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Health Psychology in Brain Injury Rehabilitation Services

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October 2006

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Acknowledgment.

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SECTION A

Preface

Section A: Preface

The work carried out in this portfolio was completed while working as a Health Psychologist in Training within a vocational rehabilitation service for adults with acquired brain injury. All pieces of work were carried out within this setting expect for the consultancy unit which was carried out within a pilot service delivered by an Adult Disability Team of a local Social Services.

Individuals with acquired brain injury often do not have full understanding of the nature, degree or impact of their deficits. One aim of rehabilitation is to develop this awareness in order that the individual can identify and achieve realistic goals. The focus of the first two research studies in this portfolio was to examine the relationship between awareness, mood and quality of life and to develop a model of the psychological impact of increased awareness, acceptance and adjustment in adults with acquired brain injury undertaking a vocational rehabilitation programme. Literature relating to treatment models and interventions to manage awareness and was used to develop a training package which was delivered to a vocational rehabilitation staff team. Further research investigated the changes in mood and health experienced by significant others of adults with acquired brain injury. The importance of provision of information and professional support for family members was highlighted. The benefit of psychosocial intervention for stroke caregivers, one population of family caregivers of adults with acquired brain injury, was investigated through systematic review.

Individuals with acquired brain injury attending vocational rehabilitation present with a range of health psychology needs including issues relating to fatigue, stress and chronic pain. The development of a group stress management-training programme, an individual stress management intervention to promote health gains and the introduction of a pain management programme are reported in this portfolio.

Vocational goals will not be realistic option for all individuals following a brain injury. However, there is a need for services to provide personal development and meaningful activity for these individuals. The delivery of consultancy services to a pilot, arts for health, project will be described.

The following sections reflect how I have developed and applied health psychology practice within services for adults with acquired brain injury.

Section B: Research

The research report includes three related research studies.

Study 1 is a quantitative study investigating the relationship between awareness, mood and quality of life in adults attending rehabilitation less than two years after injury, and more than two years after injury. The findings of this study indicate that anxiety, depression and lower quality of life are common in adults accepted for vocational rehabilitation. The degree of depression experienced was found to increase with time since injury up to two years and be sustained beyond two years. Individuals who were less than two years post injury, who reported greater awareness of their deficits, also reported higher levels of anxiety and depression indicating that reduced awareness continues to protect against low mood beyond the initial 6 month post injury period previously reported in the literature. These findings illustrate the dynamic nature of the relationship between awareness and mood and add to the existing literature by examining longer term implications.

Study 2 is a qualitative study, using the principles of grounded theory analysis to develop a theoretical model of the psychological impact of going through the stages of increased awareness, acceptance and adjustment while undertaking the vocational rehabilitation programme. The findings of this study indicate that while emotional distress can be experienced as a response to increased awareness of deficits additional factors act to moderate these mood changes and these additional factors also influence the experience of psychological distress in those who lack awareness. A theoretical model of achieving adjustment to the impact of brain injury through a process of increased awareness and subsequent adaptation to functional loss, including the changes to mood and health accompanying this process, was developed. Vocational rehabilitation was identified as facilitating greater awareness by providing opportunities to experience limitations through meaningful activities.

Study 3 is a further grounded theory study that aimed to gain in depth understanding of the changes in mood experienced by significant others of adults with acquired brain injury going through the adjustment process. The findings of this study indicate that significant others go through a process of coming to terms with the changes in roles and responsibilities that are experienced when a close family member or partner sustains a brain injury. Significant other perceive a burden of care associated with these changes. The degree of psychological distress related to this burden was found to be influenced by the emotional responses of the individual with brain injury and the degree of social support available. Significant others reported using a range of personal coping skills and open communication within the family in order to sustain a sense of health and well-being.

These studies develop the literature relating to awareness of deficits by indicating the longer term relationship between awareness and mood, providing insight into the experience of individuals undergoing adjustment following brain injury and identifying the factors indicated in increased awareness in those attending vocational rehabilitation. Few studies have taken a qualitative approach to understanding the experiences of significant others of individuals with brain injury and this study provides valuable insights into the needs of this population.

The implications of these studies can inform the development of intervention to promote awareness in individuals with brain injury and therapeutic approaches to manage changes in mood. The information and support needs of significant others are also highlighted and these findings can be applied to the development of family interventions, which may not only promote coping in the family member but may increase functioning in the individual with acquired brain injury.

Section C: Professional Practice

Teaching and training
Two training packages were designed and delivered. The first was designed to teach vocational rehabilitation staff about managing issues of awareness in adults with acquired brain injury. Evaluation of this training indicated that rehabilitation staff had gained greater understanding of the potential causes and models of self-awareness and the interventions and approaches to managing it and were able to apply this knowledge appropriately when working with clients with deficits of awareness. This training package has been developed to be delivered to new members of staff and to other professional groups working with clients who have had a brain injury.

A training package was also designed to teach adults with acquired brain injury attending the vocational rehabilitation programme about the nature of stress and to train them in the application of stress management strategies. The training incorporates understanding the nature of stress, an introduction to anxiety and anger responses and an explanation of why changes in anxiety or anger may occur after a brain injury. The training then progresses to introduce stress management strategies and to provide practice and feedback to support learners to adopt these strategies when appropriate. This training package expanded previous stress management programmes used within this setting by expanding the training from 12 to 24 sessions and by including more interactive, experiential training methods. This training package continues to be implemented within the vocational rehabilitation service.

Consultancy

The case study reports on the delivery of consultancy services within an arts for health project set up to provide an arts and crafts based activities group, with a psycho-educational approach, to adults with an acquired brain injury receiving support from a Social Services Adult Disabilities Team. This consultancy provided education, guidance and feedback to service users and supervision to workshop facilitators. The consultancy role also involved an evaluation of the functional, psychological and health gains of this pilot project. The findings of the evaluation were that overall participants perceived a positive impact of the project in terms of increased engagement and motivation, a sense of social and emotional support and increased independent functioning in terms of overcoming anxiety, using strategies to overcome cognitive difficulties and increased confidence. These outcomes were disseminated to the stakeholders in order to secure further funding to continue this novel and innovative pilot project.

Optional Units

The first case study describes the design and implementation of a stress management intervention to address the needs of adults with acquired brain injury attending a vocational rehabilitation programme. This intervention was delivered on an individual basis using cognitive behavioural techniques to promote behaviour change. Monitoring and evaluation identified that it had been successful in that the recipient was able to identify and successfully adopt stress management techniques had been achieved and health benefits were also reported. This stress management intervention model continues to be implemented and adapted to individual needs within the rehabilitation setting.

The second case study describes how a pain management intervention was designed to address the needs of adults with acquired brain injury who experience chronic pain and how an Assistant Psychologist was directed to implement this intervention. This pain management intervention is now offered as an individual intervention included in Rehab UK's range of services.

Section D: Systematic Review of literature

A systematic review was carried out to investigate psychosocial interventions for caregivers of survivors of stroke. The objectives of this systematic review were; to identify which psychosocial interventions have been tested for effectiveness in informal caregivers of survivors of stroke, to evaluate the success of psychosocial interventions in reducing the burden of caring for a stroke survivor and to identify which psychosocial approaches (e.g. counselling, cognitive behaviour therapy, problem solving training) are most effective in producing positive outcome for these carers.

The findings of this review indicate that interventions designed to target psychosocial outcomes in informal caregivers of survivors of stroke can lead to better family functioning and promote problem solving and may protect against the negative psychosocial impact of caring for someone with stroke. Such interventions may also improve independent functioning and prevent a decline in personal adjustment in the care receiver.

The clinical implications of this review would suggest that those working with survivors of stroke and their families should consider providing interventions for primary caregivers. Positive benefits can be produced by relatively short interventions that can be provided via the telephone and to more than one caregiver at a time.

SECTION B

Research

The process of increased awareness, acceptance and adjustment in adults with acquired brain injury attending vocational rehabilitation.

"The patient needs and deserves a time to place his or her tragedy into perspective and to construct their life not in spite of brain damage but in face of it" (Prigatano 1992)

It has been estimated that each year in the UK over 100,000 people are discharged from hospital with a diagnosis of head injury and at least 2000 of adults diagnosed with a brain injury each year will suffer serious impairments which remain with them forever (The Department of Health, 1998). Each year it is estimated that over 150,000 people in the UK have a stroke and that at any one time there are 250, 000 people in the UK living with disabilities, such as brain injury, caused by stroke (The Stroke Association, 2006). Many others experience brain injury as a result of, tumour, infection or other causes.

While most people who experience a traumatic brain injury make a good physical recovery (Ponsford, Olver & Curran, 1995), insult to the brain can cause a complex array of psychological changes, including cognitive deficits (which may affect attention, memory, visual perception, problem solving, abstract reasoning, information processing or planning and organization) emotional changes (including depression, anxiety, anger, lability or low self-esteem) and behavioural problems (including impulsivity, agitation or disinhibition). These changes have been found to occur after traumatic brain injury (Thornhill, Teasdale, Murray, McEwen & Penny, 2000), stroke (Hochstenbach, 1999), brain tumour (Weitzner, 1999) and infection such as encephalitis (Greve, Houston, Adams, Stanford, Bianchini, Clancy & Rabito, 2002). Following a brain injury the individual may not be aware of, or acknowledge, the range or severity of deficits they have acquired and this impaired awareness may persist for some time.

The nature of impaired awareness: Historical context

In 1881 Munk (cited by Blakemore 1977) reported that lesions experimentally produced in certain parts of the association cortex produced temporary *"mind-blindness"* in animals. That is the animals indicated that they could perceive objects, in that they did not bump into them, but did not exhibit typical reactions to the objects by expressing fear or attraction. The term agnosia was later developed to replace *"mind-blindness"*. Agnosia was used to refer to an impairment in recognition, secondary to a brain injury, that was not a result of primary sensory or motor impairment.

The term *anosognosia* meaning 'lack of knowledge of a disease' was later used to refer to a lack of awareness of hemiplegia (Babinski, 1914) in which the patient may not be able to move one side of their body and yet reports no impairment but has since been broadened to refer to 'apparent unawareness, misinterpretation, or explicit denial of an illness' (Bisiach & Geminiani, 1991). There is some evidence to suggest that an individual with anosognosia may demonstrate knowledge of their impairment on some level. Heilman (1991) gives the example of a woman who admitted that she could not move her limb but denied it was paralyzed.

Impaired awareness and rehabilitation

Prigatano (1999) states that 'disorders of self-awareness are common after many forms of brain injury, but they are poorly understood and managed'. Depending on the method of measurement 76-97% of patients with traumatic brain injury attending rehabilitation have been found to show some degree of impaired self-awareness (Sherer, Bergloff, Boake, High, and Levin 1998). Lack of awareness has also been identified in individuals who have experienced other acquired brain injuries such as stroke (Hartman-Maeir, Soroker, Oman and Katz 2003).

Individuals who have limited understanding of the nature, degree or impact of their impairments tend to overestimate their abilities, may be resistant to therapy and reluctant to learn strategies to compensate for their limitations. The ability to learn and use compensatory strategies has been shown to promote good functional outcomes (e.g. Carney, Chesnut, Maynard et al 1999). The implications of impaired awareness of deficits include impaired functioning, less vocational potential as well as strained interpersonal relationships (Sherer, Hart, Nick, Whyte, Thompson & Yablon, 2003) and in the long term can lead to financial hardship and social isolation. On the other hand, those who acknowledge their limitations, set realistic goals and actively engage in rehabilitation following acquired brain injury tend to achieve better outcomes (Berquist & Jacket, 1993; Deaton, 1986; Lam, McMahon, Priddy, & Gehred-Schultz, 1988).

It should be noted that the phenomenon of impaired awareness of deficits after brain injury is a complex one. An individual may show awareness in one area of deficit but limited, or no understanding, of other equally disabling difficulties. Research suggests that following traumatic brain injury awareness of deficits is generally more impaired for cognitive, behavioural and emotional difficulties and less impaired for deficits of physical functioning and basic activities of daily living (Fleming et al., 1998; Prigatano, 1996; Hart,Sherer, Whyte, polansky & Novack, 2004). However, cultural differences have been found in the nature of deficits reported (Prigatano, Ogano, & Amakusa, 1997; Prigatano & Leathem, 1993) and other factors such as pre-morbid personality and coping strategies (Weinstein &

Kahn 1955) and opportunity to experience deficits and to receive feedback (Dirette, 2002) may also have some influence on the development of self-awareness following brain injury.

The nature of impaired awareness of deficits: psychological or organic?

There is debate whether the nature of impaired awareness is psychological or organic in origin. Psychological theories emphasize the role of denial in the process of unawareness (e.g. Weinstein and Kahn 1955). Denial is typically thought of as a psychological defense mechanism that enables the person to avoid anxiety or grief that would accompany awareness. The use of denial has been identified in a range of medical conditions including coronary heart disease (Sirois, 1992) and cancer (Kreitler, 1999). While denial may provide a way of coping with the impact of ill-health, it has been found to be associated with delay in seeking treatment and increased health risks (Stenstrom, Nilsson, Stridh, NijmNyrinder, Jonasson, Karlsson & Jonasson, 2005). Levine and Zigler (1975) found that stroke patients displayed more denial than those with cancer and heart disease. They suggested that this reflected the greater threat to "sense of self" associated with brain injury. Weinstein and Kahn (1955) support the psychological origin of awareness deficits in their study of patients with hemiplegia (one-sided paralysis). They found that patients who exhibited anosognosia (verbal denial of hemiplegia) were more likely to use denial as a coping mechanism in other areas of their lives than those who acknowledge their hemiplegia.

Clinical experience suggests that following brain injury an individual may express denial in a number of ways. They may fail to report deficits and explicitly verbally deny their deficits when questioned, they may avoid activities and withdraw from environments in which their difficulties may be experienced, they may minimize the deficit, (accepting that there has been some change but not acknowledging its severity) or may misattribute the cause of difficulty. In a rehabilitation setting it is not uncommon for an individual in denial of their deficits to blame poor instructions given by therapists for their inability to complete a task adequately.

On the other hand, neuropsychological theories attempt to account for unawareness in terms of injury to specific brain regions either in relation to cognitive dysfunction or direct damage to the brain regions considered to be implicated in self-awareness and consciousness. The right hemisphere (Heilman, Barrett, & Adair, 1998) and frontal lobes (Schacter, 1990) have been often implicated in impaired awareness. Awareness deficits for physical, sensory or language functions are more common after right hemisphere or parietal damage, frontal lobe lesions are common for people with global awareness deficits whereas bilateral and multiple lesions were related to awareness deficits for behavioural limitations (Prigatano & Altman, 1990). The orbital frontal cortex is important in the perception of

stimulus that is novel. Damage to the frontal cortex may result in lack of awareness as the individual does not perceive changes in themselves because it is not recognized as being novel (Pribam 1987)

Mesulam (1985) proposed a 'heteromodal model' of human consciousness, based on the basic tenet that in order to achieve awareness the brain needs to process internal and external information at the same time in order to compare an internal representation of the desired outcome of a behaviour with feedback from the environment regarding the actual outcome of the behaviour. Mesulam (1985) hypothesizes that the heteromodal areas of the brain, able to integrate information from the external world with information that is received internally, include portions of the frontal lobes, anterior tips of the temporal lobes, inferior parietal lobe areas, the superior marginal gyrus and angular gyrus.

An alternative model, the Conscious Awareness System (CAS), is proposed by Schacter (1989). This model describes a central processing system that receives information from individual cognitive systems (e.g. memory, language, motor, sensory), which are analyzed and monitored in parallel. The CAS integrates this information and sends its output to the executive system, which then triggers an action. Schacter (1989) hypothesizes that damage to the CAS causes global unawareness of self and is located in the prefrontal brain region but that damage to the individual cognitive systems can cause them to become disconnected from the CAS leading to domain specific unawareness.

A further neuropsychological model is proposed by Stuss and Benson (1986) who suggest that disorders of self-awareness result from disruption to the executive control system. This model proposes a hierarchy of independent but interactive functions that coordinate complex intellectual abilities such as anticipation, goals selection, planning and organization, initiation, execution and self-regulation of goal directed behaviour. Self-awareness in terms of the ability to reflect upon thinking or action patterns is considered to be an important component of this hierarchy. It has also been suggested that other aspects of awareness such as self-regulation, motivation to change and strategy behaviour are also functions of the executive control system. (Armengol 1999)

Giacino and Cicerone (1998) suggest that the causes of unawareness are complex and may include a combination of cognitive, psychological and organic factors. While denial may be evident in some individuals with acquired brain injury who demonstrate lack of awareness of deficits, psychological defense and organic awareness dysfunction may co-exist. Individuals with awareness deficits due to organic causes may present similarly to those with psychologically motivated awareness deficits and careful assessment is necessary in order to identify an appropriate clinical approach.

