people's personal circumstances mean that it is unlikely that all the above steps could be followed in the case of every individual with a possible awareness impairment. Once there is some evidence of impaired awareness, following at least two of these steps might clarify the extent of the problem and the domains for which an individual lacks awareness.

7.7.1 Definition of awareness

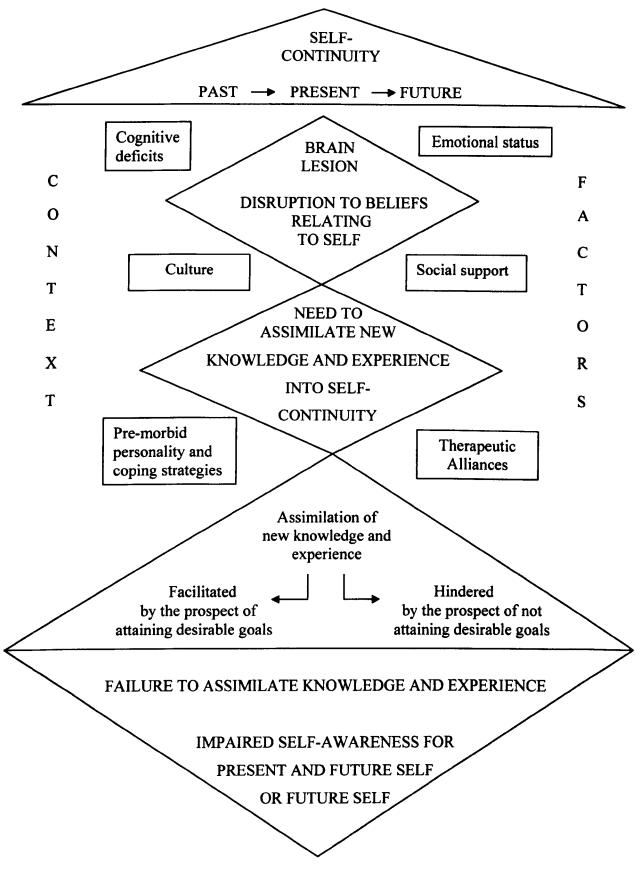
After careful consideration of likely contributory factors, impaired awareness is defined as a discrepancy between an individual's verbal report about their present or future abilities at, at least one of, the following levels of function: impairment, everyday activity or participation; and actual ability level in one of the following domains: physical, cognitive, emotional, social. Actual functional level should be ascertained by a) verbal report from at least one reliable informant, who has recently observed the individual (since the brain lesion) for prolonged periods in different contexts; and, b) testing awareness by means of structured observation of everyday living tasks and social interaction.

An individual may be deemed to lack awareness for a given domain if he or she consistently exhibits signs of lack of awareness, even though he or she might occasionally, or intermittently, appear to have intact awareness for the domain in question.

7.8 THEORETICAL MODEL OF AWARENESS

In light of the thesis findings, the theoretical model of awareness presented in Chapter 2 (page 40) was amended three ways. Pre-morbid coping strategies were found to be relevant to the manifestation of impaired awareness, and closely related to pre-morbid personality, in two of the case study participants. Pre-morbid coping strategies, therefore, were added to the pre-morbid personality box within the theoretical model of awareness (see Figure 7.1). The thesis did not demonstrate any evidence that religion might influence awareness and so specific reference to this was removed from the model. Finally, further aspects were added to the model to incorporate the notion that the assimilation of new knowledge and experience, about the self, is facilitated by the prospect of attaining desirable goals; and conversely, is hindered by limited prospect or hope of attaining desirable goals. Evidence from some of the case study participants suggested the hope, or lack of hope, of achieving goals interacted with self-awareness in this way.

Figure 7.1 Revised Theoretical Model of Awareness



7.9 CLINICAL RELEVANCE OF THE FINDINGS

The thesis findings indicate that clinicians should be cautious in determining awareness level in individuals. In attempting to determine awareness, clinicians should observe the patient's behaviour and verbal report, over a period of time. Clinicians might consider the use of a variety of measures, depending on the domain, or domains of function, for which patients appear to lack awareness.

If their patients lack awareness of everyday task ability, clinicians could use the task battery that was developed carefully within this research programme. This may be used in its full or abbreviated form, and has the advantage of incorporating behaviour and verbal report. Clinicians might now choose to elicit verbal report from their patients using the 'ease' dimension, in the knowledge that this has been found to have better discriminatory power than the 'quality' dimension (when used in the context of determining awareness in relation to everyday task ability).

The thesis findings support the use of the Hierarchical Model of Awareness (Crosson et al., 1989) as a means for clinicians to categorise patients' awareness of one or more domains of function. However, clinicians should be mindful that some patients might have no awareness of a particular domain, and clinicians might consider adding a further level to the base of the model, to reflect this. Crosson et al. (1989) claimed that intellectual awareness of deficits was a prerequisite for improving function. The thesis findings provide some evidence that improvement in the social skills domain may be brought about without awareness of social skills deficits.

In determining awareness level in their patients, clinicians could use, in addition, the theoretical model of awareness developed within this thesis (see page 248). The model incorporates six over-arching factors that might be considered to have a potential impact upon impaired awareness at the individual level. Throughout this thesis, these six over arching factors were found to be contributing to impaired awareness in the majority of acquired brain injury participants assessed. Of course, not every factor will be applicable in every case, and the relative importance of factors is also likely to vary from individual to individual.

The thesis findings gave some indication that providing individuals with an opportunity to compare present and past abilities - in contexts that are important to them - could assist in enabling them to become more aware of those abilities. Clinicians should be aware, nevertheless, that this approach has some risk of bringing about a sudden realisation of awareness, which could have an adverse effect on an individual's emotional health. The thesis findings provided some limited, indirect evidence of this.

The thesis findings indicated that pre-morbid self-concept changes slowly, but that individuals might be prepared to let go of pre-morbid self-concept, if offered an acceptable alternative, such as the likely achievement of a desirable goal.

Deciding whether or not an individual shows awareness after ABI is, thus, not a fixed dichotomous decision, but is a variable (fluctuating), multi-dimensional decision, where different dimensions, such as – ease and quality – are continua, and where a further dimension is a set of functional area categories. Hence, asking only the simple question, "Does the patient show awareness?" will inevitably lead to a meaningless answer.

7.10 RECOMMENDATIONS

7.10.1 Implications for the provision of services

At this time, uncertainty remains regarding how best to ameliorate specific awareness deficits in particular individuals. There is evidence that contextual factors may be having an adverse effect, and that these could be reduced. A potentially important factor, which could be easily overlooked, is the very way in which rehabilitation services are delivered in this country. Most patients receive rehabilitation that is very task focused, and in a context where psychological support services are in short supply. Moderate to severe brain injury is a devastating blow to an individual but the way services are provided might not be conducive to baring the soul or saying 'all that they know'. Various changes in service provision are recommended to lessen the impact of awareness impairment, and possibly, its more problematic manifestations; for example, failure to engage in rehabilitation.

Services could be provided more flexibly. If brain injured individuals are not willing to address the situation, resulting in sterile attempts at rehabilitation, they could be discharged to somewhere safe, monitored and re-admitted at a later date, when they are more psychologically ready and motivated to engage in rehabilitation. This would result in resources being administered more effectively.

There could be better 'inter-service' communication between acute units and rehabilitation units, to ensure that individuals are given consistent information, and so that acute units do not fall into the temptation of falsely bolstering hope by promising things that the rehabilitation team cannot deliver, no matter how expert it might be. This happened in Case B, and appeared to contribute to he and his wife holding on to unrealistic expectations for longer, than might otherwise have been the case. These recommendations also imply more rigorous professionalism and thoughtful liaison, rather than extra resources.

There seems little doubt that many people, both the brain injured and their families, would be helped greatly by having continuing access to psychological support, as required, after 'discharge'. This might help redress the trend towards social isolation in the longer term. Given that social skills deficits are implicated time and again in familial breakdown, this seems warranted. Initially, individuals might wish to concentrate on the physical aspects of recovery, and then wish to return home for a period of adjustment and consolidation. Subsequent social skills input could be provided at a later date, on an outpatient basis, and the individual and his or her family may be greatly supported by having access to such a service.