Prigatano and Klonoff (1998) indicate difference in presentation between individuals with impaired self-awareness and denial. Individuals with impaired self-awareness of an organic origin tend to lack information about themselves, show confusion or little emotional response when given feedback, be indifferent to rehabilitation, tend not to increase awareness with feedback or time, often have deficits in high order functions (i.e. initiation, self-monitoring) and may not spontaneously initiate tasks but respond well to prompts and structure. Individuals with denial may show partial or implicit knowledge of their deficits, resistance and emotional reactions to feedback and rehabilitation, rationalize problems or indicate external explanations and may be unwilling to admit to problems pre-injury.

Models of impaired self- awareness

It is often observed that individuals may be able to describe accurately and in detail their brain injury related deficits but continue to behave and respond as if they do not experience these difficulties. Explanations of level of awareness have been developed to account for this phenomenon. Stuss (1991) suggests that self-awareness exist on two levels; the objective knowledge of the existence of one's deficits and the associated understanding of the implication of those deficits. In the Pyramid Model, (Crosson, Barco, Veloza et al., 1989) propose a three stage hierarchical model with development of one level of awareness a pre-requisite for the next level. The first level of 'Intellectual Awareness' refers to the understanding that a particular function is impaired. However, while the individual may be able to describe their deficits accurately, they may make little attempt to adapt their goals or behaviour in line with their impairments. The construct of intellectual awareness has been further developed by Fleming and Strong (1995) who identify three further levels relation to the individuals ability describe their deficits in relation to physical, cognitive, social and emotional abilities, their ability to report the functional implications of these deficits on everyday activities (e.g. work, leisure, driving) and their ability to state realistic goals and make accurate predictions about the future. It is suggested that intellectual awareness of deficits develops for most people within the first 6-12 months after brain injury (Godfrey et al., 1993).

The second level on the Pyramid Model is 'Emergent Awareness'; this refers to the ability to recognize the problem when it is actually occurring. Lack of emergent awareness may be mistaken for lack of motivation or denial especially as the individual may be able to describe appropriate compensatory strategies for their problems but are not able to recognize and implement these strategies when required. 'Anticipatory Awareness' is the highest level of awareness in this model and refers to the ability to anticipate that a problem is going to occur because of a deficit and to plan and initiate appropriate compensatory strategies accordingly.

This model has been extended by Malia (1997) to include cognitive, metacognitive, executive, psychosocial and acceptance issues. Within this model higher levels of awareness are associated with greater degree of acceptance, which in turn is related to increased self-esteem and personal happiness.

Toglia and Kirk (2002) highlight the limitations of the Pyramid Model of Awareness in that it does not explain how the levels of awareness work together or account for discrepancies in behaviour. They developed a Comprehensive Dynamic Interactional model. Within their definition of metacognition they describe two interrelated concepts; 'knowledge' which relates to stored knowledge and self-beliefs held prior to engaging in a task, and 'on-line awareness', which refers to the ability to accurately monitor performance during a task and to self-regulate, by changing strategies and adjusting performance in response to changing task demands. They suggest that preexisting knowledge and beliefs are based on repeated experiences over time and are relatively stable whereas on-line awareness varies with the task and the context of the situation and is relatively unstable. They propose this model as a dynamic interactive process between pre-existing knowledge, on-line awareness, skills domain, tasks and situations, depth of awareness, beliefs and affective state.

Treatment models

A range of methods of managing unawareness are reviewed by Sohlberg and Mateer (1989). Individual Awareness-Enhancing Programmes are aimed at increasing the individual's level of understanding and self-awareness. Approaches that focus on providing information and brain injury education to individuals with acquired brain injury have indicated some positive outcomes. Chittum, Johnson, Chittum, Guercio, and McMorrow (1996) and Zhou, Chittum, Johnson, Poppen, Guercio and McMorrow (1996) used a board game, Road to Awareness, in conjunction with individualized training packages to increase awareness for subjects with acquired brain injury. Onsworth, McFarland & Young (2000) demonstrated the effectiveness of a 16 week group programme that involved cognitive rehabilitation, cognitive–behavioural therapy, and social skills training to improve self-regulation skills.

Alternatively experiential exercises may be used to help individuals identify changes in their ability. A number of methods can be used to help clients experience and integrate knowledge about changes in functioning. Stuss (1991) describes a combination of methods including verbal self-regulation during multi-step tasks, explicit establishing of appropriate goals, visual cues posted in the surroundings and role-playing exercises.

More recently, Liu, Chan, Le and Hui-Chan (2002) demonstrated how self-regulatory training can be used during the relearning of lost functions in elderly individuals after stroke. The individuals selected

daily tasks that related to their pre-injury functioning and roles. The self-regulatory training involved initially showing a video of healthy individuals performing tasks, the individuals then attempted to perform the tasks themselves and were video taped, they watched the tape and were encouraged to identify problems, and then identify and practice solutions. Their findings were that each individual became more independent on each task they selected however this was a case study design (N=3) and no baseline data or control group to evaluate the effects of the intervention from normal recovery.

There is some evidence that situations that involve experiencing cognitive deficits in real life settings, meaningful to the participant, are most likely to influence their development of awareness; Dirette (2002) demonstrated the importance of increased awareness of cognitive deficits through participation in functional tasks in a familiar environment. In a critical incidents qualitative case study the perspectives of participants and rehabilitation therapists were examined in order to identify the events critical in the process of developing awareness.

Participants were reported to describe development of awareness as a slow process with occasional 'aha' moments where these moments where triggered by critical incidents linked to a comparison of current performance to pre-morbid performance on functional tasks. Participants did not report that clinical testing and discussions were critical in the development of awareness and reported that although therapists had told them that they had cognitive deficits they did not believe it until they tried to do functional tasks outside the rehabilitation setting. Participant and therapist perspectives tended to concur in relation to the cognitive deficits sustained and the compensatory strategies used. However, their accounts of the process of awareness differed in that therapists reported that they believed clinical testing and discussions about cognitive deficits were critical in the development of awareness whereas no participant reported these clinical experiences as critical in their development of awareness.

The author concludes that these results support the need for 'real life' settings to develop awareness and that rather than seeing the development of awareness as a pre-requisite for functional performance a more integrated approach may be necessary. However, they advise caution in using functional activities for increasing awareness and that the timing and structure of any intervention is important to avoid adverse psychological impact. It should be noted that in this study only three clients were interviewed, only intellectual awareness was examined and that the use of interview relied on participants memory of events which, as all participants reported memory problems, may have provided limited or unreliable data.

Dirette's (2002) findings support the tenets of the Self-Determination Model (SDM) proposed by DeHope and Finegan (1999) to integrate self-awareness of social skills deficits in the treatment of

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Ylvisaker et al (1998) distinguishes between low confrontation approaches that include negotiated assessment and self-assessment, comparison of performance on tasks without and then with the use of a strategy and self-monitoring systems in which the individual keeps a record of tasks to accomplish,

individuals with traumatic brain injury. The SDM model is partially based on the pyramid model of awareness and focuses on three main phases 1) repetitive and consistent education of individuals about the brain, brain injury, self-awareness and self-determination, (to develop intellectual awareness) 2) the practice of social skills in therapeutically managed 'safe situations' repeated consistently over time and including the use of an established 'social network' (to develop emergent awareness) and 3) the development of opportunities for natural consequences in the community using the community as the rehabilitative setting (to develop anticipatory awareness).

For individuals who exhibit severe unawareness that is likely to be of an organic origin, or for those with severe cognitive impairments, an educational awareness building approach may not be appropriate. For these individuals, procedural training and environmental support may be more effective. The goal of this approach is to maximize functioning regardless of whether a client acknowledges or understand his or her limitations. It is also suggested that addressing caregiver's beliefs and attitudes through caregiver training and education is an important part of any awareness therapy programme (Sohlberg, Mateer, Penkman, Glang & Tadis, 1998). Although caregivers do not share the organically based unawareness, they may experience lack of awareness due to psychological denial or may lack information because it has not been given at such a time or in such a way that they could process it.

In a literature review of treatment issues in the intervention of awareness deficits Lucas and Fleming (2005) identified the following factors as relevant to intervention for deficits of awareness; a positive therapeutic alliance, goal setting (supportive not directive), emotionally neutral tasks that present the right level of challenge and familiarity; consideration of whether likely benefits of therapy outweigh the potential emotional consequences and the role of neuro-cognitive, psychological and social environment factors.

Lucas and Fleming (2005) also consider the benefits of a key approaches to intervention. They suggest that education may increase the accuracy of self-ratings but may not generalize beyond the specific task. Other approaches that have been indicated as effective in the intervention with individuals with impaired self-awareness include task performance experiments in which individuals estimate their performance, complete a task and then reflect on their performance, during familiar activities (e.g. Ylvisaker 1998), behavioural approaches that can target behaviours without necessarily increasing the individual's awareness (Bieman-Copland and Dywan, 2000), group therapy (Ownsworth McFarland & Young, 2000a), individual counseling or psychotherapy and occupational assessments (Katz, Fleming, Keren, Lightbody & Hartman-Maeir 2002)

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There are a number of limitations associated with these methods of assessment of awareness of deficit. Questionnaire measures rely on the individual's ability to understand written questions wereas interview methods depend on the individuals ability to understand spoken questions and to verbalise their understanding of their deficits. Both methods only assess intellectual level of awareness. Allen and Ruff (1990) propose three factors that influence the accuracy of the patients self-reporting of deficits. These are awareness; this relates to cognitive factors and the individuals ability to attend to, encode and retrieve information, appraisal; whereby the individual compares their current self with the pre-injury self and disclosure which relates to the individuals willingness to report their self-perceptions to another person. Furthermore, evidence suggests that patient awareness varies with the assessment used. Gasquoine (1992) reports that questionnaires elicit significantly greater self-reports of sensory and cognitive deficits that did the free recall format. This may be due to problems with spontaneity, memory or lack of terminology available to patients.

Approaches that compare patient and significant other and/or clinical ratings assume that these are more accurate ratings that the patients. While significant others can make pre-injury comparisons and patients do tend to under report difficulties, significant others may also demonstrate some degree of denial or decreased awareness and these may be influenced by stress levels and fatigue, length of time since injury (Brooks and McKinlay, 1983), personality type (McKinlay & Brooks, 1984), and any concerns they may have about what information is safe to reveal to professionals (Krefting, 1990). Therapists' ratings may also be influenced by the degree of information they have about the patient, their mood, attitude toward the patient and their expectations of the patient's performance and the time available to consider their ratings.

Behavioural observation can be a useful alternative method of assessment of awareness. Fordyce (1983) in work with spinal cord patients found that while verbally they denied the permanence of their deficits they continued to participate appropriately in rehabilitation. Their behaviour therefore reflected an awareness of their problems. Prigatano and Klonoff (1988) suggests that the following behavioural observations can be used as indicators of different disorders of awareness: Flat or indifferent effect may be expected after parietal lobe damage. Individuals who become embarrassed when confronted with their deficits but who clearly do not understand what they have done to cause negative feedback may have an awareness problem as a result of orbito frontal lesions. Patients who become angry or withdrawn when confronted with their deficits may be experiencing denial. The advantages of behavioral observation are that they avoid reliance on verbal reports, which can be inaccurate, and examine real life performance and can capture on-line awareness. However, their limitations are that observations are limited to specific tasks and most approaches are not standardized although some are such as the Social Sills Assessment (Godfrey et al 1993) in which the individual is asked to initiate and

direct a conversation with a person they have not previously met for 5 minutes and the Awareness of Divided Attention Task (Cock, Fordham, Cockburn & Haggard, 2003).

Ylviskar & Szekeres (1989) emphasize the importance of assessing meta-cognitive processes in situ. Such methods include interview techniques to ask the individual specific questions about what they are thinking or what strategies they are using as they complete a task, analyzing the individual's self-talk by asking them to 'think aloud' while completing a task (Meichenbaum, 1986) and observing patterns of performance on a task for example by analysing the individual's ability to detect and correct their own errors on a task (Hart, Giovannetti, Montgomery & Schwartz, 1998). Toglia (1998) developed a Dynamic Interactional Assessment, which integrated three components: awareness questioning; asking the individual to predict their performance before a task and evaluate their performance following the task, cueing and task grading and strategy investigation. During the performance on task the clinician observes the individuals ability to self-detect and correct errors.

Abreu, Seale, Scheibel, Huddleston, Zhang & Ottenbacher, (2001) developed a behavioural rating scale based on the Pyramid Model of Awareness in which individual's were asked questions concenring four daily living tasks relating to Intellectual Awareness ('Are you aware of any changes in your ability to perform the following task since your injury', 'How well do you think you will do on the following task'); Emergent Awareness ('How well do you think you did on the task?') and Anticipatory Awareness ('How do you think your performance for each of the following might affect your ability to live independently, work and have fun?'

Crosson, Barco, Velozo, Bolesta, Cooper, Werts & Brobeck, (1991) recommend that assessment should include measures of cognitive (attention, memory, information processing, visual processing) and executive deficits planning, initiation, self-monitoring). Major difficulties in these areas indicate that the individual may not have the resources to fully understand the impact of a deficit on their functional skills. Assessment should also include measures of skills that influence acceptance such as coping skills, mastery, self-esteem.

Qualitative approaches aim to explore the individual's subjective experience. Approaches include ethnographic studies (Krefting 1989) descriptive case studies, critical incidents inquiry (Dirette 2002) and biography approach. Such approaches enable awareness to be explored within a social context and allows the generation of new theories through naturalistic enquiry and inductive analysis. The use of a combination of approaches may provide most clinically relevant information about different dimensions of awareness. Cock et al (2003) suggests that it may not be prudent to ask 'who knows best' but 'who knows what?'.

TableB.1: Summary of frequently reported interview and questionnaire measures of awareness

Questionnaire measures	Author	Method	Scoring	Validity /reliability
Patient Competency Rating Scale (PCRS)	Prigatano & Fordyce (1986)	Patient and significant other rate ease with which patient is able to perform functional activities	5 point Likert Scale 1='cannot do' 5=can do with ease	Test retest reliability r=.97 (patients); r=.92 (relatives) (Prigatano, Altman & O'Brien 1990) Internal consistency (Cronbach's alpha =.91 (patients); .93 (relatives). (Fleming, Strong & Ashton 1998) External validity to be established
Head Injury Behaviour Scale (HIBS)	Godfrey, Partridge & Knight (1993)	Patient and significant other rating on 20 behavioural items	4 point Likert scale	Preliminary reliability and validity study results encouraging
Change Assessment Questionnaire (CAQ)	Lam, McMahon, Priddy & Gehred-Schultz (1988)	Patient rating on 8 times from each of the following stages of change; Pre-contemplative, Contemplative and action	5 point Likert Scale 1=Strong disagreement 5=strong agreement	Internal consistency – Cronbachs alpha of 0.85 (pre-contemplation scale), 0.91 (contemplation scale) 0.92 (Action scale) (Lam et al 1988)
Awareness Questionnaire (AQ)	Sherer, Bergloff, Boake, High & Levin (1998)	Patient, significant other and clinician ratings on physical, cognitive, behavioural items as compared to patients abilities pre-injury	5 point Likert scale 1= much worse 5 = much better	Internal consistency Cronbach's alpha of .88 for both patient and family ratings Test rest reliabilities not reported
Clinician's Rating Scale for Evaluating Impaired Self Awareness (ISA) and Denial of Disability (DD)	Prigatano and Klonoff (1998)	Clinician's ratings on two checklists.	10 items and 10 point severity scale	Internal consistency and validity not established
Interview measures				
The Self Awareness of Deficits Interview (SADI)	Fleming, Strong & Ashton (1996)	Structured interview based on 3 level model of awareness	4 point Likert scale 0= no disorder of self awareness; 3 = severe disorder	Inter-rater reliability satisfactory
Self-Regulation Skills Interview	Ownsworth, McFarland & Young (2000b)	Assesses meta-cognitive and self-regulatory skills 3 factors awareness, readiness to change and strategy behaviour.		Sound interrater reliability and test retest reliability and concurrent validity established between SRSI factors and neuropsychological functioning

Choice of awareness assessment tool

For the purpose of this study the AQ was chosen as the preferred measure of assessment of awareness of deficits. The PCRS and AQ were both considered. A comparison of these two measures was conducted by, Hart, Nick, Whyte, Thompson, &Yablon (2003). They review earlier studies to identify that the degree of impaired self awareness as measured by the PCRS is associated with injury severity, number of intracranial lesions on CT scans and patient emotional distress and highlight that it has been used with TBI populations in the US, Australia, Japan, New Zealand and Spain. Degree of impaired awareness as measured by the AQ is also correlated with injury severity and is predictive of early employability and late employability outcome. These two measures were found to be comparable in a number of ways. Patients rated themselves as more capable than therapists regardless of whether the rating was compared to pre-injury function (AQ) or to a current competency scale (PCRS). Family ratings were between patient and therapist ratings but were significantly correlated with clinician's ratings for both tools while patient ratings were not related to therapist or family scores. For both scales the patient - clinician discrepancy scores contribute to a prediction of employability ratings, as measured on the Disability Ratings Scale, while patient – family discrepancy scores of neither scales contributed to such a prediction.

Brain injury and mood

Many people with acquired brain injury experience persisting psychosocial problems of decreased social contact, decreased leisure activity, unemployment, and marital and family discord (Morton & Wehman, 1995). Such psychosocial problems have been associated with the emotional sequelae of depression, social anxiety, loneliness, and low self-esteem (Garske & Thomas, 1992). A number of studies have shed some light into the time course of emotional adjustment following brain injury. Fordyce et al (1983) found that brain injured patients referred for neuro-psychological testing within 6 months of injury were less emotionally distressed than those referred more than 6 months post injury. Lezak and O'Brien (1988), in a study of males who had experienced closed head injury, found that they were more likely to report anxiety or depression between 7 and 12 months post injury after which the incidence of moderate to severe problems declined.

One explanation for this apparent deterioration in mood some time after injury is that emotional dysfunction occurs as the individual gains insight into the extent and significance of their physical, cognitive and social deficits. While symptoms may decline they persist in some individuals for many years, Dikmen, Bombardier, Machamer, Fann & Temkin (2004) found that rates of moderate to severe depression following TBI ranged from 31% at 1 month to 17% at 3 to 5 years. They also found little

relationship between severity of injury and depression but did find that pre-injury factors of lower level of education, unstable work history and alcohol abuse predicted depression following TBI. The nature of cognitive difficulties have also been found to be related to level of depression following brain injury with impaired working memory, processing speed, verbal memory and executive functions implicated (Rapoport, McCullagh, Shammi & Feinstein et al 2005).

In a stroke sample 28% were found to experience generalized anxiety disorder within the acute stage with no decrease at 3 year follow up (Astrom 1996) and a systematic review of studies of depression indicated an average of 33% experience depression after a stroke (Hackett, Vapa, Parag, & Anderson 2005). The prevalence of depression is similar after both stroke and TBI with the order of 20-40% affected at any point in time in the first year, and about 50% of people experience depression at some stage (Fleminger, Williams & Evans, 2003).

Quality of life after brain injury

A number of studies have investigated quality of life in brain-injured populations. A relationship is indicated between quality of life and other measures of mood with lower quality of life ratings been found to be related to depressive symptoms (e.g. Vickery et al 2005).

There is some evidence to suggest that severity of initial injury influences subsequent perceived quality of life in people with traumatic brain injury with less severe injury predicting lower quality of life ratings (e.g. Dawson, Levine, Schwartz, & Stuss, 2000). However, the relationships between severity of injury and life satisfaction in the longer term may not be a linear one. Mailhan, Azouvi & Dazord. (2005) found that the lowest satisfaction scores were reported by participants with moderate disability, while individuals with severe disability did not significantly differ from the good recovery group.

Factors indicated in relation to brain injury and quality of life include employment, marital status and cognitive functioning (O'Neill, Hibbard, Brown, Jaffe & Sliwinski, 1998). Webb, Wrigley, Yoels & Fine (1995) found employment to be the strongest contributor of improvement in quality of life in a study of patients 12 years after hospital discharge. Difficulty returning to work, or driving, have also been found to be factors affecting the quality of life of following stroke (Carod-Artal 1999).

Literature also highlights the influence of coping skills and social support. Moore and Stambrook (1995) present a conceptual model describing relationships between coping patterns and quality of life outcomes following traumatic brain injury. They suggest that long lasting, behavioural, emotional, psychiatric and interpersonal after effects of traumatic brain injury may result in deficits in coping and in turn a reduced sense of subjective well being. Social support, in terms of family support, has been

found to improve quality of life in people with traumatic brain injury by reducing impairments, improving functional independence and increasing the likelihood of employment (Webb et al., 1995).

Studies have demonstrated the importance of locus of control (LOC) and attributional style in the adjustment to long term illnesses (see Strickland, 1989 for review) A number of studies have found a relationship between internal LOC and better outcomes in a variety of illness states (e.g. Affleck, Tennen, Pfeiffer and Fifield, 1987). Moore and Stambrook (1991) investigated the relationship between LOC and quality of life outcomes in 54 male patients with moderate or severe traumatic brain injuries who were on average 6 years post injury. They found no difference in LOC beliefs between those with moderate and severe brain injuries. They found a correlation between LOC scales and measures of quality of life in that high internal LOC and low external LOC were both correlated with improved quality of life. They conclude that factors such as LOC beliefs may play an important role in recovery from traumatic brain injury and that these factors may be amenable to intervention by rehabilitation. However, it is indicated that the concrete thinking common after traumatic brain injury may result in fixed cognitive styles and that individuals may lack the flexibility to adjust their beliefs readily.

The development of awareness and it's impact on mood on individuals with acquired brain injury

Research suggests a positive correlation between increased self-awareness and greater risk of experiencing emotional distress in individuals who have experienced traumatic brain injury with individuals who overestimate their abilities (relative to staff ratings) generally reporting less emotional distress (Prigatano and Fordyce, 1986; Ranseen, Bohaska and Schmitt, 1990; Wallace and Bogner, 2000; Noe, Caballero, Villodre, Sanchez, & Chirivella 2005).

There is some evidence that an association between self-awareness and mood is indicated for some time after the injury. Godfrey, Partridge and Knight (1993) carried out a study of groups of traumatic brain injury (TBI) subjects 6 months, 1 year and 2-3 years post injury and compared these with an orthopedic control group. They found that at 6 months post injury subjects tended to under report behavioural and neuropsychological problems and over estimate social skills. At 1 and 2-3 years post injury subjects reported significantly more behavioral impairments and higher levels of emotional distress than a control group of orthopedic patients. This is supported by Fleming, Strong and Ashton (1998) who, at 1 year post injury, found a relatively greater motivation to change and more emotional distress among a high self-awareness group. These findings suggest that the return of insight is associated with increased risk of mood disorder.

It is often hypothesized e.g. (Sherer 2002) that individuals with greater self-awareness of deficits achieve better functional outcomes, in terms of community integration or vocational outcome, as a

result of their enhanced motivation to comply with treatment and adopt compensatory strategies. Ezrachi et al (1991) found that level of awareness was the best predictor at admission for vocational status six months after hospital discharge. A trend toward an increased likelihood of return to work amongst those who underestimated their abilities than those who overestimated them was found by Cavello et al (1992) and a significant relationship has been fond between acceptance of disability and work status.

Lam, McMahon & Priddy & Gehred-Schultz, (1988), in a sample of 45 traumatic brain injury patients, used the Change Assessment Questionnaire (CAQ) to identify 3 groups; a Pre-contemplation group who denied deficits, and Ambivalent group who had mixed feelings about their deficits but reported some readiness to change and a Participation group who had awareness of their deficits and were actively trying to change. They found a significant difference between these two groups in relation to performance in treatment with the Pre-contemplation group having the worst performance in treatment, and the Participation group the best performance in treatment. Hoofien, Gilboa, Vakil and Barak (2004) examined the relationship between level of awareness of cognitive deficits and functional outcome among a sample of traumatic brain injury patients. They found that awareness was significantly related to psychiatric symptomatology and partially associated with behaviour disturbance and daily functioning but was not related to vocational outcome. Individuals with traumatic brain injury who overestimated their cognitive abilities were found to function worse on most measures expect for vocation than those who did not overestimate their abilities.

However, evidence is mixed and some studies fail to support this hypothesis e.g. Fleming et al (1998) found no significant difference in outcome between high and low self-awareness groups at one year follow up. One explanation given for this is that in the high self-awareness group depression formed a feedback loop influencing motivational state, which led to a reduction in positive coping behaviours. In an earlier study Fleming and Strong (1997) identified three subgroups of adults with acquired brain injury related to awareness and outcome. The largest group consisted of individuals with good self-awareness and high levels of emotional distress, likely to be caused by their awareness of deficits. These individuals had poor functional outcomes. The second largest group consisted of individuals with low awareness and poor functional outcomes and it was concluded that poor outcomes were related to an inability to acknowledge problems and make the necessary compensatory changes. A smaller group of individuals with 'good recovery' in terms of good awareness and good functional outcomes was identified. However, these individuals did not appear to have profound cognitive deficits or reduced executive functioning. The authors concluded that low deficit awareness and high deficit awareness with associated stress both result in poor daily functioning.

These conclusions are discussed by Martelli, Zasler and Pickett (2000) who suggest that, over time, the high self-awareness group may work through their emotional distress and their high involvement in rehabilitation may begin to show results. The complex relationship between self-awareness and mood is discussed by Fleminger et al (2004) who hypothesize that, while greater insight over time post-injury may be associated with greater depression, changes in mood may result in altered awareness.

Adjustment following brain injury

Literature relating to the adjustment to disability suggests that individuals work through a number of stages similar to a grieving process. Horowitz (1983) presents a model of adaptation to sudden physical disability, which includes the following phases of recovery: outcry, denial, intrusiveness, working through and completion. The grieving process outlined in Kubler-Ross (1981) work on death and dying include the stages of denial, anger, "why me" depression, bargaining and ultimate acceptance of loss. Langer (1995) relates that during the grief process future goals and aspirations may be destroyed and what is 'known' about the present challenged and replaced by anxieties for the unknown future with depression a frequent response to multiple losses. However, while emotional distress is indicated in the early stages of this adjustment, it is suggested that if this process is negotiated successfully emotional adjustment or 'completion' is reached.

Kerr (1961) suggests that the ultimate goal of adjustment to disability is to not look on the disability as 'bad' but to achieve a position where the disability can be looked on as 'different'. The way in which an individual adapts to and represents their injury may be influenced by a number of factors including the nature of brain pathology (i.e. the severity and location of injury); the meaning of the disability as determined by pre-morbid experiences, personality and values and the milieu or environment in which the behaviour is elicited or observed (Prigatano and Weinstein, 1996). Ben-Yishay, Lakin, Piasetsky, Ross, Silver, Zide & Ezrachi, (1985) has described the stages of the rehabilitation process through which the individual may achieve adjustment as engagement, awareness, mastery, control, acceptance and identity. The individual must negotiate these stages in order to achieve a new identity and a meaningful life as someone with a disability.

Godfrey, Knight and Partridge (1996) proposed a stress-appraisal-coping (SAC) model of emotional adjustment to chronic illness including TBI. "The SAC model hypothesizes that individuals experience emotional distress when they appraise their environmental demands as exceeding their personal and socially available coping resources" (Godfrey, Knight & Partridge, 1996). They identify that stress is an expected response to the, often devastating, impact of brain injury on the individual's lifestyle, plans, goals and values and that this stress may be expressed through depression, low self-esteem, and

defensive denial. They indicate that in order to achieve a reasonable quality of life following traumatic brain injury the individual must achieve healthy adaptation on the following three levels: a) Somatic Health, affected by psychobiological stress reactions, harmful coping behaviors, and a lack of adaptive behaviour b) Morale and Life Satisfaction - which required adaptation to the impact of the TBI on lifestyle, self-esteem and the patient's outlook on life and c) Work and Social Living- which may require a radical change in behavior and activity if the TBI is extensive. Social support was identified as a crucial prerequisite for healthy adjustment to traumatic brain injury, which is often lacking for many traumatic brain injury patients.

Individuals who look for a positive explanation for a traumatic event tend to demonstrate improved psychological adaptation (Thompson 1985). Jannoff-Bulman (1992) indicate that individuals may use various strategies in striving for emotional stability including comparisons, self-blame and transforming the experience. Some seek conformation that 'it could have been worse' by comparisons with others less fortunate, self-blame may be adaptive when the individual confronts their role in the tragedy but separates their behavior form the self as a person, Transforming the experience relates to the ability to view the event as purposeful and learning valuable life lessons in the process. Curran, Ponsford and Crowe (2000) investigated coping strategies in relation to emotional adjustment in individuals with TBI compared with participants who had sustained serious orthopedic injuries. They found that coping strategies characterized by worry, wishful thinking and self-blame were associated with higher levels of depression and anxiety in both groups. Strategies focusing on problem solving and having a positive outlook were related to lower anxiety levels. Few differences were found between traumatic brain injury and orthopedic groups.

The attitude of the individual toward disability may be relevant to their acceptance of their acquired disability following brain injury. Snead and David (2002) found significant correlations between measures of positive regard for other's disabilities and one's acceptance of disability, higher health status and community integration. Qualitative approaches have investigated the experience of living with and adjusting to an acquired brain injury. Jumisko, Lexell and Soderberg (2005) used a phenomenological hermeneutic method to investigate the meaning of living with moderate or severe traumatic brain injury by interviewing 12 participants who had lived with TBI for 4-13 years. Their study indicated that people with traumatic brain injury had 'lost their way', this included experiences of waking up to unknown, missing relationships and experiencing the body as enemy and struggling to achieve a new normalcy. These experiences were reflected in the responses of recovering the self, wishing to be met with respect and finding a new way of living. It was highlighted that participants reported feeling alone in their suffering and felt they needed more support from healthcare professionals. However, there is often a lack of appropriate support programmes available to support

individuals through their coping and adjustment after discharge from hospital (Delmonico, Hanley-Peterson & Englander 1998).

The relationship between mood and health after acquired brain injury

The link between emotion and ill health has long been established in terms of models of stress (e.g. Cannon 'fight or flight' theory 1932) and it is recognized that stress can effect the health of an individual via both behavioural (Krantz, Glass, Contrada & Miller, 1981) and physiological changes (Kiecolt-Glaser and Glaser 1986).

Access to health care may also have an impact on the physical health of individuals following brain injury. In a sample of individuals with spinal cord injuries lack of access to health services were found to be associated with experiencing secondary conditions (Beatty & Bingham, 2002). Participants who did not receive basic health services including primary and specialty care every time they were needed within the first year post-injury were more likely to report the presence of a range of health issues including, ulcers, urinary tract infections, spasticity, contractures and osteoporosis in the second year. Participants who did not receive physical rehabilitation services every time they were needed in the first year were more likely to report experiencing spasticity and contractures in the second year.

Hodgkinson, Veerbangsa, Drane and McCluskey (2002) documented service utilization by people with traumatic brain injury at 18 months, 2-4 years, 6-9 years and 10-17 years post injury and identified that there was only a moderate decline in service use over time and that the use of medical and allied health services remained high in all four groups. Severity of injury, physical and cognitive disability and psychosocial disability were all predictors of service utilization. Psychosocial disability was strongly associated with ongoing service utilization and it was concluded that this may be a better predictor of service use than physical and cognitive disability alone.

Man, Le, Tong, Yip, Lui & Lam (2004) investigated mood perceived quality of life and satisfaction with health services in individuals with brain injuries in Hong Kong. They identified that the lowest quality of life scores were obtained in the domains of material well-being, place in community and productivity. People whose injuries had occurred relatively recently (less than 5 years) were found to have higher intimacy quality of life scores than those injured more than 5 years ago. Mood in terms of positive affect scores correlated significantly with overall quality of life scores. Individuals reported being satisfied with the services they valued as important and the most important services were reported as medical services, occupational therapy, physiotherapy, vocational counseling and social work.

Summary and Purpose of Study

Awareness of deficit following an acquired brain injury may be related to increased functional outcome. However, greater self-awareness may also be associated with greater psychological distress. While the initial stages of developing awareness may result in lower mood it is likely that over time, as the individual accepts and adjusts to their injury, mood will improve. There is very little literature on the longer term impact on mood of increased self-awareness.

One aim of rehabilitation is to support individuals to develop the awareness necessary to set and achieve realistic goals. It is unclear what factors best facilitate development of awareness but there is some evidence that awareness intervention can promote this process. However it is important to understand the emotional and psychological impact of increased awareness on the individual in order to develop a therapeutic rehabilitation programme and provide appropriate support in response to changes in mood.

In these studies the process of increased awareness, acceptance and adjustment in adults with acquired brain injury attending vocational rehabilitation was investigated. The aim of Study 1 was to examine the relationship between awareness, mood and quality of life in adults attending rehabilitation less than two years after injury, and more than two years after injury, in order to shed light on the dynamic nature of this relationship and to add to the existing literature by examining longer term implications.

The aims of Study 2 was to develop, through interview with a sample of participants, a model of the psychological impact of increased awareness, acceptance and adjustment in adults with acquired brain injury undertaking a vocational rehabilitation programme.