As already noted, individuals experiencing acquired brain injury are often young adult males, with many years of life ahead of them, who have sustained a traumatic brain injury. Many of these individuals greatly desire to work but the services available to aid them in finding appropriate work, and supporting them in this endeavour, are extremely sparse. Some services exist, such as Rehab UK, that was set up for this purpose and has some success but Rehab UK is currently available only in London, Birmingham and Glasgow. Some individuals in Oxford and Aylesbury can undertake the Working Out programme at a community head injury service in Aylesbury; this service was established 12 years ago. The service strives to take on new referrals but is small and still provides support to keep some individuals in work, 12 years on. This gives some indication of the resource injection

that would be required properly to address this largely unmet need. Provision of meaningful work alone appeared to contribute considerably to G's improvement in social skills.

7.11 FUTURE AREAS OF RESEARCH

It now remains to provide evidence of what would work, and what would be practicable in terms of addressing impaired awareness within a clinical setting. Health rationing seems here to stay and, until further evidence is gathered, it will remain difficult to justify the prioritisation of interventions, aimed at increasing awareness, over other interventions. This is a demanding challenge since there is growing evidence that profiles of awareness vary greatly. It is argued that single case methodologies should continue to be used, given that people's awareness profiles are so diverse. It is suggested that, in order to develop a suitable intervention for a given individual, it is important to enter as much as possible into that person's 'phenomenological world'. Only in this way can a researcher be confident that he or she understands the goals and beliefs of a particular individual. There seems to be some grounds for thinking that interventions that will enable individuals to reach a desired goal would have more likelihood of success. Understandably, individuals might be unwilling to engage in treatment or intervention, which they do not believe will benefit them.

If an individual with acquired brain injury has a close personal relationship with another person, one possible intervention could entail modifying the communication between them. Some individuals accept information more readily from a close significant other, as opposed to a clinician. There is evidence that an individual will accept feedback from someone they trust greatly, even if they cannot 'see it' fully themselves.

An intervention aimed at increasing awareness, but in the context of a cognitive rehabilitation programme, could also have potential. The main part of the programme is frequently delivered in a group context, which can enable people to learn more about themselves from the feedback of peers.

As regards factors that could bring about change in awareness status, clinicians did report change in the course of the research, though not in response to the interventions attempted. There was evidence that participants relinquished unrealistic beliefs, when this resulted in getting closer to a desired goal. For instance, Case B was able, temporarily, to set aside his (unrealistic) aim to walk prior to discharge, when he realised that he would be able to return home without being able to walk. As previously mentioned, evidence from one case study supported Dirette's (2002) contention that, if brain-injured persons have the opportunity to carry out familiar tasks in a familiar environment, this can help them compare their past and present performance and result in 'aha' moments of realisation.

At a more theoretical level, future research remains to show how impaired awareness in persons with acquired brain injury differs from those with Alzheimer's disease, psychosis and learning disability. Many of Clare's observations of those with Alzheimer's disease could be said of those with brain injury; particularly that individuals will say different things to different people, on the basis on the interviewer's attributes (age, gender, perceived social status, role) and on the basis of how they think (rightly or wrongly) the information will be used. Further research might indicate whether the difference in the manifestation of awareness in persons with Alzheimer's and acquired brain injury is only to do with life stage.

Finally, recent reality television shows, particularly talent shows, indicate that, apparently healthy, individuals can lack awareness of their abilities to a surprising degree. Further examination of extreme cases of impaired awareness amongst the healthy population could help increase our understanding of this complex area.

7.12 CONCLUSIONS

Determining awareness status in individuals with acquired brain injury by recourse to verbal report alone is of questionable validity. The findings of this thesis indicate that behaviour must be taken into account also when determining awareness. An innovative task battery was developed in the course of the thesis, which could be used in its full, or abbreviated, form as a behavioural measure of awareness.

The thesis findings suggest wide variation in impaired awareness in different individuals. Variations were found in underlying mechanisms, objects of awareness, and factors contributing to both awareness and how much an individual was prepared to divulge about their awareness.

In assessing an individual's awareness, particular account should be taken of pre-morbid personality and coping strategies that could affect both its behavioural manifestation and verbal report.

Differences in awareness profiles between individuals suggest that impaired awareness is not a unitary concept. Further detailed examination of single cases is recommended to draw out particular profiles. Further knowledge should enable different models of awareness to be generated that apply fully to a particular profile, and which can be used as a basis for developing specific, targeted interventions. In turn, this could result in more than one definition of impaired awareness.

The thesis findings lend little support to the likely success of intervention approaches. However, on the partial basis of thesis findings and recent published studies it is hypothesised that two intervention approaches do have future potential to increase awareness. Firstly, engaging individuals in *behaviour*, especially familiar, meaningful activities that will allow them the opportunity to compare present and past performance. Secondly, if a brain injured individual has a close relationship with a significant other, it is hypothesised that providing this person with accurate, timely information about acquired brain injury and its aftermath, would assist in increasing awareness in the brain injured individual.

Lastly, the thesis findings support the findings already documented that lack of awareness of social skills deficits greatly interfere, at the participation level of function. Considering the resultant distress caused to those with acquired brain injury and their families, this challenging area warrants further clinical and research attention.

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Appendix 1. Search strategy

A literature search was conducted of databases PsychINFO 1908–2005, CINAHL 1982–2005, AMED 1985–2005, MEDLINE 1966–2005 using search terms:

Stroke OR acquired brain injury, traumatic brain injury, head injury, closed head injury, blunt head injury, head trauma, brain damage AND Impaired awareness, impaired self-awareness, OR awareness impairment, impaired insight, reduced insight, reduced awareness, reduced self-awareness, unawareness, anosognosia, denial, denial of illness, denial of disease, denial of impairment, denial of deficit, denial of disability, consciousness.

Relevant articles, reviews and chapters were examined for further references. The above databases were re-examined at monthly intervals. Key psychology and occupational therapy journals were hand-searched at the Radcliffe Science Library and Oxford Brookes University Library respectively.

Finally, advice was sought from the following individuals regarding more recent literature, including in-press articles, relating to impaired awareness following acquired brain injury: Professor George Prigatano, Professor Barbara Wilson, Professor Jonathan Evans, Dr Linda Clare, and Dr Andrew Tyerman. Professor Susan Greenfield was consulted on literature relating to consciousness and impaired awareness following acquired brain injury.

The last search was conducted in November 2005.

Appendix 2. Research Settings

(i) Rivermead Rehabilitation Centre – Specialist Neurological Rehabilitation Service

Rivermead Rehabilitation Centre, part of the Nuffield Orthopaedic NHS Trust, is a neuro-rehabilitation unit based in Oxford. Persons are seen on either an in-patient or outpatient basis, according to their individual needs and circumstances. Most of the individuals admitted to the service are aged between 18–70 years and have severe and complex neurological disability, following acquired brain injury.

The unit serves Oxfordshire but also takes patients from Northamptonshire, Buckinghamshire and less often from other parts of the country and abroad. Assessment and treatment are provided via interdisciplinary teams of nursing, neuropsychology, occupational therapy, physiotherapy, speech and language therapy, medicine, and social work professionals. In addition there is a specialist leisure service, a specialist disability information service and input from a psychiatrist on a sessional basis. The charity Headway had use of the leisure service facilities on two days a week, and a number of people who have undergone rehabilitation at Rivermead attends.

In July 2002, the centre moved to a new facility in the grounds of the Nuffield Orthopaedic Centre. The Centre now forms part of the Oxford Centre for Enablement. This relocation coincided with the conclusion of the measurement phase of this study.

(ii) The National Spinal Injuries Centre, Stoke Mandeville Hospital

The National Spinal Injuries Centre is based in Stoke Mandeville – just outside Aylesbury, Buckinghamshire. The catchment area for admissions includes the South East region, but people are admitted from other areas of the UK and from abroad. The centre has 116 beds including six high-dependency beds, 96 acute/intermediate/rehabilitation beds including a four-bed domicilary ventilation unit and 16 pre-discharge beds. Individuals with acute conditions are admitted as soon as they are fit for travel. Disciplines involved in delivering rehabilitation include: nursing, medicine, physiotherapy, occupational therapy and clinical psychology. A teacher provides education for children within the unit. There is an

Appendix 2. Research Settings

independent living bungalow and extensive indoor and outdoor sports and recreational facilities.

After discharge, individuals are followed up on a life-long basis. People may be readmitted if complications arise.