Setting

All studies were carried out within two Brain Injury Vocational Centers managed by a registered charity that provides assessment, training and development programmes to support people with disabilities to enter or re-enter the workforce. The vocational rehabilitation programme consists of 3 elements. Element A, Element B and Job Seeking. The aims of Element A are to rebuild basic work related skills and help the individual to identify appropriate vocational options. It is a 12-weeek, center based course that includes cognitive retraining, stress management, work-related socials skills training, vocational profiling, group projects and IT training. This element also includes a weekly brain injury awareness workshop to provide brain injury education and facilitate the individual's understanding of the effect of their brain injury and the impact of any deficits on their future goals.

The aims of Element B are to fine tune work related skills and help the individual make a final choice of occupation and be supported to achieve it. This Element includes a combination of continued center based training and supported voluntary work placements. These work placements support the individual to transfer strategies learned within the center to a real work environment. They also provide experiential learning of the impact of their brain injury related difficulties on their potential to return to work in their chosen job goal. The Job Seeking element supports the individual to identify suitable vacancies and to apply for competitive paid employment and takes place at the stage at which the participant has completed a work placement successfully.

Study 1

Design

A cross sectional survey design was used. Retrospective clinical data was extracted from medical records to examine the relationship between awareness of deficit and both mood and quality of life in adults with acquired brain injury categorized as either early post-injury (those who are no more than 2 years post-injury at time of data collection) or late post-injury (those who are more than 2 years post-injury at the time of data collection). Two years was decided as the dividing point as it is generally considered that spontaneous recovery continues to be made up to two years following a brain injury after which time recovery reaches a plateau.

Participants

Participants were individuals with acquired brain injury (ABI) attending the vocational rehabilitation centers between April 2002 and January 2006. Consecutive sampling was applied, whereby the files of all individuals enrolled on the programme, from the time that the relevant data began to be routinely collected for assessment purposes, were obtained. Data was collected from all records where the participant and the significant other had completed the relevant version of the Awareness Questionnaire and the participant has also completed the Hospital Anxiety and Depression Scale and / or the Toronto Quality of Life Profile.

In total 103 participants were identified as fitting this criteria. The age of participants ranged from 18 to 64 (M= 36.4); 79 respondents were male and 24 female. This is generally representative of the brain injury population; most estimates indicate a male: female ratio for traumatic brain injury (TBI) of 2-3: 1. All participants had an acquired brain injury and had acquired their injury between the ages of 13 to 63 years of age (M= 32.5).

The mean time in years between injury and enrollment on the programme was 3.93 years (range 25 weeks to 24.5 years). See Table B.2 for demographic characteristics of the sample. Medical records were searched for data relating to location and severity of injury. Reports of location of injury were available for 60 cases. Where records indicated injury to more than one area of the brain the main site of injury was recorded. The majority of participants had sustained damage to the frontal lobes (N=25; 41.6%). Duration of post-traumatic amnesia (PTA) is most commonly used as a measure of injury severity. PTA is characterized by disorientation in time, place and person, impaired attention and an inability to store and retrieve new information (e.g. Brooks 1984). PTA is generally measured from the point of the accident, including any period of coma, and is taken to end at the return of continuous memory.

On collecting data it was noted that PTA was not available for all participants but that in some cases Glasgow Coma Scale (GCS) was given. The GCS (Teasdale and Jennett 1976) was developed as a measure of the presence, degree and duration of coma. In order to maximize the number of cases in which severity of injury could be estimated a scale was used incorporating both a classification of PTA (Jennett and Teasdale 1981) and GCS score (Teasdale and Jennett 1976). It should be noted that where duration of PTA is not given but length of time in coma is, coma duration was used in lieu of PTA and therefore gives a conservative estimate of severity. See Table B.1 for classification of severity of injury.

Table B.2   Estimates of Severity of Injury based on duration of PTA or GCS score

PTA duration*	GCS	Severity
> 5 minutes		Very Mild
5 – 60 minutes	13-15	Mild
1 – 24 hours	9-12	Moderate
1 – 7 days	1-8	Severe
1 – 4 weeks		Very severe
> 4 weeks		Extremely severe

* or duration of Loss of Consciousness if length of PTA not given

Participants were grouped into those early (less than two years) post injury (n=50) and those late (more than two years) post-injury (n=53). There were no significant differences, when tested by chi-squared analyses, between these two groups on the demographic variables of ethnicity, gender, employment status at injury and severity of injury (which was further grouped into 'mild to moderate' and 'severe to extremely severe' to provide adequate number of cases in each cell). It was not possible to compare groups on location of injury due to the small numbers in most cells. Given the implication of the frontal lobes in impairment of awareness this variable was further grouped into frontal or non-frontal lobe damage and no significant difference between the two groups was indicated.

It is noted that there was a significant difference between groups on the variable diagnosis ($\chi 2 = 7.08$, df = 2, p <0.05). More participants in the late post-injury group had sustained a TBI whereas more participants in the less then two years group had suffered a stroke (CVA). A plausible explanation for this discrepancy is that adults acquiring a traumatic brain injury sustain a more severe brain injury and subsequently require a longer hospitalization and period of recovery before being ready for vocational rehabilitation. A significant association between diagnosis and severity of injury was found in this sample ($\chi 2=17.11$, df=2, p<0.001). Although no association was found between the early and late post injury groups and severity of injury this was close to significance ($\chi 2=3.81$, df=1, p=0.051). This discrepancy between groups will be considered when analyzing the results of this study.

Independent t-test analysis did not identify any significant difference between groups in mean age at start of rehabilitation (the time of data collection). However, the mean age at time of injury in the early post-injury group (M=36, SD = 11.17) was significantly higher (t = 3.04, df = 101, p<0.01) than the mean age at injury of the late post injury group (M= 29.17, SD 11.31). Again this may be explained by the difference between diagnosis between the two groups with TBI tending to occur at a younger age and CVA occurring more often in older age groups. The mean age of those who had experienced a CVA (M=40.4, SD=10.51) was significantly higher (t= 4.19, df=90, p<0.001) than those who had experienced a TBI (M=28.81, SD=11.23)

Table B.3: Sample characteristics of demographic variables

	Early post injury (n = 50)	Late post injury (n= 53)	Total sample (n= 103)
	Mean (SD)	Mean (SD)	Mean (SD)
Age	37.28 (11.56)	35.64 (10.84)	36.44 (11.17)
Age at injury	36.00 (11.47)	29.17 (11.31)	32.49 (11.84)
Years post injury	1.24 (0.40)	6.48 (5.17)	3.93 (4.54)
	n (%)	n (%)	n (%)
Gender			
Male	40 (80)	39 (73.6)	79 (76.7)
Female	10 (20)	14 (26.4)	24 (23.3)
Ethnicity			
White	38 (76)	46 (86.8)	84 (81.6)
Black	6 (12)	4 (7.5)	10 (9.7)
Asian	6 (12)	3 (5.7)	9 (8.7)
Diagnosis			
TBI	27 (54)	38 (71.7)	65 (63.1)
CVA	19 (38)	8 (15.1)	27 (26.2)
Tumour	3 (6)	2 (3.8)	5 (4.9)
Other	1 (2)	5 (9.4)	6 (5.8)
Severity	(n= 40)	(n=42)	(n=82)
Very mild to moderate	13 (32.5)	6 (14.3)	19 (23.2)
Severe to extremely severe	27 (67.5)	36 (85.7)	63 (76.8)
Location of injury (hemisphere)	(n=25)	(n=29)	(n=54)
Left	13 (52)	9 (31)	22 (40.7)
Right	8 (32)	14 (48.3)	22 (40.7)
Bilateral	4 (16)	6 (20.7)	10 (18.5)
Location of injury	(n=30)	(n=30)	(n=60)
Frontal	12 (40)	13 (43.3)	25 (41.7)
Non-frontal	18 (60)	17 (56.7)	35 (58.3)

confirmed its intended usefulness as an instrument to 'flag' or identify possible clinical cases requiring further assessment (Spinhoven, Ormel, Sloekers, Kempen, Speckens & van Hemert, 1997).

The Quality of Life Profile for Adults

Quality of life was measured using the Quality of Life Profile for Adults (QOLP) designed by The Quality of Life Research Unit within the Center for Health Promotion in the Department of Public Health Sciences, University of Toronto. This profile identifies nine areas of life in 3 domains; Being (Physical, Psychological, Spiritual), Belonging; (Physical, Social, Community), Becoming (Practical, Leisure, Growth). It is a 54 item questionnaire (6 for each of the 9 areas of life) with each of the 54 items being scored in terms of how important it is to the individual and also how satisfied they are with that aspect of their life. Each item is given a score between 1–5 with 1 being of very little importance, or satisfaction, and 5 being very high importance, or satisfaction. There are also subsections rating how much control an individual feels they have over aspects of their life and how many opportunities for change they perceive themselves to have.

A computer based version of the QOLP was used and a computer generated formula produce domain sub-scores and an overall quality of life score. The overall quality of life score only was recorded for this study. This score ranges between −10 and +10 with scores above 0 reflecting positive quality of life, and those below 0 representing negative quality of life. Overall, a score of >1.50 is considered excellent and scores of .51 to 1.50 indicate a very acceptable situation. Scores of -.50 to +.50 indicate an adequate situation, scores of -.51 to -1.50 are problematic, and scores of <.-1.50 are very problematic.

Internal consistency coefficients (Cronbach's alpha) have been calculated for QOLP scores within each domain and sub-domain. For Importance, all domain and sub-domain indices exceeded .70, except for Spiritual Being (=.68) and Community Belonging (=.62). For Satisfaction, all coefficients exceeded .70 (all but two sub-domains were >.80). The nine Control items were also internally consistent (=.87) as were the nine Opportunities items (=.92).

Procedure

Case files of all participants starting the vocational programme since April 2002 (London) and October 2003 (Birmingham) were checked to identify those which contained records of awareness data mood and quality of life data.

The awareness questionnaire was routinely completed by participants either at a pre-intake assessment day, which is held no more than two weeks prior to the start of rehabilitation, or within the first two weeks of the rehabilitation programme. The HADS and QOLP were administered during initial assessments carried out within the first two weeks of the start of programme. These assessments were carried out by, or under the supervision of, a psychologist or assistant psychologist familiar with administering these tools. Additional support was provided to participants who required help to read or understand the written items. Where participants had indicated an AQ rating of 'a little better' or 'much better' this was queried with the participant to ensure they had understood that the comparison to be made was between their current level of functioning and their level of functioning before their injury. In some cases participants indicated improvement since their injury; this tended to be due to changes in lifestyle. On completion of the AQ each participant was asked to identify a significant other, who knew them prior to their injury and whom they have retained contact with since their injury, and they were asked to give written consent for the family version of the Awareness Questionnaire was sent to this named individual

Analysis

Descriptive statistics and frequencies were calculated for mood and quality of life data. Correlation analysis was carried out using Pearson's r to investigate relationships between time since injury, measured in weeks, and scores on awareness, mood and quality of life measures. Differences between the mean scores of the early post-injury and late post-injury groups on awareness, mood and quality of life measures were investigated using independent t-tests.

To allow further analysis and more meaningful quantification of data HADS scores were classified within the "caseness", "borderline" and 'non-'caseness" scales for both the anxiety and depression subscales. Quality of life was quantified as either 'positive' (>0) or 'negative' (<0) based on QOLP score and awareness scores were quantified as 'higher' or 'lower' awareness using a method suggested by Sherer (personal correspondence 2004). Lower AQ scores indicate less discrepancy between participant and significant other rating and therefore indicate less impaired awareness while higher AQ scores indicate greater discrepancy and more impaired awareness. Those scores below the median split (median = 4.0) were considered to have greater awareness. Those scoring above the median where considered to have lower awareness.

T-test and chi-squared analysis was carried out to investigate differences in mood and quality of life between these two awareness groups. Analysis was also carried out separately between those scoring in the greater and lower range of awareness within the early post-injury group and those scoring in the higher and lower range of awareness within the late post injury group.

Equivalent data in previous literature was not available in order to carry out power analysis. It is noted that the sample sizes included in some of the analysis were small and sufficient only to detect a large effect size and therefore analysis may be subject to type II error.

Results

Mood and quality of life
HADS data was available for 87 (84.5%) participants. Of those who completed the HADS, 29.9% of participants scored within the 'caseness' range for anxiety with a further 28.7% scoring within the 'borderline' range. On the depression scale 21.8% scored within the 'caseness' range and a further 24.1% within the 'borderline' range.

Sixty participants (69%) scored within the 'borderline' or above range on at least one of either the anxiety or depression scales, 31 (35.6%) scored in the ''caseness'' range of, at least, one of these two scales and 14 (16%) scored in the ''caseness'' range on both scales. QOLP data was available for 83 (80.6%) participants. Of those who had completed the QOLP, 23 (27.7%) scored within the 'negative' (0 to -10 range).

Comparison of early and late post injury groups
In the early post injury group 22% of participants fell within the caseness range for anxiety and 12% fell within the caseness range for depression on the HADS. In the late post injury group 28% fell within the caseness range for anxiety and 24% fell within the caseness range for depression. No significant difference was found between the mean AQ score, HADS-A score, HADS-D score or QOLP score of the early post injury and late post injury groups. See Table B.3 for mean group scores.

Table B.3. Mean awareness, mood and quality of life scores of early and late post-injury groups

	Early post injury (n = 50)	Late post injury (n= 53)
	Mean (SD)	Mean (SD)
AQ Score	4.1 (9.1)	3.8 (9.6)
HADS-A	8.2 (3.9)	9 (4.6)
HADS-D	6.8 (3.8)	7.8 (4.4)
QOLP	1.3 (2.3)	1.8 (3)

Comparison between participants scoring within the greater and lower awareness range

No significant difference was found between those scoring in the greater awareness range and those scoring in the lower awareness range in terms of gender, diagnosis, severity or location of injury and time since injury, for the overall sample.

No significant difference was found between the mean HADS-D scores of the greater awareness group (M=8.23, SD=4.28) and lower awareness group (M=6.55, SD=3.84) and no significant difference was found between the mean QOLP scores of the greater awareness group (M=1.19,SD=2.77) and the lower awareness group (M=1.86, SD=2.49). However, the mean HADS-A score of the greater awareness group (M=9.64, SD = 4.05) was significantly higher (t=2.07, df=84, p=<0.05) than the mean score of the lower awareness group (M=7.77, SD 4.29).

A significant difference was also found between these two groups in terms of HADS-A "caseness" scale ($\chi 2$=8.2, df=2, p=<0.05) with noticeably more participants within the lower awareness group scoring within the 'non-caseness' range than those in the greater awareness group and more participants in the greater awareness group scoring within the 'borderline' or 'caseness' range than those in the lower awareness group. See Table B.4.

Table B.4. Number of participants within the greater awareness and lower awareness groups scoring within the 'non-caseness', 'borderline' and 'caseness' range of the HADS-Anxiety scale.
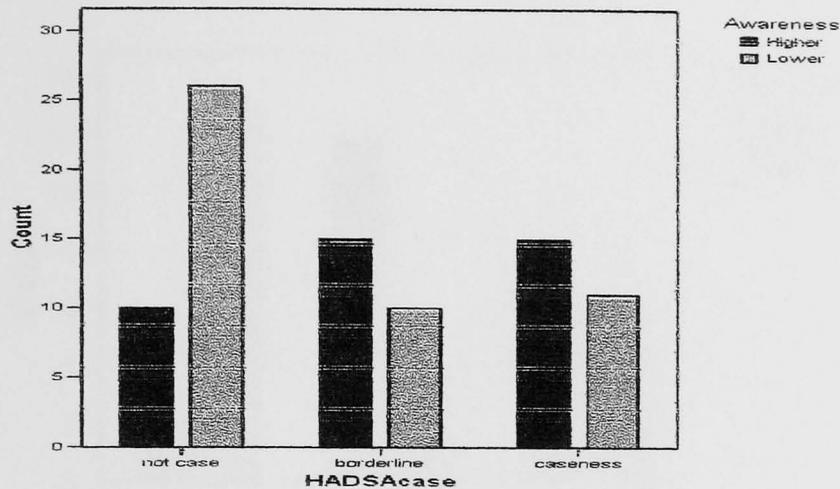
Analysis of early post injury group

The early post injury group was divided into those with greater awareness (below median split) and those with lower awareness (above median split). The mean HADS-Anxiety score was significantly higher (t=2.39, DF=40, p<0.05) in the greater awareness group (N=19, M=9.73, SD=3.22) than in the lower awareness group (N=23, M=7, SD =4.03). Similarly, the mean HADS-Depression score was significantly higher (t=2.56, DF=40, p<0.05) in the greater awareness group (N=19, M=8.37, SD=3.86) than in the lower awareness group (N=23, M=5.56, SD =3.23). No significant difference was found between the mean QOLP score of those scoring in the higher awareness range (N= 20, M=0.94, SD=2.4) and those scoring within the lower awareness range (N=22, M=1.68, SD = 2.17).

Chi-squared analysis revealed a significant difference between HADS-Anxiety category and level of awareness (χ2=10.18, DF=2, p=<0.01). More participants in the lower awareness group scored within the 'non-caseness ' range of the HADS Anxiety scale than those in the greater awareness group and more participants in the greater awareness group scored within the borderline range of the HADS Anxiety scale that those in the lower awareness group. See table B.5.

Table B.5. Number of early post injury participants within the higher awareness and lower awareness groups scoring within the non-caseness', 'borderline' and 'caseness' range of the HADS-Anxiety scale.
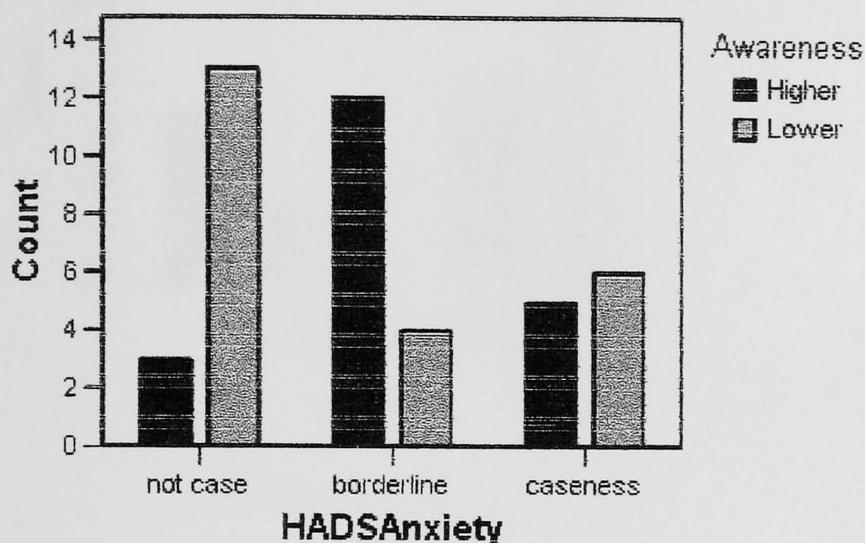
Correlational analysis revealed a significant positive relationship between time since injury and HADS-D scores in the less than two years post injury group (N=42, r=0.37, p=0.016).

Analysis of late post injury group

The more than two years post injury group was also divided into those with greater awareness and those with lower awareness. No significant difference in mean HADS-A, HADS-D or QOLP scores was found between those scoring within the high awareness range and those scoring within the low awareness range and no significant relationship was found between time since injury and HADS-D scores.

Chi-squared analysis revealed a significant difference between HADS-Depression category and level of awareness ($\chi 2$=7.25, DF=2, p=<0.05). However, as 2 cells within this cross-tabulation had an expected count of less than 5, categories were combined into 'caseness' or 'below caseness' (including borderline) range. The difference between these two categories was significant ($\chi 2$= 4.2, df =1, p=<0.05) with more participants in the higher awareness group scoring within the 'caseness' range than those in the lower awareness group and more participants in the lower awareness group scoring within the 'below caseness' range than those in the higher awareness group. See Table B.6.

Table B.6. Number of late post injury participants within the higher awareness and lower awareness groups scoring within the 'caseness' and 'below caseness' range of the HADS-Anxiety scale.
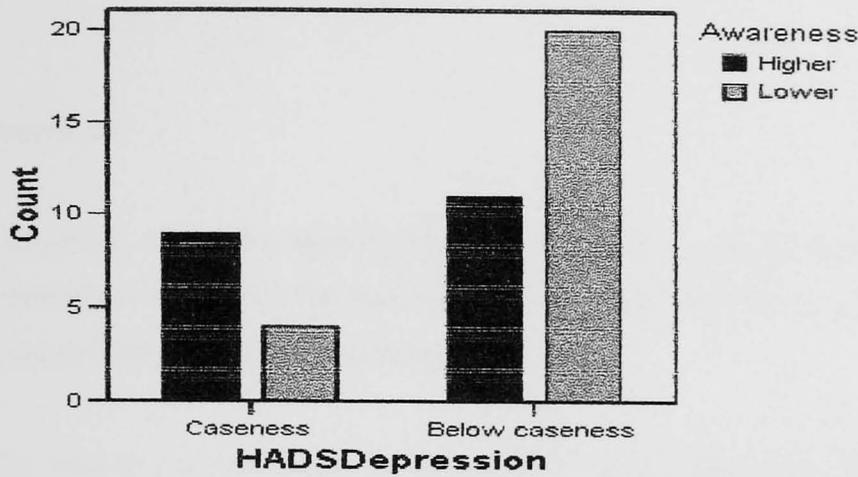
Study 2

Design

A qualitative methods design involving semi-structured interviews and grounded theory analysis was used. Sohlberg, Mateer, Penkman, Glang & Todis (1998) encourage the use of qualitative inquiry to examine awareness of deficits from a client's perspective and Dirette (2002) suggests that qualitative study allows the examiner to explore what is meaningful and helpful to the clients.

A semi-structured interview of approximately 45 –60 minutes were conducted with a sample of participants who had completed the educational and experiential elements of the vocational programme. This interview explored the experience of increased self-awareness of deficits following brain injury, within the context of vocational rehabilitation, and the changes in mood and health which accompanied this process (see Appendix A for Interview Protocol).

Participants

Ten participants agreed to take part in this study. All had completed Element A (the educational element) and Element B (the experiential element) of the vocational rehabilitation programme including attending at least one work experience placement of no less than four week duration. Of the participants 4 were female and 6 were male. Age at start of programme ranged between 23 and 48 years (M= 30). All participants were at least 6 months post-injury at the time of starting the programme.

Time since injury at start of programme ranged between 10 months and 19 years (less than 2 years post-injury N=2, between 1-2 years post-injury N=3, more than 2 years post-injury N=5). Eight participants had sustained a traumatic brain injury, one participant had a stroke and one other had undergone surgery to evacuate a brain tumour.

Procedure

Individuals who were approaching the end of the work placement stage of the programme were informed in writing of the nature of the study and invited to attend for interview and gave written consent if they agreed to participate.

The semi-structured interviews were carried out at the brain injury rehabilitation center at a time convenient for the participants. Participants were informed again of the nature of the interview and gave written consent to be interviewed and for the interview to be audio-taped for transcription purposes. The confidentiality of data was emphasized.

Due to the potential emotional nature of the interview participants were informed that the interview could be terminated at any time at their request and they were encouraged to indicate if there were any questions they did not feel comfortable to answer. At the end of the interview sources of additional support were discussed with the participant and written information was available.

As a psychologist working within the clinical team, the interviewer was familiar to participants. The participants were asked at the start of the interview to answer questions fully and to assume no prior knowledge by the interviewer. It is acknowledged that due to this working relationship this research was conducted within the context of a 'joint enquiry' within the 'participant observation' (Jorgensen, 1989) framework of research

Analysis

The interviews were tape recorded and transcribed verbatim and a grounded theory approach (Strauss & Corbin, 1998) was used for data analysis in order to move from providing descriptive accounts of participant's experiences towards the development of theory. Grounded theory involves the systematic gathering and analyzing of data provided by participants (Glaser & Strauss, 1967 and attempts to generate theories that are grounded in the participant's lived experiences (Bowers, 1990).

In Strauss and Corbin's (1998) method of grounded theory, analysis and data collection is carried out concurrently and theoretical sampling, whereby data is looked at selectively in light of the emerging theory, is applied. An abbreviated version (Willig, 2001) of grounded theory was employed for data analysis in this study. That is, the data was analyzed using coding and constant comparative analysis to develop themes, but further data were not collected as the study progressed.

This analysis began with open coding. Transcripts were read line for line and segments of the data labeled to begin to develop concepts reflecting what was being reported. During this process comparison was made between what was being said with what had been said elsewhere by that participant or by other participants. The recurrence of concepts across participants was seen to indicate shared meaning and these shared concepts were identified as the substantive codes underpinning the developing theory. These codes were listed and comparative analysis was carried out to identify similarities and differences between them.

At this stage themes began to emerge and codes that were found to be conceptually similar were grouped into categories. A discussion with my supervisor was held to review the developing themes and how they could be linked together to form a theoretical model. The connection between categories were considered further and grouped into higher-order categories with sub-categories within them. Axial coding was then carried out to identify how these categories related to each other on a conceptual level.

At this stage of analysis a core category of *adjustment* was identified to represent the central theme linking the other major categories of *increased awareness, mood changes, health changes* and *adaptation*. A visual model of this conceptual process was developed. The original list of codes was then re-evaluated to ensure that they represented a good fit with the proposed model and that all relevant concepts were included.

Results

The core category emerging from the analysis relates to how participants experienced the process of *adjustment* following their brain injury as they progressed through the vocational rehabilitation programme. Other major categories identified were *increased self-awareness of deficits, mood changes* accompanying increased awareness, *changes to health* and *adaptation to functional loss*. A model illustrating this process of adjustment and relationship between categories based on this grounded theory analysis is presented in Figure B8.

Increased Self Awareness

All participants reported an increase in self-awareness of some area of deficit during the course of rehabilitation. Participants reported having already gained some level of awareness of the impact of their brain injury prior to attending the rehabilitation programme. Physical and communication difficulties were most frequently reported as the main areas of deficit recognized at the start of vocational rehabilitation. Early awareness of deficits were reported to have occurred at the point of re-engagement in familiar functional activities, usually after discharge from hospital, and participants gave descriptions of specific events that highlighted these deficits.

During the rehabilitation process participants reported gaining greater insight into their cognitive deficits. Increased awareness of physical limitations, stamina and social skills were also reported by some participants.

A key factor in facilitating increased awareness was reported to be opportunities to experience functional changes and to learn from 'mistakes'. While a few participants reported having considered feedback from clinicians, regarding the implications of their brain injury, this was not generally described as a factor facilitating adaptation in terms of use of strategies to compensate for impairments.

Participants reported the need to experience changes for themselves, sometimes repeatedly through 'trial and error', before accommodating this information into their schema of self. These experiences were reported to be more pertinent if considered relevant to the individual in terms of their functional or vocational goals.

I learnt that when you are given an instruction just to try and write down as much as you can. The thing is I found that quite, I was quite embarrassed about going on about, you know 'hang on a second just let me write it all down', but when I did do that the results were always spot on and when I didn't do that I must just forget something and I'd think oh God I wish I'd written it down.

The experiencing of deficits promoted self-awareness of deficits by enabling the making of making of functional comparisons. Some participants reported comparing their performance on a task with their predicated performance on a task.

'if I was given some tasks to do on paper I could look at it and think I should be able to do this, by and large I did manage it, but it took a whole lot more effort than I thought it would'

Figure B.1: A model of adjustment to increased self-awareness of deficits in adults with acquired brain injury attending a vocational rehabilitation programme
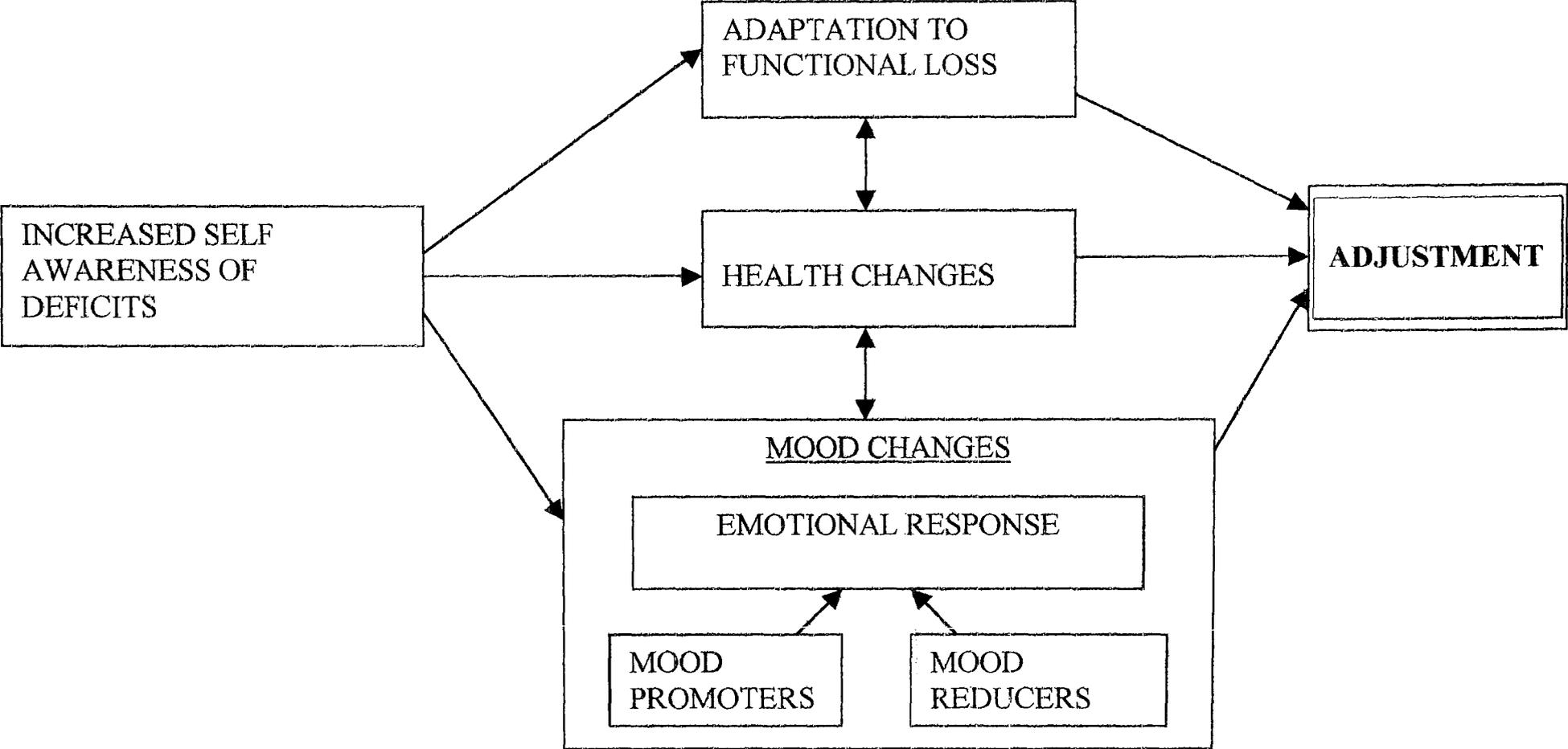
Measures

The Awareness Questionnaire

Level of awareness of deficits was measured using The Awareness Questionnaire (AQ) developed by Sherer et al. (1998a). The AQ consists of 3 forms; one to completed by the person with a brain injury, one by a significant other and one by a clinician familiar with the individual. On each form, the abilities of the individual to perform various tasks after the injury, as compared to before the injury, are rated on a five-point scale ranging from "much worse" to "much better." For the purpose of this study the clinicians rating was not included as, at the outset of the programme, objective data on which to base an assessment (e.g. neuropsychological assessment report) was often not available and judgments about a participants level of awareness would be based on the self report of the participant and / or significant other. It was considered therefore that a clinician's rating would not add any additional value.

Indices of the degree of impaired self-awareness are calculated by subtracting the total for the significant other ratings from the total for the participant self-ratings. These discrepancy scores can range from -68 to 68, although negative scores are reported to be rare. Higher discrepancy scores are associated with greater degrees of impaired self awareness. Reliability studies of the AQ have revealed internal consistencies (Cronbach's alpha) of 0.88 for both patient and family ratings. Test–re-test reliabilities have not been reported.

Hospital Anxiety and Depression Scale

Mood was measured using the Hospital Anxiety and Depression Scale (HADS), designed by Zigmond and Snaith (1983) to identify "caseness" of anxiety disorders and depression among patients in non-psychiatric hospital clinics. It is divided into an Anxiety subscale (HADS-A) and a Depression subscale (HADS-D) both containing seven items. Each item is scored from 0 to 3, and the HADS-A and HADS-D scores are the sum of the relevant item scores. According to Zigmond and Snaith (1983)each patient may subsequently be allocated to one of three 'caseness' categories for anxiety and depression, based on the individual final scores: 0–7 = non-case; 8–10 = 'borderline' case; and ≥11 = definite case.

Internal consistencies (Cronbach's alpha) of .90 for both the anxiety and depression subscales have been found (Moorey, Greer, Watson, Gorman, Rowden, Tunmore, Robertson & Bliss, 1991). Test–retest reliabilities over intervals up to 6 weeks generally range between .75 and .85, with correlations in the region of .70 having been reported for longer periods (Elliott, 1993; El-Rufaie & Absood, 1995; Herrmann & Buss, 1994; Visser, Koudstaal, Erdman, Deckers, Passchier, van Gijn & Grobbee, 1995). Attempts to use the HADS for diagnostic purposes in both medical and psychiatric populations have

Comparisons between current performance and performance on similar tasks earlier in recovery or with perceived performance of others were also indicated. Others compared their current abilities with their recalled pre-injury level of functioning.