(iii) The Radcliffe Infirmary

The Radcliffe Infirmary, part of the Oxford Radcliffe NHS Trust, is based in Oxford city centre. It has four geratology wards, as well as other specialist services. Usually, persons on the geratology wards have been transferred from the acute medical wards at the John Radcliffe Hospital, when further rehabilitation is indicated. One of the geratology wards, 'Beeson,' is designated to take a majority of individuals who have had a stroke. Despite the 'geratology' designation, persons aged under 65 years may be admitted, when beds are not available at a more suitable facility.

(iv) The Community Head Injury Service

The Community Head Injury Service is part of the Vale of Aylesbury Primary Care NHS Trust and is based just outside Aylesbury town centre, in the Cambourne Centre. The service offers specialist assessment and rehabilitation programmes to facilitate the long-term adjustment of persons with head injury and their families. The inter-disciplinary team comprises clinical neuropsychology, nursing, occupational therapy, physiotherapy, speech and language therapy, and work placement consultants. The service is part of the Buckinghamshire Brain Injury Strategy and networks closely with Social Services, Jobcentre Plus and other clinical units in Oxford and Buckingshamshire.

(v) Community Neurological Rehabilitation Service, at Rayner's Hedge

The Community Neurological Rehabilitation Service also forms part of the Vale of Aylesbury Primary Care NHS Trust, based in Aylesbury. The service provides a specialist neuro-rehabilitation service primarily to individuals who have had a stroke or who have multiple sclerosis. Individuals are seen mostly on an outpatient basis, but the unit also has 10 in-patient beds. The service is delivered by multi-disciplinary teams, comprising

Appendix 2. Research Settings

clinical psychologists, occupational therapists, speech and language therapists, nurses, doctors, physiotherapists, a dietitian, and chaplain.

Appendix 3. LREC Approval Letter 1

Stoke Mandeville
Hospital NHS Trust

Buckinghamshire Health Authority

Aylesbury Vale Local Research Ethics Committee

Mandeville Road, Aylesbury Buckinghamshire HP21 8AL Telephone (01296) 315000 Direct Line: (01296) 316784

28th February 2001

Ms M Murphy
Head Occupational Therapist
Oxford Centre for Health Care
Research and Development (OCHRAD)
School of Health Care
Oxford Brookes University
44 London Road
Headington
Oxford OX3 7PD

Dear Ms Murphy

Re: NC1036 - Impaired awareness following acquired brain injury (ABI)

I refer to your application to the Local Research Ethics Committee for consideration of the above project. I am pleased to inform you that the Committee approves the project on ethical grounds on the understanding that:

- i. Any ethical problem, arising in the course of the project, will be reported to the Committee.
- ii. Any change in the protocol will be reported to the Committee.
- iii. The Data Protection Act 1998 be adhered to.
- iv. There is compliance, throughout the conduct of the study, with good clinical research practice.
- v. The Committee be informed if the research is discontinued for any reason.
- vi. A report be submitted after completion.
- vii. Ethical approval is for three years from the date of this letter

Ethical approval by the Committee is not an authority to proceed. You are advised to discuss your proposal with all heads of departments and others who might be affected, particularly if there are financial and/or staffing implications.

Members: Dr M. Webley (Chairman), Mrs M. Aston, Mrs E. Nurse, Dr A. Watson, Dr R. Bunsell, Mr I. Curne, Dr S. Holdich, Dr A. Tyerman, Dr L. Hickey, Mrs W. Currie. Secretary: Mr P. Mansfield

Appendix 3. LREC Approval Letter 1

Please note that your research will be subject to review annually by the Committee.

Yours sincerely

PETER MANSFIELD Secretary to AVLREC

Oxford Radcliffe Hospitals NHS Trust

Our Ref: JB/SKH/A01.003

Ms M Murphy OCHRAD Oxford Brookes University 44 London Road HEADINGTON Oxford OX3 7PD Applied & Qualitative Research Ethics Committee
Research & Development Department
Room 13, Manor House
The John Radcliffe
Headley Way
Headington
Oxford
OX3 9DU

Tel: 01865 222758 Fax: 01865 222699

Email: samantha.hatzis@orh.nhs.uk

Dear Ms Murphy

5 December 2001

Re: A01.003 - Impaired Awareness following Acquired Brain Injury (ABI)

Thank you for your letter dated 28 November 2001, requesting approval for the changes to the submitted protocol. There seems to be no problem with this and I can now confirm AQREC approval for this addendum.

Please note:

- Ethical approval is valid for three years from the date of this letter.
- No significant changes to the research protocol should be made without appropriate research ethics
 committee/chairman's approval. Any deviations from or changes to the protocol which increase the risk to
 subjects, affect the conduct of the research or are made to eliminate hazards to the research subjects, should
 be made known to AQREC.
- AQREC should be made aware of any serious adverse events.

Best wishes with your continuing study

S. K. Hetus

Yours sincerely

Dr Jenny Butler

Chair

Applied and Qualitative Research Ethics Committee

Chair - Dr Jenny Butler

Appendix 5. LREC Approval Letter 3

Stoke Mandeville Hospital NHS Trust

Thames Valley Strategic Health Authority

Aylesbury Vale Local Research Ethics Committee

Mandeville Road, Aylesbury Buckinghamshire HP21 8AL Telephone (01296) 315000 Direct Line: (01296) 316784 E-mail: Peter Mansfield@smh.nhs.uk

19th June 2002

Ms M Murphy
Oxford Centre for Health Care Research and Development
Oxford Brookes University
44 London Road
Headington
Oxford OX3 7PD

Dear Maggie,

Re: Project NC1110 - Impaired awareness following acquired brain injury (ABI)

I refer to your application to the Local Research Ethics Committee for consideration of the above project. I am pleased to inform you that the Committee approves the project on ethical grounds on the understanding that:

- i. Any ethical problem, arising in the course of the project, will be reported to the Committee.
- ii. Any change in the protocol will be reported to the Committee.
- iii. The Data Protection Act 1998 be adhered to.
- iv. There is compliance, throughout the conduct of the study, with good clinical research practice.
- v. The Committee be informed if the research is discontinued for any reason.
- vi. A report be submitted after completion.
- vii. Ethical approval is for three years from the date of this letter

Ethical approval by the Committee is not an authority to proceed. You are advised to discuss your proposal with all heads of departments and others who might be affected, particularly if there are financial and/or staffing implications.

Members: Dr M Webley (Chairman), Mrs M Aston, Mrs M Jeffcoat, R Bunsell, Mr I Curne, Dr S Holdich, Dr A Tyerman, Dr L Hickey, Mrs J McVea Sezretary: Mr P Massfield

Appendix 5. LREC Approval Letter 3

Please note that your research will be subject to review annually by the Committee.

Yours sincerely

PETER MANSFIELD

Secretary to Local Research Ethics Committee

Oxford Radcliffe Hospitals NHS Trust

Our Ref. JB/SKH/A02.027

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Headley Way
Headington
Oxford
OX3 9DU

Tel: 01865 222758 Fax: 01865 222699

Email: samantha.hatzis@orh.nhs.uk

Dear Ms Murphy

28 June 2002

Re: A02.027 - Impaired Awareness Following Acquired Brain Injury (ABI)

Thank you for supplying confirmation of indemnity for the above study from the Nuffield Orthopaedic Centre. I can now confirm final approval and wish you every success with your study.

Yours sincerely

Samantha Hatzis
AQREC Administrator

Applied & Qualitative Research Ethics Committee

mente Hehis

Chair - Dr Jenny Butler



School of Health and Social Care

Appendix 7. Patient Invitation Letter

Date:
AVLREC No.
AQREC No.
Study Title: Awareness of Difficulties with Everyday Tasks
Dear
Re: Invitation to take part in the above study.
My name is Maggie Murphy, I am a qualified Occupational Therapist and I have recently started a PhD in Healthcare. I am writing to invite you to take part in a study that will form part of the PhD. Following a stroke or head injury, people sometimes have problem understanding their strong and weak points in relation to carrying out everyday tasks/communicating in the most effective way with others. The study would look more closely at this.
There are further details on the attached information sheet. If you would like to take part or have any concerns or queries, please do not hesitate to call me on (01865) 485293.
Thanking you in anticipation,
Yours sincerely,
Maggie Murphy
Makkie mmhn





Appendix 8. Patient Information Sheet.

Note: There were approximately 30 versions of the information sheet for different participants in different phases of the research programme. This information sheet was given to participants taking part in the first phase.

AQREC Number: A01.003 (Version 1, 14 November 00)

Information Sheet

Title of study: Awareness of Difficulties with Everyday Tasks

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it would involve. Please take time to read the following information carefully and discuss it with friends, relatives and your doctor if you wish. Ask me or your Occupational Therapist if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

When people have a head injury or a stroke, they are sometimes less aware of difficulties they have with everyday tasks, such as making snacks or gardening. The main aim of the study is to help people to be more aware of their strengths and weaknesses when doing these everyday tasks.

Why have I been chosen?

You have been chosen because those treating you feel that you may be suitable.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you would be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you would still be free to change your mind at any time and without saying why. Changing your mind would not affect the standard of care you receive.

Appendix 8. Patient Information Sheet

What would happen to me if I take part?

If you agreed to take part, you would be asked some questions about how you feel in yourself, and what you think of your ability to do everyday tasks. I would then ask you to do some tasks, similar to those your Occupational Therapist might ask you to do, for example making a hot drink, phoning a train station. All of this would take about one or one and a half hours. If you get tired we could do this in 2 shorter sessions. At a later date, I might ask you if you would be willing to take part in a second study but agreeing to take part in this study does not mean that you have to take part in the second one.

I would also ask a member of your family or a friend, and one of your therapists, questions about your abilities with tasks. These people would not know what you had said about your abilities, and you would not know what they had said.

What are the possible disadvantages or risks of taking part?

There would be no disadvantages or risks involved with you taking part in this study.

What are the possible benefits of taking part?

The study would not benefit you directly, though your taking part may help to increase what is known about awareness problems.

Would my taking part be kept confidential?

All information which is collected about you during the course of the research would be kept strictly confidential. Any information about you which leaves the hospital would have your name and address removed so that you cannot be recognised from it.

What would happen after the study?

The results of the study may be shown to other people but they would not know that you had been involved. The results of the study would mainly be used to find ways of helping people understand more about their abilities.

Appendix 8. Patient Information Sheet

Who is organising the research?

This study is part of a PhD I am doing in the School of Health Care, at Oxford Brookes University. I am taking time out from my usual work at Rivermead Rehabilitation Centre. I worked there for 3 years as Head Occupational Therapist. The consultant at Rivermead, Professor Derick Wade, is one of the people advising me while I am doing this study.

Contact number for further information?

If, at any time, you have any questions about the study I would be happy to speak to you. My name is Maggie Murphy and you can contact me directly at my office in Oxford Brookes on (01865) 485293. If it is easier, you can tell your Occupational Therapist that you would like some further information, or that you would like to take part, and they will pass the message on to me.

Thank you for reading this information sheet.



School of Health and Social Care

Appendix 9. Consent Form

AQREC Number: A01.003

CONSENT FORM

Awareness of Difficulties with Everyday Tasks

Name of Researcher: Maggie Murphy - PhD Student

Maggie Murphy Tel: (01865) 485293

_	esearcher	Signature	Date				
	ame of Person taking consent different from researcher)	Signature	Date				
Na	ame of Participant	Signature	Date				
4.	I agree to take part in the above	study.					
3.	I agree that any words I may say used, anonymously, in the prese		lated to this study, may be				
2.	I understand that my participation time, without giving any reason.		I am free to withdraw at any				
1.	I confirm that I have read and us November 2000 for the above st						
	Please initial box:						

1 for participant, 1 for researcher.

Patient Competency Rating (Patient's Form)

Source: Prigatano, G.P. and Others (1986). Neuropsychological Rehabilitation After Brain Injury. Baltimore: John Hopkins University press.

Identifying I	nformation			
Patient's Nam	e:			····
Date:				
Instructions				
practical skills you are asked	s. Some of the quest to complete each queshould judge how each	hat asks you to judge you ions may not apply direct lestion as if it were some asy or difficult a particul	tly to things you cathing you "had to	often do, but do". On each
Competency	Rating			
1	2	3	4	5
Can't do	Very difficult to do	Can do with some difficulty	Fairly easy to do	Can do with ease
1. Ho	w much of a proble	m do you have in prepar	ing your own mea	als?
2. Ho	w much of a proble	m do you have dressing	yourself?	
3. Ho	w much of problem	do you have in taking c	are of your persor	nal hygiene?
4. Ho	w much of a proble	m do you have in washii	ng the dishes?	
5. Ho	w much of problem	do you have in doing th	e laundry?	
6. Ho	w much of a proble	m do you have in taking	care of your finar	nces?
7. Ho	w much of a proble	m do you have in keepir	ng appointments o	n time?
8. Ho	w much of a proble	m do you have in startin	g conversation in	a group?
	ow much of a proble en when bored or tir	m do you have in stayinged?	g involved in wor	k activities
10 Ha	w much of a proble	m do vou have in remen	nbering what you	had for dinner

last night?

Appendix 10. Patient Competency Rating Scale

- 11. How much of a problem do you have in remembering names of people you see often?
- 12. How much of problem do you have in remembering your daily schedule?
- 13. How much of problem do you have in remembering important things you must do?
- 14. How much of a problem would you have driving a car if you had to?
- 15. How much of a problem do you have in getting help when you are confused?
- 16. How much of a problem do you have in adjusting to unexpected changes?
- 17. How much of a problem do you have in handling arguments with people you know well?
- 18. How much of a problem do you have in accepting criticism from other people?
- 19. How much of a problem do you have in controlling crying?
- 20. How much of a problem do you have in acting appropriately when you are around friends?
- 21. How much of a problem do you have in showing affection to people?
- 22. How much of a problem do you have in participating in group activities?
- 23. How much of a problem do you have in recognising when something you say or do has upset someone else?
- 24. How much of a problem do you have in scheduling daily activities?
- 25. How much of a problem do you have in understanding new instructions?
- 26. How much of a problem do you have in consistently meeting your daily responsibilities?
- 27. How much of a problem do you have in controlling your temper when something upsets you?
- 28. How much of a problem do you have in keeping from being depressed?
- 29. How much of a problem do you have in keeping your emotions from affecting your ability to go about the day's activities?
- 30. How much of a problem do you have controlling your laughter?

Appendix 11. Self-Awareness of Deficits Interview

Self-Awareness of Deficits Interview

1. Self-awareness of deficits

Are you any different now compared to what you were like before your accident? In what way? Do you feel that anything about you, or your abilities has changed?

Do people who know you well notice that anything is different about you since the accident? What might they notice?

What do you see as your problems, if any, resulting from your injury? What is the main thing you need to work on/would like to get better?

Prompts

Physical abilities (e.g. movement of arms and legs, balance, vision, endurance)?

Memory/confusion?

Concentration?

Problem-solving? decision-making, organizing and planning things?

Controlling behaviour?

Communication?

Getting along with other people?

Has your personality changed?

Are there any other problems that I haven't mentioned?

2. Self-awareness of functional implications of deficits

Does your head injury have any effect on your everyday life? In what way?

Prompts
Ability to live independently?
Managing finances?
Look after family/manage home?
Driving?
Work/study?
Leisure/social life?

Are there any other areas of life which you feel have changed/may change?

3. Ability to set realistic goals

What do you hope to achieve in the next 6 months? Do you have any goals? What are they?

In 6 months time, what do you think you will be doing? Where do you think you will be? Do you think your head injury will still be having an affect on your life in 6 months time? If no: are you sure?

Appendix 11. Self-Awareness of Deficits Interview

Scoring

1. Self-awareness of deficits

- O Cognitive/psychological problems (where relevant) reported by the patient/client in response to general questioning, or readily acknowledged in response to specific questioning.
- 1 Some cognitive/psychological problems reported, but others denied or minimized. Patient/client may have a tendency to focus on relative minor physical changes (e.g. scars) and acknowledge cognitive/psychological problems only on specific questioning about deficits.
- 2 Physical deficits only acknowledged; denies, minimizes or is unsure of cognitive/spychological changes. Patient/client may recognize problems that occurred at an earlier stage but denies existence of persisting deficits, or may state that other people think there are deficits, but he/she does not think so.
- 3 No acknowledgement of deficits (other than obvious physical deficits) can be obtained, or patient/client will only acknowledge problems that have been imposed on him/her, e.g. not allowed to drive, not allowed to drink alcohol.