'you kind of know what you used to be capable of'

Aspects of rehabilitation were identified as significant in facilitating this awareness process. These included rehabilitation exercises and task during the educational element of the programme and the work experience in the experiential element of the programme.

Within center based rehabilitation the cognitive retraining sessions were most frequently reported as promoting awareness. This training includes education about aspects of cognition often affected by brain injury, such as attention, memory or executive functions, and includes cognitive exercises to demonstrate and assess these cognitive functions with feedback from the tutor.

cognitive retraining was really useful because that kind of highlighted where I had problems and then I also had ways to work around them.

The use of behaviour monitor logs introduced in these sessions were also reported to increase awareness.

fatigue diary really helped because it made be realize what specifically makes me tired, which are very visual things, which I wasn't really sure about until I came here .

These exercises helped participants *'pinpoint'* the nature of specific deficits which was recognized as necessary in order to address and compensate for areas of difficulty.

(I) needed to know exactly what the problem was and how to deal with it ..it was a bit vague

However, the work placement was reported by most participants as key in understanding the functional implications of their brain injury related difficulties.

People say 'I can do it' but can you do it in the work placement, in that environment

By assessing their skills in a specific, relevant context participants reported greater awareness of their degree of functional limitation.

stamina was one thing that I never realized, I knew it was affected but I never realized to what extent

The work placement also promoted an acceptance of the need to adapt and use strategies to compensate for deficits and increased insight into the implications of their deficits on their long-term vocational goals.

'I think when I was finally sort of forced into a situation of working, when you have to work slightly more independently on new stuff, so you feel like you're a little bit more on your own, so therefore I start seeing the holes...I could see my faults and I had to deal with it'

Table B.8: Substantive codes included in the categories of increased awareness, characteristics of adaptive behaviour and characteristics of adjustment.

Increased awareness	Characteristics of adaptive behaviour	Characteristics of adjustment
Opportunity for experience	Independent strategy use	Recognition of long term implications
Learning from mistakes	Transfer of strategy	Acceptance of self
Trial and error	Seeking support	Managed mood
Comparison making	Confronting challenges	

Mood changes

All but one participant reported some change in mood in response to the impact of their brain injury. Within the main category of *mood changes* subcategories of *emotional response* and *factors influencing mood* were identified. Emotional response related to the psychological impact of increased awareness of deficits and a range of psychological reactions were identified. These emotional responses were divided into two further themes: *enduring*, occurring over a prolonged period of time and not related to a particular trigger and *situational*; occurring in response to a particular event or context.

Factors influencing mood related to additional factors that were reported to impact on the emotional response to increased awareness. These factors were identified as either *mood promoters*: factors that improved or protected mood and *mood reducers*; factors that contributed to emotional distress. See Table B.8 for list of substantive codes included within the sub-categories of mood changes

Emotional response: Enduring

Emotional responses to the impact of brain injury, which were enduring in nature, ranged from low confidence to significant levels of anxiety and depression. Of participants who reported more severe emotional responses most indicated that these began to occur prior to the start of rehabilitation. However, one participant, who started the rehabilitation programme less than one year post-injury, reported the acknowledgement of depressive symptoms during the vocational rehabilitation process.

I was just trying to be like, well this happened to me and I'm just going to go on, its fine. So I don't think it hit me until quite a few months after starting here.

This participant related her depression to gaining greater insight into the effect of her brain injury and understood this emotional response in terms of bereavement and loss of self.

I had these issues that I didn't really think I had .....and I suppose that was a quite scary realization ....and I think I did get very sad and depressed about it, that I had changed from the person who I was before, obviously I had changed and had these issues now and I was quite suppose angry and all those things you go through.....I was going through some kind of bereavement, you know who I was before and who I was now

Most participants referred to a sense of loss of the person they used to be when discussing the long-term psychological affect of acknowledging the impact of their brain injury.

you are also dealing with a person who is different and it is an unbelievable amount to handle as a person, so there's a lot to come to terms with.

The loss of functional abilities, loss of opportunities and goals and no longer being able to engage in activities previously enjoyed all contributed to the experience of low mood.

I can't be the person I was before which was always working, always out every night in the week and I can't do that.

Emotional response: Situational

Situational emotional responses were immediate or temporary changes in mood following a particular event or stage in recovery. Most participants reported experiencing frustration in situations when difficulties or limitations where highlighted.

> *If I'm doing something I want to finish it and do it correctly as well and I suppose if I couldn't do that then I suppose that is why I got frustrated*

> *I would get angry when, you know if you sat in a lesson and people would just be fiddling with their stuff really loudly and that would just drive me insane because I couldn't concentrate I couldn't switch off that background noise,*

Participants also reported feelings of anger following feedback they were not ready to receive and apprehension or anxiety when facing new experiences, for example starting work experience placement or approaching the point of returning to paid work.

> *I'm more nervous because it's like any job really. I am not too sure I can do it, that's what makes me nervous*

Situational responses also occurred in response to stages in recovery or rehabilitation. Some participants reported impaired mood at a point when speed of recovery slowed or plataued or when the gains made in rehabilitation were less observable.

You make all those massive leaps in the first sort of term or first element and then you kind of forget that you are still making, and that's when you get a bit down and it's like 'oh I'm still here'.

Mood Promoters

Activities that led to a sense of achievement were identified as mood enhancing. This included the opportunity to identify retained skills, develop new skills and apply strengths in a work placement. Participants generally reported the first module of vocational rehabilitation as having a positive impact on mood and building confidence as skills are learned and achievements are visible. The introduction of structure and a work like routine at the start of rehabilitation is also identified as mood promoting.

So my handwriting got better which in turn again my confidence boosted and then I found that
after the first semester I found that all around on every level I felt better about myself

Emotional support was important in maintaining psychological well-being. Some participants noted the importance of support from a significant other.

I suppose it made it easier having someone else....to speak to, to discuss all the fears and
actually have a dialogue about it, because without anyone else it is only left in my own head and I could
only see the negative

Some participants highlighted the benefits or receiving support from professionals and form rehabilitation staff who understood brain injury. Peer support and the opportunity to share experience with other people who had sustained a brain injury was also reported as a valuable.

I suppose being in a really supportive environment and being with fellow classmates.....
supportive of each other.....it helped, you weren't the only one going through that

Most participants reported using mood management strategies. These included applying stress management techniques developed through the rehabilitation programme, keeping active, and using exercise as a method of moderating mood. Two participants reported accessing external therapeutic support, in terms of Cognitive Behavioural Therapy to address mood issues during the course of vocational rehabilitation.

Mood reducers

Mood was negatively affected by situations leading to a sense of loss of autonomy, lack of social support and secondary stresses.

In general terms loss of autonomy was reported in relation to feeling that there was lack of certainty and lack of control about the future. These feelings were highlighted during the rehabilitation programme when a participant began to question the realism of a job goal they had been working toward or if they experienced a 'waiting' period for a suitable work placement to be found or for an employer to make a decision about the readiness of the individual to return to the job held before the brain injury.

Social isolation or reduced social contact was frequently experienced. The reasons given for this related to a number of factors including reduced confidence, difficulties with speech and

communication and removal from social network, when this was situated at work or educational establishment. One participant reported a cycle of poor mood and social withdrawal.

But the depression started getting so bad, I started, well I avoided all contact with my friends because I somehow felt ashamed, I felt embarrassed that I wasn't the same person with a disability

Secondary stresses or external pressures also contributed to low mood following brain injury. These included financial pressures, moving house, relationship breakdown and dealing with a legal claim in relation to the brain injury.

It is noted that within each participant's accounts an interplay between these sub-categories of mood change was related. All participants reported some situational emotional responses, however some did so in addition to more enduring and sometimes severe deterioration in mood. Most identified both factors that acted to protect their mood and factors that impacted negatively on mood. Usually these factors would exert their influence at different periods of time or stages in rehabilitation. However, some mixed emotions or conflict of feelings were reported whereby the participant acknowledged symptoms of impaired mood but also reported some positive emotions.

I would dwell on .... what had happened to me and it's really depressing and why did this happen. But then that went through periods with elation as well, kind of elation that I was alive and very lucky, I could have been so much worse and then I felt like well no actually this is very unfair

Table B.9: Substantive codes included in the sub-categories of the category of mood changes

Emotional Response	
Situational	**Chronic**
Frustration when experiencing limitations	Depression
Anger in response to feedback	Anxiety
Apprehension of novel situations	Low confidence
Factors Influencing Mood	
Mood Promoters	**Mood reducers**
Opportunity to achieve goals	Lack of autonomy
Structure regained	Social islolation
Emotional support	Secondary stresses
Mood management strategies	

Health changes

Most participants reported relatively good general health subsequent to their brain injury. However, some perceived a relationship between changes in their mood and their health and reported stress related illness. All participants reported adopting health lifestyles after their brain injury and most perceived a relationship between their health behaviours and their recovery, health or mood.

A number of examples were given whereby physical health issues were perceived to have been exacerbated by anxiety or stress factors associated with brain injury, such as fatigue.

I'm rarely ill but if I get anxious I have a difficulty with mouth ulcers which can be really quite severe

One participant attributed an increased risk of infection to the fact that he was not able to maintain a level of physical fitness achieved prior to his injury, due to reduced mobility.

I eat as healthily as I can and you know rarely I'm in pretty good shape I think considering what has happened to me but you know it's not a bit of how I was like beforehand when I used to play squash and that, so yeah my immune system is definitely affected.

All participants reported adopting healthy behaviours to promote better general health after their injury. The cessation of unhealthy behaviours such as smoking, drug use or alcohol were more extreme examples. However, changes to diet and the maintenance, or introduction, of an exercise regime was mentioned by all participants.

Well I go to a health club now, I go swimming, running stuff like that to keep healthy

These health behaviours were perceived as having contributed to physical or cognitive recovery after brain injury.

I think having a very good diet helped and also starting to do a bit of exercise and they said that made a massive improvement

if I was a chubby lad with no exercise then that's when there would be problems with the head injury

Nutrition and exercise were perceived as important in maintaining a stable mood and most described engaging in exercise specifically for the purpose of managing stress.

'and I run, ...if I feel, you know, a tiny bit low I know that if I do exercise then that will just make me feel better, so that has helped a lot'

Adaptation to functional loss

Following gains in self awareness of deficits participants reported making adaptive behaviour changes in response to their functional loss as a result of recognition of the need to compensate for limitations. One of the key characteristics of this adaptive behaviour was identified as independent strategy use. Some participants reported beginning to use strategies to compensate for brain injury related difficulties when these were introduced within the rehabilitation programme, or were suggested by a member of the rehabilitation team, but continued to do so independently.

The transfer of strategies from one environment to another was also indicative of adaptive behaviour as was the willingness to seek support and inform relevant persons, such as employers or colleagues of support needs.

The work experience stage in the rehabilitation programme was significant in facilitating the adoption of adaptive behaviours. One participant described compensating for fatigue in the work place by ensuring sufficient breaks.

I know that from being at (the rehabilitation programme) and the medical problems that I've had, I have to have an hour and that is it, ... a lot of people go 'oh you're going lunch again', and it's like 'whatever, I'm going lunch, see you later' and I'll come back. As long as I'm doing my job

Another participant described how the use of note-taking to compensate for memory difficulties was not used consistently within the rehabilitation programme but was effectively adopted in the work place.

So I could write notes on things that needed to be done specifically to the work placement, which was very useful as well, and a notebook which you are encouraged to use here, which I haven't really been using for the last few weeks, but yeah, in the work placement I used that and I plan to start really having a book you know all the time

Participants reported negotiation the adaptation process as one of confronting reality and attempting to overcome challenges. Some participants reported seeking out opportunities engage in activity experienced as difficult in order to practice and *'try and improve it'*.

All participants reported some aspects of adaptive behaviour by the time of interview, which took place at the end of work experience. However, one participant highlighted the transitional nature of progressing from increased awareness of deficit to the adaptation to functional loss.

if someone says to me 'you need a book' (notebook) then I agree with them but I'm just the kind of person that I just don't do it until I realize myself that I really must have a book. You see I still don't have a book but I know that I need a book. So I mean a few more mistakes and then I'll definitely just go and get a book.

During interview, participants referred to earlier stages in their recovery when they had been in denial of the full implication of their brain injury. They recalled avoiding situations in which a deficit may be highlighted, externalizing the cause of any difficulty experienced and resistance to using strategies. The process of moving from denial, through increased awareness to adaptation was identified as a gradual, fluctuating process in which adaptation to individual deficits may occur at different times.

Adjustment

This model illustrates a process of increased awareness, acceptance and adaptation to the impact of brain injury of participants attending a vocational rehabilitation programme as they work toward adjustment to the implications of their brain injury related deficits. Recognition of the long-term implications of brain injury related deficits, acceptance of self and managed mood are identified as key concepts in the achievement of adjustment following brain injury.

Recognition of the long-term implications was indicated were participants reported believing that current level of functioning was permanent and adaptive behaviours and strategy use would be lifelong changes. Acceptance of self involves the individual accepting that they are not the same person they were before their brain injury and coming to terms with their current strengths, weaknesses and lifestyle.

'on every level I felt better about myself and I was more accepting of myself, more accepting of what I am now...this is what I am now and it is still quite a lot'

When acceptance of self is reached some level of emotional adjustment is reported. While participants may continue to report some emotional response in relation to their brain injury, mood is generally stable, positive coping strategies are being implemented and some positive view is held of the future.

It's going to be a bit of a struggle. But then ....you know, I'm going to be optimistic about everything and I've been given a second chance if you like and I'm going to make the most of it and I think things are going to be difficult and I've just got to try and use strategies to overcome any issues I have, ...and I don't need to live that life that I was living before

These aspects of adjustment were not reported by all clients by the time of interview. Two participants described this stage of adjustment; these participants were four years and eight years post-injury. Other participants reported some aspects or acknowledged that they were not yet at this point. However, by time of interview the all participants reported general positive mood. This was generally described, as 'good and bad days' and negative emotional responses reported at this point in time were generally situational for example low mood reported in response to rejection from job applications or anxiety regarding beginning paid work. Where participants had reported clinically significant emotional distress these were described as improved by this point in the rehabilitation programme and only one participant was continue to receive additional external professional support with mood management.

Discussion

The development of self-awareness is an important task for vocational rehabilitation. However, if greater awareness of deficit is associated with higher levels of anxiety and depression, as previous literature suggests, a balance must be reached between supporting the development of the individual's understanding of their difficulties while minimizing emotional distress. The aim of this study was to examine the relationship between awareness, mood, quality of life and health in adults attending vocational rehabilitation in order to provide some indication of how this may be achieved.

The aim of the first study was to examine the relationship between awareness, mood and quality of life in adults attending rehabilitation less than, and more than, two years after brain injury to investigate changes in this relationship with time. In the second study a grounded theory approach was used to investigate the relationship between these outcomes, as an individual progresses through vocational rehabilitation.

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For participants starting vocational rehabilitation less than two years after their injury, higher levels of anxiety and depression were found in those who indicated greater awareness of their deficits than in those who indicated lower levels of awareness. This supports earlier findings that increases in awareness of deficits can results in a deterioration in mood. It is noted that it is rare for an individual to begin vocational rehabilitation less than 6 months post injury. This early post injury group included only one participant less than six months and therefore represents largely a 6-month to 2-year sample. As such, this eliminates those in the very early stages of recovery who are reported to experience lower levels of anxiety and depression (e.g. Fordyce et al 1983). This is also the stage when awareness is generally lowest (Godfrey, Partridge & Knight 1993). This study suggests that reduced awareness continues to protect against mood disorder in the longer term, up to at least two years post injury.

No relationship was found between awareness score and time since injury, indicating that the gains made in self-awareness after the first 6 months are variable in timescale. However, in the early post injury group longer time since injury was related to higher levels of depression. Increases in depression over this time may be facilitated by additional changes that have been found to relate to the experience of depression following brain injury such as reduction in contact with professional support (Ponsford 1996) not having returned to employment (Franulic, Carbonell , Pinto & Sepulveda 2004) and increased social isolation (Morton & Wehman, 1995). This is supported by qualitative data that indicates that while emotional distress can be experienced as a response to increased awareness of deficit and the experience of functional loss, additional factors act to moderate these mood changes.