2. Self-awareness of functional implications of deficits

- O Patient/client accurately describes current functional status (in independent living, work/study, leisure, home management, driving), and specifies how his/her head injury problems limit function where relevant, and/or any compensatory measures adopted to overcome problems.
- 1 Some functional implications reported following questions or examples of problems in independent living, work, driving, leisure, etc. Patient/client may not be sure of other likely functional problems, e.g. is unable to say because he/she has not tried an activity yet.
- 2 Patient/client may acknowledge some functional implications of deficits but minimizes the importance of identified problems. Other likely functional implications may be actively denied by the patient/client.
- Little acknowledgement of functional consequences can be obtained; the patient/client will not acknowledge problems: except that he/she is not allowed to perform certain tasks. He/she may actively ignore medical advice and may not engage in risk-taking behaviours, e.g. drinking, driving.

3. Ability to set realistic goals

- O Patient/client sets reasonably realistic goals, and (where relevant) identifies that the head injury will probably continue to have an impact on some areas of functioning, i.e. goals for the future have been modified in some way since the injury.
- Patient/client sets goals which are somewhat unrealistic, or is unable to specify a goal, but recognizes that he/she may still have problems in some areas of function in the future, i.e. sees that goals for the future may need some modification, even if he/she has not yet done so.
- 2 Patient/client sets unrealistic goals, or is unable to specify a goal, and does not know how he/she will be functioning in 6 months time, but hopes he/she will return to pre-trauma, i.e. no modification of goals has occurred.
- 3 Patient/client expects without uncertainty that in 6 months time he/she will be functioning at pre-trauma level (or at a higher level).

Appendix 12. Task Hierarchy

PROCESS TASK HIERARCHY

VERY EASY TASKS

Putting on socks Drink from fridge Upper body dressing

MUCH EASIER THAN AVERAGE TASKS

Eating a meal Brushing teeth Making a bed

Folding a basket of laundry

EASIER THAN AVERAGE TASKS

Instant drink

Upper body grooming Hand wash laundry

Setting a table for one or two persons Watering plants and removing dead leaves

Polishing shoes

Upper and lower body dressing

Sweeping the floor Hand washing dishes Cleaning windows

Ironing a shirt (board already up)

AVERAGE TASKS

Cold cereal and juice Meat or cheese sandwich

Jam sandwich Changing sheets

Ironing a shirt (setting up board)

Upper body grooming and total body dressing

Sweeping outside Pot of tea

Vegetable preparation Vacuuming a room Mopping the floor Boiled eggs

Tea or coffee served with biscuits Ironing multiple garments

Repotting a plant Vacuuming a car

HARDER THAN AVERAGE TASKS

Toast and instant drink Toast and tea Fresh fruit salad

Tossed salad with dressing

Beans on toast

Scrambled or fried eggs and beverage

Vacuuming on two levels

MUCH HARDER THAN AVERAGE TASKS

Omelette or scrambled eggs with added ingredients and bev

Pasta with sauce, green salad, and beverage

MOTOR TASK HIERARCHY

VERY EASY TASKS

MUCH EASIER THAN AVERAGE TASKS

Eating a meal Brushing teeth

EASIER THAN AVERAGE TASKS

Drink from fridge

Folding a basket of laundry Upper body grooming/bathing

Upper body dressing

Instant drink

Putting on shoes and socks Hand washing dishes Hand washing laundry Ironing a shirt (board already up) Setting a table for one or two persons Watering plants and removing dead leaves

Polishing shoes

AVERAGE TASKS

Pot of tea

Cold cereal and juice Meat or cheese sandwich

Jam sandwich Repotting a plant

Upper body grooming and total body dressing

Boiled eggs

Tea or coffee served with biscuits

Sweeping the floor

Upper and lower body dressing

Toast and instant drink

Toast and tea

Scrambled or fried eggs, toast and beverage

Tossed salad with dressing

Beans on toast Vegetable preparation Cleaning windows Sweeping outside

Ironing a shirt (setting up board)

HARDER THAN AVERAGE TASKS

Omelette or scrambled eggs with added ingredients and bev

Fresh fruit salad

Pasta with sauce, green salad, and beverage

Mopping the floor Changing sheets Ironing multiple garments

Vacuuming a room

MUCH HARDER THAN AVERAGE TASKS

Vacuuming a car

Vacuuming rooms on two levels

Appendix 13. Rail (phone) task

Participant no
Please complete the task which is ticked.
Train information:
a) Call National Rail Enquiries to ascertain the time of the next train to Paddington from Oxford.
b) Call National Rail Enquiries to ascertain the time of the next train to Paddington from Oxford and time of arrival.
c) Call National Rail Enquiries to ascertain the time of the next train to Paddington from Oxford, the time of arrival, the price of the ticket i returning tomorrow morning before 9 am.
National Rail Enquiries: (9) 08457 484950
Write your answer or answers below:
Time of next train:
Time of arrival in Paddington:
Price of ticket:

Appendix 14. Phone restaurant task

Restaurant information task

a) Call Caffe Uno in Oxford and ask if it possible to reserve a table on Friday night.

OR

b) Find the number of Caffe Uno in telephone book and ask if it is possible to reserve a table on Friday night.

OR

c) Find the number of Caffe Uno in telephone book and ask if it is possible to reserve a table on Friday night; also find out times in the week when tables may be reserved

Appendix 15. Planning a day out task

Plan a day out:

a) Calculate the cost of return travel for 2 Oxford to London, state the means of transport: car, coach, train.

OR

b) Calculate the cost of a day out in London for 2 including return travel and visit to a moderately priced restaurant for lunch.

OR

c) Calculate the cost of a day out in London, including return travel, visit to a moderately priced restaurant for lunch and visit to visit to a museum or similar.

Appendix 16. Planning a shopping list task

Plan a shopping list:

a) to provide breakfast for 2 for 2 days, say/write down what you would include on a shopping list, assuming they were starting with nothing i.e. no milk etc.

OR

b) to provide breakfast and lunch for 2 days for 2 people, say/write down what you would include on the shopping list

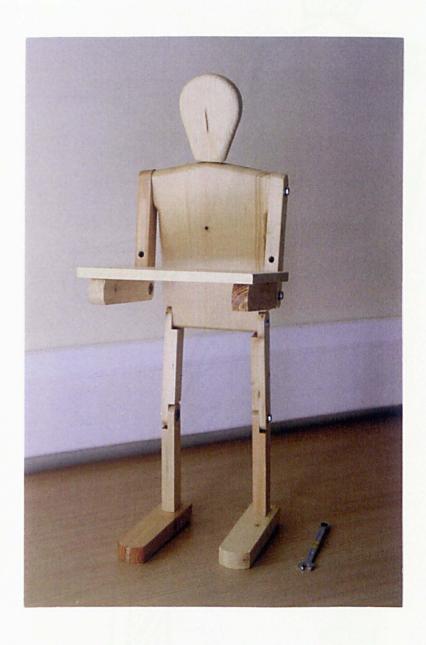
OR

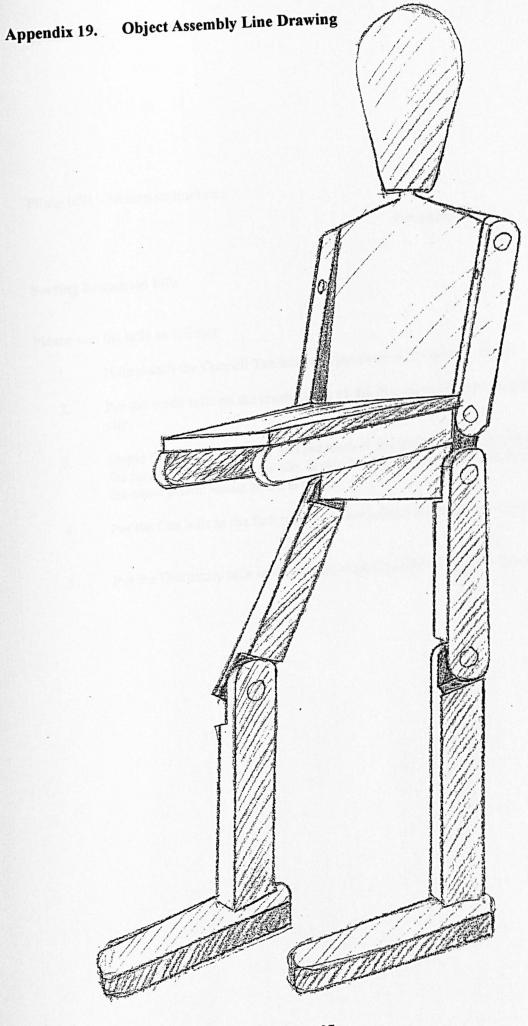
c) As above, but include dinner

Appendix 17. Ease and quality dimension questions

Likert scale response options for the ease/difficulty and quality dimensions:

- 1. How easy or difficult do you think the task will be/was? (Ease)
 - 1 Can't do
 - 2 Very difficult to do
 - 3 Can do with some difficulty
 - 4 Fairly easy to do
 - 5 Can do with ease
- 2. How well do you think you will do/did the task? (Quality)
 - 1 Badly
 - 2 Not very well
 - 3 Reasonably
 - 4 Quite well
 - 5 Well





Appendix 20. Filing task

Filing bills – written instructions	
	Participant no

Sorting household bills

Please sort the bills as follows:

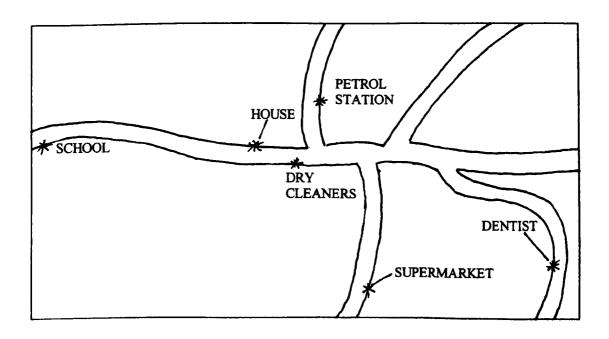
- 1. Hole-punch the Council Tax bills and put them in the lever arch file.
- 2. Put the water bills on the inside cover of the file, fastened with the bulldog clip.
- 3. Staple the BT bills together and put them in the plastic wallet attached to the inside back cover of the file. Staple the Mercury bills and put them in the same plastic wallet as the BT bills.
- 4. Put the Gas bills in the first plastic pocket behind the Council Tax bills.
- 5. Put the Electricity bills in the second plastic pocket behind the Gas bills.

Appendix 21. Time-table task instructions

Time-table task instructions

It is 8.30 on a Monday morning. Mr Smith needs to do the following tasks today. How many of the following tasks could he fit in? Sort out the order he would do things in.

- * Note: The most important things he needs to do: to drop off and collect the children, let the plumber in and to get petrol.
- Drop the children off at school by 9 am and collect them by 3.30pm at the latest. It takes 10 minutes to get to the school.
- Have lunch.
- Let the plumber in, he is expected between 11am and 2pm.
- Collect the dry cleaning from the nearest shops, a two minute walk down the road. It is not possible to park close to the shops. The dry cleaning shop closes at 4pm.
- Do the shopping for the week (family of 4). It takes 15 minutes to get to the supermarket.
- Telephone for flowers to be sent to a close friend tomorrow. For next day delivery, he must make the call before 12 noon.
- Telephone the dentist to confirm whether he will take the 9.45am or 3.20pm appointment for a check-up today. Attend for a dental check-up. The dentist is twenty minutes away.
- Get petrol. The petrol tank is almost on empty. The petrol station is 5 minutes from the house.



Appendix 22. Diary page for Time-table task

'Diary' page for time-table task responses Time-tabling task	Participant no
8.30	
9.00	••••••
9.30	
10.00	••••••
10.30	
11.00	
11.30	
12.00	
12.30	
1.00	
1.30	
2.00	
2.30	
3.00	
3.30	
4.00	
4.30	
5.00	• • • • • • • • • • • • • • • • • • • •
5.30	•••••

Appendix 23. Time-table task scoring matrix.

DROP KIDS OFF	SHOPPING	PHONE FOR FLOWERS
1.5 COLLECT KIDS	1	1
1.5		
AWAIT PLUMBER	CALL DENTIST	HAVE LUNCH
3	1	1
GET PETROL	GO TO DENTIST	GET DRY CLEANING
GETTEIROE	00 10 22.11.51	ODI DILI ODDININO
3	1	1
	•	•

SCORING SYSTEM

1	2	3	4	5
1 – 3.5	4-6.5	7 – 9.5	10 – 13	13.5 - 15

ADDITIONAL GUIDELINES:

- 1. If activities are scheduled which involve leaving the house between 11am and 2pm, the 3 points for 'Plumber' should be deducted.
- 2. If activities are scheduled at the wrong time, e.g. collecting the children an hour early, or attending the dentist at a time other than stipulated, no points will be scored for such activities.

Appendix 24. Social Communication Skill Questionnaire

SOCIAL COMMUNICATION SKILLS QUESTIONNAIRE

Rating:

1 2 3 4 5
Never Rarely Sometimes Often Always

1. When you express you opinions:

- (a) You state your ideas clearly
- (b) You stay focussed on the topic
- (c) Your thoughts are organised
- (d) Your support your opinions with fact wherever possible
- (e) You are able to reword your comments if the listener doesn't understand your point
- (f) You use a tone of voice that is assertive but not aggressive
- (g) You avoid insulting the person you are talking with

2. When people give opinions that differ from yours:

- (a) You allow them to express themselves completely without interruption
- (b) Your are able to control your facial and body expressions
- (c) Your respond with a tone of voice that is assertive but not aggressive
- (d) Your are able to control your temper

3. In general conversation:

- (a) Your speech is clear and easy to understand
- (b) The rate at which you talk is easy for people to listen to
- (c) You avoid dominating the conversation
- (d) You avoid using words that might offend others
- (e) You maintain eye contact with the person you are talking with
- (f) You select topics that won't offend the person you are talking to
- (g) You can answer questions that come up in the conversation
- (h) If you interrupt someone, you do so in a way that fits smoothly into the flow of the discussion

4. In conversation with people you don't know very well:

- (a) You are able to begin a conversation
- (b) You are able to change the subject smoothly
- (c) You are able to keep the conversation going
- (d) You know when and how to end a conversation

Appendix 24. Social Communication Skill Questionnaire

5. Other situations:

- (a) In situations where you are being instructed, you ask for an explanation when you don't understand something
- (b) When asking someone to join you for a social activity, you know where and when to give them the invitation
- (c) When you are at a social event, you know how much, or how little physical contact to use

Semi-structured interview schedule (for participants lacking awareness of social skills)

Initial session:

Since your brain injury/stroke, have you noticed any difficulty communicating or getting on with others (other patients/therapists/nurses/family/friends)? Have you noticed any problem making yourself understood?

(If so) In your view, what might be causing this?

Physical problems? Difficulty finding the right word? Other people being a bit awkward? Anything else?

Has anyone spoken to you about difficulties communicating or getting alone with others? What have they said? Do you agree with them?

Subsequent sessions:

What types of therapy have you been involved in this week?

Prompts:

Occupational Therapy?
Physiotherapy?
Psychology?
Speech and Language Therapy?
Any other sessions?

Would you say that you have learnt anything new about yourself this – as a result of any of these sessions or other significant things which have happened in your life generally?

Have you noticed anything about your ability to communicate with others that you hadn't noticed before/last time we spoke? What do you think might be causing the problem/improvement?

Appendix 26. Semi-structured interview schedule - Everyday task version.

Semi-structured interview schedule (for participants lacking awareness of everyday task ability)

Initial session:

Since your brain injury/stroke, have you noticed any difficulty or would you anticipate any difficulty carrying out everyday tasks?

Prompts

Getting washed and dressed?
Writing, reading or using the phone?
Preparing drinks or meals?
Using the computer?
Anything else?

Subsequent sessions:

What types of therapy have you been involved in this week?

Prompts:

Occupational Therapy?
Physiotherapy?
Psychology?
Speech and Language Therapy?
Any other sessions?

Would you say that you have learnt anything new about yourself this – as a result of any of these sessions or other significant things which have happened in your life generally?

Appendix 27. Eye Contact Form - Case S

Eye contact form (tick or underline)

No. of times eye contact given:

- 0. No eye contact given
- 1. Too fleeting
- 2. Too brief but more than fleeting
- 3. Normal duration

Comments:

Appendix 28. Verbal Response Questionnaire – Case S

Verbal Response Form - Case S

Topic areas and approximate wording of question, if recalled:

S's responses to question (tick or underline):

- 1. No verbal response given (e.g. yes, no, ok)
- 2. Single word answer given
 - a) appropriate in the circumstances
 - b) more than single word desirable
- 3. Brief response given
 - a) appropriate in the circumstances
 - b) further expansion desirable
- 4. Expands appropriately
 - a) needed further prompting to expand further
 - b) expanded without prompting
- 5. Answered question and sought view of other

Comments:

Appendix 29. Intervention Programme for Case S

Details of the Intervention Programme for Case S

S was given clear information regarding objectives for each session. Target behaviour was positively reinforced with praise. Constructive criticism was always given by means of the sandwich method, i.e. critical feedback given flanked by positive feedback. Conveying of constructive criticism was mostly dealt with by giving S feedback and asking S to comment on the effect his behaviour/verbal communication might have on a third party. Accurate responses were positively reinforced, inaccurate responses countered with information. In the later case, efforts were made to ensure that S understood the feedback and found it reasonable. If not, alternative examples and ways of explaining the feedback were employed.

S's doubts and questions were handled in a positive and supportive manner.

Sub-optimal performance was always viewed as a 'springboard' from which to do better next time.

S was also encouraged to critique the investigator's social interaction in order for S to learn that other people's social 'performance' is not always optimal. Shortcomings in the investigator's social interaction were brought to S's attention as they arose.

Repetition.

Format of programme

- Rudiments of verbal and non-verbal communication (NVC). Stressing the importance of NVC in transmitting the meaning of what is said.
- Enumerating, defining and explaining by means of examples the main components of NVC: gesture, eye contact, facial expression, posture, role of dress and grooming in the presentation of self.
- Role play focussing on displaying interest in what others are saying by verbal and non-verbal communication; asking questions to encourage others to expand further.
- Role play exploring how S could communicate his interests in a more appealing way to third parties; exploring ways of speaking about adverse events/circumstances which are constructive, rather than overly negative. Exploring how speaking in a negative and bitter manner can make others feel.

Appendix 29. Intervention Programme for Case S

- Making a good first impression, practice greeting people, taking into account facial expression, posture, clothing. Practice entering/leaving rooms.
- Role-play with video feedback, focussing on open facial expression and maintaining adequate eye contact.
- Brain-storming strategies for continually updating topics of conversation.
- Being constructive. Practice countering negative comments with more positive comments. Exploring and practising ways of changing topics of conversation smoothly.
- Social protocols, e.g. what to say when arriving late for an appointment.

 Practice using polite forms of address.
- Strategies for dealing with unexpected comments for questions from others.

Appendix 30. Intervention Protocol – Case B

Details of Intervention - Case B

- A way of judging any task by means of a percentage formula. For example, if an individual is able to complete a task without any assistance they could be judged to have completed 100% of the task independently. By the same reasoning the following way of judging degree of assistance was proposed:

80-99% of task completed independently = A little assistance

50-79% of task completed independently = A moderate amount of assistance

20-49% of task completed independently
 0-19% of task completed independently
 Maximal assistance

- Explanation of the above and agreement from participant PB that the formula was reasonable.
- Testing B's understanding of the formula, for example, 'If a person completes 65% of task independently, how much assistance do they require?'
- Breaking down the standing-frame task into its component parts and assigning a percentage score to each component. Components divided into one of three categories, according to the degree of difficulty of a given component:

Easy component	Moderately difficult component	Hard component	
1.Fasten buckle 12.Fasten buckle 23.Hold onto frame with hands	1.Remove 'peanut' cushion from shoulder 2.Position wheelchair in relation to frame 3.Position self close to frame in wh/ch	1.Put strap under hips2.Put strap under arms3.Put strap around feet	
4.Position hands on tray in standing	4.Position knees against frame support5.Organise straps ready for fastening	4.Keep feet on ground as get into standing	
5. Press button for 'lift-off'	or a supplication of the s	as Sec into similaring	
Easy steps are worth a total	Moderately difficult steps are worth	Hard steps are worth	
of 20% of task	a total of 30% of the task	a total of 50% of task	
i.e. each step = 4%	i.e. each step = 6%	i.e. each step = 12.5%	

- B's understanding of this rationale was tested, for example, 'If an individual carried out all easy steps independently, one moderate step independently but none of the hard steps, how many percentage points would they have achieved?' (26%). 'How much assistance would we judge the person had required with the task?' (A lot of assistance).
- The video was paused after each step of the task and B was invited to say whether or not he had completed the component independently. If he claimed to have completed a

Appendix 30. Intervention Protocol - Case B

step independently, but the videotape indicated this was not so, the investigator asked whether he were sure. If he replied in the affirmative, his view was not challenged further and the process was repeated for all 14 steps.

- The investigator noted concurrently whether component parts of the task were completed independently and assigned percentage points accordingly. After viewing the videotape of all 14 components of the task, the participant was asked to add up the percentage points to achieve a percentage total. The investigator also added up the percentage points she had assigned to achieve a percentage total.

Appendix 31. Assistance to stand questionnaire

Assistance to stand questionnaire

Date:

Prior to task/activity:

Ask participant how much assistance he will require with this task/activity.

- 1. I wouldn't manage any part of it without assistance
- 2. A lot of assistance
- 3. A moderate amount of assistance
- 4. A little assistance
- 5. No assistance

Following the task/activity:

Ask the participant how much assistance he thought he required with the task/activity.

- 1. I couldn't manage any part of it without assistance
- 2. A lot of assistance
- 3. A moderate amount of assistance
- 4. A little assistance
- 5. No assistance

At this stage the therapist should complete his/her view without sharing this with the participant.

Appendix 32. Semi-structured data – Case R

Month	Jan 03	Feb 03	Mar 03	Apr 03	May 03	Jun/Jul 03
Rehabilitation phase	Active rehabilitation			Discharge	Post discharge/ Outpatient follow -up	
Relationship with mother And family		Admits that mother is person he trusts most Parents comment that team trying to get rid of him			Acknowledges his mother has strong influence	Outbursts – anger and frustration at parents treating him 'like a young child'
Теат арргоасһ	Team decision not to collude with unrealistic goals	Team stressing need to concentrate on 'here and now'				Encouraging less dependence upon team
Emotional status	Euthymic		Mother: he is excited about discharge 'a boost'	Feels more confident		Volatile – dissatisfaction with slow rate of recovery
Fatigue	Mother: pre-morbidly viewed tiredness as weakness to be ignored		OT: voluntary work in rehab shop made him accept advice re: fatigue (to sit down when tired)			

Appendix 32. Semi-structured interview data – Case R

Month	Jan 03	Feb 03	Mar 03	Apr 03	May 03	Jun/Jul 03
Rehabilitation phase	Active rehabilitation			.Discharge	Post discharge/ Outpatient follow	
Awareness in relation to:						
- Difficulties focusing on task in hand		Physio: taking part in research has made him focus more in in therapy				Acknowledges difficulty with time-keeping – at local gym
- Driving			'Bravado' about driving but anxious when given chance to be tested (OT)			
- Returning to Saturday job			OT: rationalises – 'won't go back to work so soon as busy with therapy'	2-hour trial in sports shop	Continues with part-time work	Continues to work part-time
- Resuming university		Admits (to mother) that he can't return to university this year				
- Relations with girls of his age			Admits saying 'silly things' to girls. Upset that team said he had been inappropriate with female staff		Admits he is like 'a bull in a china shop'	Feels he thinks before speaking to girls of his age

Month	Jan 03	Feb 03	Mar 03	Apr 03	May 03	Jun/Jul 03
Rehabilitation phase	Active rehabilitation			Discharge	Post discharge/ Outpatient follow -up	
						He is more demanding with therapists 'realises from their reactions'
- Other			Moves timeframes back when realises he won't achieve targets he has set for himself (OT) Comments he is more understanding about others with disabilities now			
Factors affecting disclosure of awareness (identified by third parties)		Physio feels uses questions as avoidance strategy in therapy Mother states that he coped previously by proving others wrong				

Appendix 33. Semi-structured interview data - Case G

Timescale	Oct/Dec 02	Jan 03	Feb 03	March 03	April 03	May 03	June 03
Key events/circumstances	Out- patient	Obtains job against advice of rehab team Will work in same complex as his father though different office Working away from home but returning at week- ends	Father works away from usual workplace for one week Snowed in one weekend – so at home for only a few hours End of probationary period – not successful in interview to make job permanent	Father goes abroad to work at short notice and indefinitely G at home for full month, is planning holiday in Greece with money he has saved in his job	Fails second job interview Goes alone to Greece on holiday for 2 weeks	Obtains another temporary job for same organisation	In work Father has returned from working abroad
					G is un- employed		