Reduction in social contact was highlighted as a factor leading to deterioration in mood while emotional support and regaining structured activity acted to alleviate emotional distress. Li & Moore (1998) in a sample of 1,266 adults with disabilities in the US found that self-esteem and emotional support from family and friends played important roles in participants adjustment to disability. However, the tendency to seek out others for support when under stress has been shown to decrease under certain conditions (Buunk & Hoorens 1992). Charmaz (1983) also described how 'feeling discredited by others and unable to reciprocate social support or fulfill the obligations implicit in past role relationships are important factors in the suffering and consequent social withdrawal related to chronic illness'.

The role of secondary stresses, including relationship breakdown and financial pressures, common after brain injury add to the complexity of understanding mood changes following brain injury. It should also be noted that additional factors not investigated in this study may play also influence adjustment following and acquired brain injury. Skell, Johnstone, Schopp, Shaw & Petroski (2000) indicated that estimated pre-morbid ability accounted for more variance in distress following traumatic brain injury

than either level of cognitive functioning or indices of cognitive decline with individuals with higher estimated pre-morbid abilities reporting lower levels of distress.

Additional factors may also promote deterioration in mood in those with lower awareness. It is noted that although not significantly different, the mean anxiety and depression scores in those indicating lower awareness in the late post injury group were higher than in the early post injury group whereas the mean mood scores in those indicating greater awareness were relatively the same in the early and late post injury groups. It may be that the contributing factors indicated in maintaining low mood in individuals with greater awareness over time may also lead to a deterioration in mood in those who lack such awareness. There is evidence that long-term unemployment is detrimental to mental health (Jahoda 1982) and given that individuals who attend for vocational rehabilitation are those who have not made a successful return to work it may be expected that those who have been out of work for some time will present with poor psychological health.

While it is identified that at the outset of the vocational rehabilitation programme some individuals have greater level of self-awareness than others, qualitative data indicates that vocational rehabilitation promotes greater gains in awareness of deficits, particularly in relation to cognitive difficulties. A theoretical model of achieving adjustment to the impact of brain injury through a process of increased self-awareness of deficits leading to adaptation, with accompanying changes to health or mood was developed. It is suggested during vocational rehabilitation individuals with acquired brain injury develop greater self- awareness by experiencing limitations through activities that are meaningful and relevant to their perceived goals and that the work experience placement is important in offering these experiential opportunities.

This supports the view that awareness of deficit is developed through familiar functional activity real life settings, familiar or meaningful to the individual (Dirette, 2002). However, this presents a challenge for rehabilitation services in that they should adhere to the principal of 'first do no harm' and therefore protect against the emotional impact of failure. Opportunities to gain a sense of achievement was identified as a factor promoting mood, it is clearly important to find a balance between providing experiential learning about deficits with activities that highlight strengths or develop skills.

Increased self-awareness was reported to be achieved by participants by making comparisons of their current performance with a prediction of performance. This is consistent with Toglia and Kirk's (2002) model of awareness being dependent on metacognitive knowledge, including self beliefs, and 'online awareness' including the ability to self-monitor. The individual's self-beliefs on which their prediction is based may relate to their perception of pre-injury self, the expectations of their recovery, their

perception of their abilities in relation to others. Accurate self-monitoring is required if the individual is to accurately assess their current performance in order to make a comparison with their expected outcome.

Different aspects of rehabilitation are indicated in developing different levels of awareness as proposed within the Pyramid Model of awareness, (Crosson, Barco, Veloza et al., 1989). Individuals attending the vocational rehabilitation programme have an intellectual awareness of at least some of their deficits. The center based rehabilitation provided within the educational element of the programme may develop this level of awareness for further areas of deficit previously not recognized or denied as participants report clarifying the nature of their deficits at this stage. Emergent awareness may also be evident as individuals recognize that they are experiencing difficulties during rehabilitation exercises and activities. The work experience placement during the experiential element of the programme is indicated as the stage where anticipatory awareness is more fully developed as individuals begin to appreciate the implications of their deficits on their return to work.

Through this exposure and sometimes repetition of these experiences the recognition that compensatory strategies may need to be adopted is developed and adaptation made to the functional losses experienced. Some similarity can be seen with a transtheoretical stage of change model (Prochaska and DiClemente, 1982) whereby individuals progress through contemplation and preparation, indicated where individuals reported acknowledging the need to use strategies and report the intention to do so but have not yet implemented these intentions. Followed by action and maintenance, indicated here when individuals begin to adopt adaptive behaviour and apply strategies over time and in different environments.

For most individuals this process is accompanied by some impact on mood which for some may be severe and require clinical input. Negative changes in mood may be perceived to result in poorer health and in stress related illness. Studies in psycho-immunology have established mechanisms by which stress can impact on health (Evans, Hucklebridge & Clow, 2000) and individuals in this study made illness attributions consistent with a psychobiological approach. Engaging in health lifestyles were perceived as aiding physical recovery and promoting better general health. Mood was also perceived to be moderated by health behaviours such as nutrition and particularly exercise. Moderate exercise has been found to increase psychological well-being in the general population (Daley & Maynard, 2003).

It should be noted that not all individuals may experience an emotional response to the impact of brain injury. In the qualitative study one individual reported maintaining a positive mood throughout recovery and did not indicate any negative response to the understanding and experiencing of limitations. While,

clinical experience suggests this is not common, further research with individuals who adjust to their brain injury without psychological distress would be of interest to indicate how mood is protected in these cases.

Coping strategies may be one factor protecting individuals from mood disorder following brain injury. Active coping strategies are associated with better mood states following brain injury, whereas lack of active coping strategies are associated with apathy and avoidant coping associated with depression (Finset & Andersson, 2000). Hermann, Curio, Petz, Synowitz, Wagner, Bartels & Wallesch (2000) indicate that coping strategies do not generally differ across different diagnoses of brain injury, such as traumatic brain injury, stroke or brain tumours, although differences in coping style are found in relation to age and social factors. Malia, Powell & Torode, (1995) identified four key ways of coping, common to traumatic brain injury patients: problem-focused coping, emotional-focused coping, avoidance coping, and wishful thinking. Malia et al (1995) state that 'Avoidance coping, wishful thinking and emotion-focused coping strategies all relate to poor psychosocial functioning, and seem to be inappropriate coping strategies in both the short and long term'. Comparison with others has been posited as a coping strategy in the face of uncertainty and anxiety when information is limited such as in chronic illness or disability (Molleman, Pruyn & Van Knippenberg, 1986). Some studies suggest that downward comparisons with those perceived as worse off or with imagined 'worse worlds' can promote well-being and self-regard in individuals in stressful conditions (e.g. DeVellis et al 1990). However, other studies have suggested that downward comparison can promote negative affect under certain conditions (e.g. Hemphill & Lehman, 1991)

Loss of self

Those who report persistent psychological distress tended to relate these feelings to a sense of loss of self. The need to reconstruct a self-identify in the face of chronic illness has emerged as a theme in many studies of a range of chronic conditions. Charmaz (1983) states that ' a fundamental form of suffering is the loss of self in chronically ill persons who observe their former self-images crumbling away without the simultaneous development of equally valued ones'. In a recent review Myles (2004) reported that loss of sense of self is common following brain injury. He considers this within a psychodynamic framework of Relational Frame Theory and proposes three senses of self; the conceptualized self, self and an ongoing process of verbal knowing and self as context. The importance of developing a new enduring self in order to accept and adjust to changes in functioning is highlighted. A lack of sense of belonging (Bay, Hagerty, Williams, Kirsch & Gillespie, 2002) and feeling threatened by the labels that it is felt that society puts on people with disability (Nochi, 1998) are also found to contribute to a loss of self after brain injury.

Nochi (2000) in a qualitative study using grounded theory analysis identified the self-narratives reflecting renewed ways to view the self during the experience of coping or adjustment to disability following TBI. These narratives were classified into five categories: 'the self better than others', 'the grown self', 'the recovering self', 'the self living here and now', and the protesting self'. Different stages within the reconstruction of self are indicated in previous literature.

Tyerman & Humphreys (1984) found that following head injury patients viewed themselves as having changed significantly as a result of their injury, yet anticipate a return to 'past self' within a year. Patient's perception of past self were generally more positive of their view of a 'typical person' and they compared their 'present self' more favourably than a 'typical head injured person'. This suggests that following a head injury unrealistic expectations are held. Tyerman and Humphrey (1984) suggest that these expectations may protect the individual in the short term but will ultimately hamper rehabilitation and adjustment. The importance of developing a new enduring self in order to accept and adjust to changes in functioning is also highlighted in this study and it is indicated that at least some individuals do achieve this state of emotional acceptance, although it may take a number of years to do so. Follow up studies would be useful to clarify the possible timeframes involved and to identify individual differences between those who achieve a new sense of self and those who struggle to do so.

Krefting (1989) proposes three strategies used by individuals to cope with loss of self-identity and the psychological impact of their injuries over time: Concealment; this involved a conscious effort to reduce the visibility of deficits and to appear 'normal. At this stage the person puts more effort into hiding their disability than into coping with the effects. Blind spots; this includes strong beliefs held in the face of contrary concrete evidence and suggests lack of knowledge of deficits. These are more common in the early stages of recovery and may decrease with time. These typically occur for selective aspects of disability such as non-physical deficits. Redefinition; this relates to altering a commonly accepted meaning in view of the experience of disability whilst retaining the value.

In a study by Morse & O'Brien (1995) unstructured interviews were conducted with patients who had survived serious traumatic injury, and their experiences from impact to recovery analyzed using grounded theory. A four-stage process of 'vigilance', 'disruption', 'enduring the self', and 'striving to regain the self' was delineated. The basic psychological process of 'preserving self' explained the strategies used in each stage, and required deliberate action, focused energy and tremendous effort and will. The strategies used to preserve self changed in each stage of the model. At the beginning, when physical survival was in jeopardy, the strategies were primarily physical. Protecting self was a process of 'taking time out' and of shutting down, in the stage of disruption. In the stage of enduring the self, it

was passively learning to 'take it' and to bear the treatments. Finally, in the stage of striving to regain the self, preserving the self was the work of regaining and redefining the self as a disabled person.

Psycho-therapeutic intervention has been applied as a means of promoting development adjustment and developing a new identity following brain injury. Prigatano (1989) has described his therapeutic input with individuals who have sustained a traumatic brain injury and has proposed that the rehabilitation process should include the use of symbols, concepts, and analogies to help to adapt to the experience of brain injury and to regain a sense of normality. Prigatano (1989) proposed that the symbols of work with its components of cooperation, efficiency, effectiveness, and reliability as well as the core tenets of 'love'; commitment, intimacy and passion were useful to help traumatic brain injury survivors adapt to their post injury level of functioning. He also identified the importance of 'play', or the ability to indulge in playful thoughts, actions, and feelings, in helping to put the person in touch with their unique inner world of being and thus experience a sense of their "old" identity

Study limitations

There are some weaknesses to these studies. In study one, sample sizes become small when the early and late post-injury groups are further subdivided into those with greater and lower awareness. Further, there is the difficulty of quantifying measures. It is noted that the method of identifying greater and lower levels of awareness has not been previously reported and no standard cut off point for 'impaired self-awareness' has been established. Despite a strong correlation between the quality of life scores and both anxiety and depression measures the results indicated for mood measures where not replicated for quality of life. This may be partly due to an inadequate method of categorizing quality of life scores. The use of the full range of categories suggested by the authors of this assessment tool resulted in too small cell sizes for adequate analysis. However, the positive score and negative score division used may be too crude to provide meaningful results.

It was noted that the early post injury group contained a larger proportion of participants who had suffered CVA than the late post injury group, which contained a larger proportion of participants who had suffered TBI. It might be expected that any disparity in mood or awareness between individuals with different diagnoses would be mediated by differences in severity or location of injury and this was not indicated in these results. However, most previous research into awareness after brain injury has been conducted with TBI samples and, with a larger sample, it would have been interesting to compare these groups separately to establish whether the results found in participants with TBI generalize to other brain injury populations.

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In study two the previous relationship the interviewer had with the participants in the qualitative study, in that she had worked with them within the rehabilitation setting, is acknowledged. It was considered that this relationship may have had an influence on the findings. On the one hand a rapport was already established which may have facilitated openness and enabled the interviewer to use some shared knowledge of the participant to explore deeper issues. However, the participant's knowledge of the interviewer's role within the rehabilitation team also had the potential to incur reluctance to disclose or a bias toward what may have been perceived as expected or acceptable responses. This study is therefore recognized as being understood within the context of participant exploring with a member of the therapy team the themes relevant to the research.

Paterson and Scott-Findlay, (2002) highlight the difficulties of interviewing participants with brain injury who, due to cognitive impairments, may not be able to effectively recall and articulate experiences, feelings, and perceptions. In the above studies participants were asked to discuss incidents and events that may have occurred several months ago and may have resulted in impoverished data. Also histories may have been influenced by the individuals current perceptions and not accurately reflect events at the time. In order to avoid these issues it would be beneficial to investigate these themes using more regular interviewing or diary techniques.

The validity of the grounded theory study could have been improved by giving the results of the study to some participants for member checking (Lincoln & Guba, 1985) and feedback requested to indicate whether experiences were accurately reflected.

The specificity of the context and sample group of both studies should be noted. Individuals are generally not accepted onto vocational rehabilitation programmes if their awareness is assessed as impaired to the extent that they would not engage in and benefit from rehabilitation. As this sample was taken from those accepted for rehabilitation, this represents a cross section from which those with clinically observed severely impaired self-awareness are excluded. These results therefore refer to a group who generally has a moderate level of self-awareness may not be representative of other brain injury settings.

Clinical implications

The results of these studies have some clinical implications for therapists working within vocational rehabilitation services. The importance of assessment of mood at outset of vocational rehabilitation is indicated. Where mood issues are highlighted further clinical assessment may be required to ascertain the nature of these and identify appropriate sources of support. The clinician should also be aware that mood disorder may be sustained for many years subsequent to the emergence of awareness and support may be required to highlight strengths and maintain motivation and positive coping. Where awareness is assessed to be in the relatively lower range the individual may still experience mood problems, especially if they present for assessment more than two years post-injury.

The importance of structure provided by rehabilitation in improving mood was highlighted. The relevance of activity and structure for well-being has been indicated in studies of the psychosocial benefits of employment (Jahoda 1982). The promotion of meaningful activity and routine at earlier stages in recovery may contribute to moderating the emotional impact of recognizing functional loss.

There is some indication that, in the initial educational element of the programme, improvements to mood and confidence occur that cannot be sustained. Clinical experience suggests that during the early stages of vocational rehabilitation individuals can become over confident, have unrealistic expectations of the rehabilitation programme to resolve their difficulties and set unachievable goals. It is not uncommon for an individual to abandon goals stated at the outset of programme for more ambitious aims during this first element. Vocational rehabilitation needs to find ways to address these expectations. It is noted that within the rehabilitation setting in which this research was conducted the highest levels of psychological support are provided in educational element of the programme and it may be appropriate to designate additional psychological resources to later stages of rehabilitation.

Conclusion

Anxiety, depression and lower quality of life are common in adults accepted for vocational rehabilitation and the incidence of depression increases with time since injury, up to two years post injury. The relationship between greater degree of self-awareness of deficits and higher levels of anxiety and depression is supported, at least up to two years after an acquired brain injury; although there is some evidence that awareness continues to be a factor in moderating depression beyond two years. The emotional challenge accompanying increased self-awareness is described as adjusting to the 'loss of self' and acceptance of the new self. However, additional psychosocial consequences of brain injury and unemployment may contribute to maintaining low mood in those with greater awareness and lead to poorer psychological outcome in those with lower awareness.

Individuals who have attended a vocational rehabilitation programme report that greater understanding of deficits is developed through the rehabilitation process. The awareness of the implications of their deficits on a return to work is developed through experiencing functional changes in specific context relevant to their individual goals. Mood and health are perceived as interrelated by many individuals following brain injury and the promotion of healthy behaviors are perceived as promoting well-being. These findings have clinical implications for professionals assessing and planning rehabilitation programmes with adults referred for vocational rehabilitation. The models described here are preliminary and are not proposed as fixed. Further research is required to develop these concepts further.

Coming to Terms With Change: A Grounded Theory Study of the Adjustment Process of Significant Others of Adults with Acquired Brain Injury Attending Vocational Rehabilitation.

'Family difficulties after brain injury can include increased burden, psychological distress and social isolation associated with negative changes in their family member's cognitive functioning, personality and behaviour' (Florian, Katz & Lahav, 1989).

The occurrence of an acquired brain injury not only affects the individual who sustains the injury but can significantly impact on those close to the individual and can affect the entire family system (Williams & Kay, 1991). It has been suggested that the impact of brain injury can be at least as great for families and that the family member may be more distressed that the injured person (Brooks, 1991). The emotional distress of individual family members, particularly parents and spouses, has been well documented, with depression and anxiety most frequently reported. Poorer quality of life and higher rates of psychiatric morbidity amongst carers of people with brain injury than in the general population have also been indicated (Moules and Chandler 1999) and Lamont (1993) found incidence of 'caseness' on General Health Questionnaire of 60% among relatives of individuals following brain injury.