Timescale	Oct /Dec 02	Jan 03	Feb 03	March 03	April 03	May 03	June 03
Social skills deficits reported by mother	Tactless	None	None	None	None	None	None
	Interrupts and doesn't know when to stop when they (parents) have friends around						
	Doesn't pick up cues that others are tiring of him or don't want him there						
	Has to be the centre of attention						
	Asks embarrassing questions and makes embarrassing comments						

Appendix 33. Semi-structured interview data - Case G

Timescale	Oct/Dec 02	Jan 03	Feb 03	March 03	April 03	May 03	June 03
Awareness in relation to social skills deficits	'He has been spoken to about his lack of social graces. He seems to understand what is said but he just expects others to pick up the pieces'						
Factors possibly implicated in improve- ment in social skills (as identified by G's mother)		He was naturally the centre of attention at the weekend – as it had been his first week at work He is responding better to a more disciplined atmosphere at work Feeling better about himself now he has a job	'He's got better' he seems more confident/acting more his age — perhaps work fulfills his need for attention He managed fine when his father was away (usually sees him each evening)		Stayed positive Focused on holiday in Greece		Loves current job - given extra respon- sibility

Appendix 34. Semi-structured interview data – Case H

Timescale:	Early April 03	Late April 03	May 03	June 03	Beginning July 03
Rehabilitation Phase:	In-patient weekend leave began 2 weeks earlier	In-patient weekend leave continues	In-patient discharge	Approaching home visit with adaptations in place	Pre-discharge
Cognitive status	Short-term memory deficit Orientation varies Reduced attention to left side	Found lost in reception very close to ward entrance	Episodes of confusion at home (wife)		
Coping style	Physio: Avoidance by talking when finds things difficult	If challenged, becomes argumentative/ lashes out (wife/ physio)	Lashing out verbally at home if thwarted Accuses wife of being negative (wife) Focusing more on walking 'then life can start again, I'll do stairs, play golf'	'Devious' in excuses for not being able to do things – difficulty grasping golf club claimed he had always held it that way. 'You don't know about golf, I know about it.' When struggles with parallel bars says physio's feet are in the way	

Appendix 34. Semi-structured interview data – Case H

Timescale:	Early April 03	Late April 03	May 03	June 03	Beginning July 03
Notable events circumstances		Change of physio	Increase in use of 'innuendo' with female therapists. Adjusted well to change in physio Wife under pressure trying to sell house and buy bungalow Home visit at end of May	Trial of day centre and Headway – mid-June	As above, with discharge date set for mid-July
Confabulation	Claims never previously used his left side — unclear whether he believes this Confabulation has decreased steadily recently (physio)	Steep increase in argumentativeness/ confabulation: in hydro claimed, once again, that had never (pre-morbidly) used left side of body When challenged reluctantly admitted he had used left side of body 'but only for walking and clutch control – nothing else.' Excuses he uses are always external to him (OT/physio)	Increase in confabulation (wife)	Some comments still indicate lack of realism: 'look forward to the day when I can wake up and my arm is working again.' (Physio)	

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Appendix 34. Semi-structured interview data – Case H

Time-scale:	Early April 03	Late April 03	May 03	June 03	Beginning July 03
Emotional status	Presence of pain negatively affects mood (physio) Fear/anxiety results in being over- cautious (physio)	Steep increase in anxiety Admits that prospect of change in physio is very difficult Fears that change from large male physio to female will result in fall		More relaxed as home visit indicates that house can be adapted – no need to move Wife also very relieved about this	Emotional outburst on home visit – huge emotional impact – concrete evidence that house needed to be changed. Wife in tears H calmer later.
Self-awareness	Wife/OT/Physio report improved self-awareness since admission especially in past 2 weeks		By end of May has modified goals		
- Work - Of risk	Awareness of capacity to work fluctuates (wife) Doesn't foresee risk in relation to wheel-chair footplates Anticipation of hazards fluctuates (OT/physio)		Intermittently claims he is returning to work in July (wife)		Intermittent failure to anticipate risk results in arrangements for H never to be left alone at home

Appendix 35. Semi-structured interview data – Case A

Timescale	End of Jan 03	Feb 03	March 03	April 03	May 03	Jun/July 03
Rehab Phase	Early in-patient	In-patient		Planning for discharge	Discharge	Out- patient
Notable events	Refusing OT Will attend PT only	Now agrees to OT (applies self well to woodwork project) OT Disturbed sleep pattern affecting ability to do things Change of Medication Wife allowed to move to England from Pakistan	Financial pressures at home Team contributes to booklet linking therapy sessions to 'broader picture'		Psychology assistant leaves end of May	
Mood	Low	Low – but less so (OT) More aware he can do things, therefore more motivated (Brother)		Low in mood apparently frustrated that walking has not returned to pre-morbid level	Very low for 2 days, stayed in room at home. Later said he was upset that he couldn't do things as he had before (Brother)	

Appendix 35. Semi-structured interview date - Case A

Timescale	End of Jan 03	Feb 03	March 03	April 03	May 03	Jun/July 03
Rehab Phase	Early in-patient	In-patient		Planning for discharge	Discharge	Out- patient
Physical status	Marked ataxia all limbs/mobile with a frame Balance problems	Mobility improving	Improving — now mobilising with a stick	Continues to improve		Able to walk without aids Very ambitious to walk normally Tries to get you to say that every thing will be fine
Awareness:			?More insightful Told psychology assistant that therapy was was helping him	It is unclear whether his insight has improved or he is just expressing his thoughts more openly (psych. assistant)		
- Driving/work	Feels able but 'not allowed'	See below	Believes he could drive and confides his intention to do so (knows he is 'not allowed') under pressure to return to work — family finances? Appears to understand why he should not, but maybe he is just saying this to please the team			Feels able to drive but not allowed (A)

Appendix 35. Semi-structured interview date – Case A

Timescale	End of Jan 03	Feb 03	March 03	April 03	May 03	Jun/July 03
Rehab Phase	Early in-patient	In-patient		Planning for discharge	Discharge	Out- Patient
Awareness (cont/)						
- Walking		'Can't walk properly' would affect work ('getting in and out of car')	Not able to go shopping and do everyday things as before as not walking properly		Hopes to walk 'properly' by June	
- Speaking	Difficulty 'getting words out'	'Can't talk properly'				
- Laughing	Difficulty stopping laughter	Acknowledges on-going difficulty	Better able to control laughter			
- Cognition	Memory affected 'quite a lot' (A)				'Slower in head than before'(A)	
- Future	Certain of full recovery	Certain of full recovery	Uncertain of full recovery but not sure 'Speech possibly still affected'	Feels he will recover fully but unsure	Hopes to recover fully	Not sure about recovery
- General		Doesn't give much away (Physio) 'Can't eat or do anything like I used to'		Asks every week when he will recover, because of need for reassurance, or cannot cope with answers that are not concrete		

Appendix 35. Semi-structured interview data - Case A

Timescale	End of Jan 03	Feb 03	March 03	April 03	May 03	Jun/July 03
Rehab Phase	Early in-patient	In-patient		Planning for discharge	Discharge	Out- patient
Awareness (cont/)						
- Risk taking		Not following advice Fell on stairs – was told he needed supervision. Found walking around room without aid – told not to ? lack of awareness or rational decision (physio)	On day of home visit asked if he could walk home (approx. 4 miles) When asked if he thought he was able to do so he said no but that he would be able to, later that same day (physio)		Seemed aware that he couldn't run but asked if he could (physio) Demonstrates improved road safety (physio)	'People think think I can't be left alone at home'(A) Found by brother about to go for cycle ride in middle of night as he couldn't sleep (brother)
Unusual health beliefs	Believes he will recover by mere fact of being in rehab unit — therefore doesn't see need to attend OT	No unusual beliefs expressed ? related to change in medication (OT)	Confided alarm that hair was growing on his face (psychology assistant) asked psychology assistant for tablets to stop this. Some realisation that this was an odd request when explained to him			

Appendix 35. Semi-structured interview data – Case A

Timescale	End of Jan 03	Feb 03	March 03	April 03	May 03	Jun/July 03
Rehab Phase	Early in-patient	In-patient		Planning for discharge	Discharge	Out- patient
Unusual health beliefs (cont/)			Makes no distinction between different therapists/ disciplines. Calls psychology assistant 'Doctor' Expresses belief that the reason he is being discouraged from laughing inappropriately is that it 'annoys the team'			
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