A number of phase models have been developed to conceptualise the families' initial response to brain injury, most of these relate to the impact of traumatic brain injury, in which where the onset is sudden and unexpected. A family's initial response to a traumatic brain injury has been characterized by the stages of shock, expectancy, reality, mourning and adjustment (Lezak 1986; Douglas 1990; Cope & Wolfan 1994; Kay & Cavallo 1994; Kwasnica & Heinemann 1994; Curtiss, Klemz &Vanderploeg 2000; Degeneffe 2001). The stages of shock and expectancy generally occur during the inpatient phase of medical treatment. During the critical stages of injury medical stabilization is the priority and the family directs its focus toward the injured person and the will that they will survive. When any immediate threat to life is over there is often a sense of relief as the injured person begins to show sings of recovery. This may be accompanied by feelings of expectancy and hope for a full recovery. At this stage any obvious changes in cognition or behaviour may be ignored or denied (Romano, 1974).

Awareness of the reality of the impact of the injury often does not occur until after the individual has been discharged from hospital and families are faced more directly with changes in the individual's behaviour or personality and by their attempts to cope. At this stage the family members may experience depression, anger, anxiety, guilt and despair as the individual mourns the loss of the person

they knew before the injury. Eventually, for many a process of adjustment is negotiated in which the family member reconciles themselves to long-term, and possible permanent, changes in the injured person and to family roles and relationships. Kubler-Ross' (1981) model of coming to terms with death is often associated with adaptation within families following illness or injury. However, Verhaeghe, Defloor & Grypdonck, (2005) note that when adjusting to a brain injury within the family the fact that the person being grieved over is still alive can interfere with the normal grieving process. The act of grieving involves not only mourning the person who was prior to the injury and their unfulfilled potential but also adjusting to the new person who has survived the injury. "Patients and those close to them seem endlessly stuck between euphoric hope and resignation....burden of alternating hope and despair continues for many years" (Perlesz et al 1989).

In the longer-term family members often take on the role of caregiver to the person who has sustained the injury with the subsequent impact of stress and perceived burden. Adapting to the long term care needs of an individual who has had a brain injury has been associated with diminished quality of life (Kolakowski-Hayner, Miner and Kreutzer, 2001) and change in roles (Frosch, Gruber, Jones, Myers, Noel, Westerlund and Zavisin, 1997) with caregivers who care for a person in the home showing a larger number of role changes than those who do not provide direct care. These issues can become exacerbated as caregivers may give up their employment and leisure interest to provide support at the expense of their own health needs and emotional well-being (e.g. Oddy 1984).

Stress created by these changes does not appear to dissipate over time. The majority of care givers of individual's who had sustained traumatic brain injury indicate at least mild negative life changes one year after the injury (Wallace, Bogner, Corrigan, Clinchot, Mysiw and Fugate, 1998) and Marsh, Kersal, Havill, and Sleigh, (1998) found that, one year after traumatic brain injury, clinically significant levels of anxiety and depression were evident in over 1/3 of caregivers with a quarter of caregivers reporting poor social adjustment. Brooks, Campsie, Symington, Beattie and McKinlay (1986) found a significant increase in subjective burden between one and five years and in some families levels of stress have been found to remain high for as long as 10–15 years following injury (Rappaport & Herero 1989; Minnes, Graffi, Nolte, Carlson & Harrick, 2000).

The nature of the relationship to the person with brain injury may also influence the psychosocial response. Most research has investigated the impact of brain injury on marital and parental relationships with fewer studies considering the impact on children. There is evidence of a decline in the quality of marital relationships when one partner sustains brain injury with a high level of divorce in the long term. Wood and Yurdakul (1997) found that, in a sample of 131 couples after brain injury, only 42% were able to sustain their relationship for more than 5 years. Where separation has not occurred

relationship difficulties are often reported. Rosenbaum and Najenson (1976) found that wives of men who sustained a brain injury reported drastic life changes associated with depressed mood, feelings of loneliness and isolation, tense family relationships and role reversals between themselves and their husbands. Depressed mood was found to be highly correlated with the degree of reduction in marital sharing and childcare and with the perception of a childlike dependency in the husband.

Marital adjustment is found to be greater when wives report lower levels of financial strain, perceive their spouse to have relatively low level of psychopathology and when injury is relatively mild (Peters, Stambrook, Moore and Esses, 1990). In a comparison of male and female spouses, Willer, Allen, Liss & Zicht, (1991) found that wives of husbands who had sustained traumatic brain injury identified loss of emotional support, sharing and companionship as significant problems whereas husbands of wives with traumatic brain injury expressed more concern over dependency, insecurity, over protectiveness, reluctance to leave the home and mood swings on the part of their wife.

Where the person with a brain injury is a parent there is often also an impact on the children in the family. The uninjured parent may have less time and energy to spend with their children due to the responsibilities of caring for the injured spouse, whereas the injured parent may be less able to share activities with their children and may present with mood issues including anger or irritability. This may result in a decline in the relationship with the injured parent and the child may demonstrate behavioural and emotional problems (Pressaro, Coad, Linn & Willer, 1993). The ability of children to cope is not related to the severity of the injury but is influenced by the gender of the affected parent and the emotional response of the unaffected parent (Pressaro et al. 1993). If the injury is sustained by the father, children present more 'acting out' behaviour. These behavioural problems increase significantly if the mother displays symptoms of depression.

There is also evidence of considerable stress to families when a parent is caring for a brain-injured son or daughter with the parent often reporting anxiety about the future of their injured child and difficulties managing issues of independence as their children recover (Kao and Stuifbergen, 2004). One parent may give up a job to care for a head injured son or daughter (Jacobs 1988) or parents may be near retiring age and themselves have failing health (Weddell, Oddy and Jenkins, 1980). In a study that employed a phenomenological approach to investigate the meaning of the experience of the relationship between young adults with traumatic brain injury and their mothers, Kao and Stuifbergen (2004) identified that mothers adopted both positive and negative actions during the period of uncertainty following brain injury and found it difficult to balance protecting their children and letting them become independent. They also described struggling to maintain harmonious relationships with people both inside and outside the family and recognised that sometimes parent's marital relationships were at risk.

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In review of the literature relating to traumatic brain injury, Verhaeghe, Defloor & Grypdonck, (2005) conclude that the injury has a greater impact on partners than on parents. They suggest that the relationship between partners becomes less stable and the stress experienced is greater and that partners report more health and psychological complaints, score higher on depression scales and face crisis situations more often than parents (e.g. Cavallo,, Kay & Ezrachi ,1992, Hall 1994, Kreutzer, Gervasio & Camplair , 1994b, Siders 1999). Parental stress is greater when the brain injury is sustained by a child living at home rather than grown-up child living away from home.

The coping skills of the caregiver may play a role in mediating their response to the burden of caring for a family member with brain injury (Sander, High, Hannay & Sherer, 1997). In relation to coping following a stroke, caregivers who use positive coping strategies report fewer psychiatric symptoms than those using passive avoidance strategies (Hodgson, Wood & Langton-Hewer, 1996) and problem solving ability is found to be a moderator between disability of the stroke survivor and negative affect in their caregivers (Shanmugham 2001).

Willer et al (1990) found differences between the coping strategies used by men and women when a spouse sustained a traumatic brain injury. Husbands of women with traumatic brain injury reported suppression of feelings when reacting to mood sings as the most effective coping strategy with other strategies including not attributing all family problems to the injury, mutually defining new roles and responsibilities, support groups for their wives and maintaining a sense of humour. Wives of brain-injured husbands reported their most effective coping strategy was the development of a realistic but optimistic outlook and the development of assertiveness skills in relation to their husband, health care providers, in-laws and financial institutions. Other strategies included acknowledging the need to allow the injured husband to become independent and the need to take time for oneself and family outings and participation in support groups.

Social support may also play a buffering role against stress however, the support needs of caregivers are not always met (Kolakowskie-Hayner, Miner & Kreutzer, 2001). In a study assessing the needs of family members of individuals with brain injury, Murray, Maslany and Jeffrey (2006) respondents indicated that approximately one half of needs had gone unmet, or only partly met. It was identified that the most important needs were related to health information and that most needs perceived as unmet were related to emotional support. The importance of needs and degree to which needs are not met is indicated as a significant predictor of caregiver burden (Nabors, Seacat & Rosenthal, 2002). Poor communication with health professionals may also influence family members coping with 50% of families reporting this as a major stress (Panting & Merry, 1970).

Studies of overall family functioning suggest that the family environments may change when a member sustains a brain injury, with these families demonstrating higher levels of control, less evidence of spontaneous decisions making or change to daily routines than families without a brain injured person. Gan, Campbell, Germeinhardt & McFadden (2006) found significant distress in family functioning following an acquired brain injury and reported that higher caregiver strain and the injury being sustained by a female within the family were predictive of poorer family system functioning.

Gan et al (2006) concluded that the effects of brain injury extend beyond the injured person and the primary caregiver and they support the need for a family systems approach to family intervention after ABI. Within a family systems framework of adaptation to illness or injury the onset of illness or injury affects each individual and the family system as a whole. A family member sustaining a brain injury constitutes a significant disruption to the stability within this system. Each individual and the entire family as a system must adapt and strive to establish a regained sense of equilibrium. Otherwise the family may become stuck in a specific stage, and be unable to complete the development tasks necessary to grow and progress to the following stage (Leaf 1993).

Families in which a member has sustained a brain injury tend to communicate less about their concerns and problems and participate less in activities outside of the family environment (Douglas 1987). The demands of care giving may leave little time for socialising (Lezak 1988) and family members may avoid social contact where the individual with the brain injury presents with socially inappropriate behaviour (Walker 1972, Lezak 1988). Kozloff (1987) described how, as the size of the injured person's social network decreases, the relationships and functions served by family members increase and the family becomes increasingly socially isolated. Boyle and Haines (2002) suggest that the elevated levels of depression, decreased ability to express feelings, decreased time and energy for social and recreational activities and increased control evident in family members following severe traumatic brain injury could contribute to family isolation, which could last for many years.

However, there is evidence that some families cope well and may become stronger (Brooks 1984). Families who adapt best are those who support one another, are able to express feelings and emotions openly and are able to be flexible in the face of change (Douglas 1994). Intervention may be beneficial in promoting psychosocial adjsutment in families of a brain injury survivor. In an evaluation of an 8 week community based programme for family members of survivors of brain injury, Man (1999) reported that the programme was effective at empowering family members and improving psychological well-being, self-efficacy and subjective experience of burden and the end of programme and at 3 month follow up.

However, while a number of models for intervention have been developed, for example Tyerman and Booth (2001) describe components of family intervention provided within a community head injury service in the UK that incorporates educational workshops, follow-up workshops, individual family support and marital counselling, there is a lack of empirically sound evaluation studies of family interventions following acquired brain injury and very few randomised control studies. Oddy and Herbert (2003) in a review of existing literature suggest that in the absence of methodologically sound evidence, practice should be based on studies that have investigated how families adapt and the difficulties they face in the process.

Ponsford, Lover, Ponsford and Nelms (2003) in a study of long term adjustment of families following brain injury, where comprehensive rehabilitation had been provided, found that families were on average functioning in the normal range as measured by the Family Assessment Device. Anxiety and depression was more likely to be present in those responsible for the care of the injured relative however, no difference was found between the functioning of spouse or parents of the injured person. The presence of cognitive behavioural and emotional changes in the person with the injury were the strongest predictor of anxiety and depression in relatives and of unhealthy family functioning.

The relationship between behavioural and affective changes in the person who has sustained the brain injury and emotional distress in their close family members is a consistent finding the literature. While severity of injury has been found to be related to some aspects of the psychosocial impact of a brain injury on family members, with higher levels of anxiety, insomnia, social dysfunction and perceived burden reported throughout the first year after injury in relatives of individuals who sustain a severe brain injury compared with relatives of those with mild brain injury (Livingstone, Brooks and Bond, 1985), the severity of the injury is not found to be related to the experience of depression in family members (e.g. McKinlay & Pentland 1987). However, personality changes and behavioural, emotional and intellectual problems have been found to be most strongly related to the experience of pressure, anxiety and depression reported by family members in the long term. Knight, Devereux and Godfrey (1998) studied subjective burden in primary caregivers of individuals with traumatic brain injury on average of 6 years post injury. A high prevalence rate of emotional and behavioural changes in the person with brain injury was found and the amount of distress caused by these symptoms were found to be predictive of burden.

Marsh, Kersel, Havill and Sleigh (1998) found that at one-year post injury, emotional difficulties expressed by individuals with traumatic brain injury, in particular the anger, apathy and dependence caused greatest distress for caregivers. In as study comparing a group of couples who had divorced, or separated, from their injured partner in the years following a brain injury with those who were still in

the relationship Wood, Liossi & Wood (2005) concluded that unpredictable patterns of behaviour, or mood swings, as perceived by partners of brain injured individuals, impose the greatest burden on personal relationships and may contribute to relationship breakdown. Even up to 10– 15 years after a brain injury the primary physical problems sustained are reported as less stressful to family members than the individual's cognitive, emotional and behavioural problems, which may become more apparent over time (Thomsen 1984, Koskinen 1998).

In a study of the factors associated with emotional distress in caregivers of survivors of stroke, Anderson, Linto and Stewart-Wynne (1995) found that while, at one year after stroke, almost all caregivers reported adverse effects on their emotional health there was no significant relationship between emotional illness among caregivers and degree of physical disability. Scholte op Reimer, de Haan, Rijnders, Limburg, and van den Bos (1998) in a study of partners of stroke survivors at 3 years follow up found higher levels of perceived burden were primarily related to partners emotional distress and less to the amount of care they provided or to patient characteristics.

Emotional and behavioural functioning of the injured person is also a strong factor determining the outcome of family functioning (Kosciulek and Lustig, 1999). Junque, Bruna and Mataro (1997) found that family relationships were especially affected by problems behavioural and affective symptoms and by a decrease in patient quality of life. These perceived changes were most closely associated with the need expressed by family members for information concerning the consequences of traumatic brain injury.

Research suggests as the individual who has sustained the brain injury gains greater self-awareness of their deficits they experience greater risk of emotional distress (e.g. Prigatano and Fordyce, 1986; Ranseen, Bohaska and Schmitt, 1990; Godfrey, Partridge and Knight, 1993; Wallace and Bogner, 2000; Noe, Caballero, Villodre, Sanchez, & Chirivella 2005). Some studies have investigated the relationship between these changes in self-awareness and psychosocial response in significant others. Wallace and Bogner (2000) found a high incidence of depression and anxiety in individuals with brain injury and their significant others but did not find a significant relationship between emotional distress of significant others and self-awareness of the brain injured individual. However, Marcia (1991) found that greater self-awareness in the person with brain injury was a positive significant predictor of an individual's marital consensus and adjustment and the spouses' well being, marital satisfaction and affectional expression.

Awareness of deficit was also indicated as a potential predictor factor in a model of caregiver distress by Ergh, Rapport, Coleman, and Hanks (2002). This study examined predictors of family dysfunction

and caregiver distress among 60 pairs of persons who sustained a traumatic brain injury and their caregivers. They evaluated the relative influences of time since injury, awareness of deficit, neurobehavioral and neuropsychological functioning of the person with injury and caregiver perceived social support. Consistent with previous research neurobehavioral disturbance in the person with injury was found to be the strongest predictor of caregiver distress. However, social support was a powerful moderator of this relationship. In the absence of adequate social support, caregiver distress increased with longer time after injury, cognitive dysfunction, and unawareness of deficit in care recipients, whereas these characteristics were not associated with distress among caregivers with adequate social support.

Evidence is therefore mixed, while unawareness of deficits in the individual with brain injury may predict emotional distress at least for significant others who lack social support, there is evidence to suggest that lower mood and higher levels of perceived burden in significant others are related to emotional changes in the individual with acquired brain injury. It is important to understand the emotional and psychological impact of increased awareness on both the individual and their significant other in order to develop a therapeutic rehabilitation programme and provide appropriate support in response to changes in mood.

Research questions

The aim of this study was to gain in depth understanding of the changes in mood and health experienced by significant others of adults with acquired brain injury going through the stages of increased awareness, acceptance and adjustment while undertaking a vocational rehabilitation programme. The initial research questions where:

- How is the mood and health of the significant other affected by the impact of brain injury?

- How is the mood and health of the significant other affected by the mood of the person with brain injury?

- How do changes in mood that accompany the development of awareness by the person with brain injury affect the significant other?

- How can the above process be understood within the context of the vocational rehabilitation programme?

Method

Participants

Participants were the significant other (a close relative or partner) of individuals who had sustained an acquired brain injury (ABI) and were attending Rehab UK's vocational rehabilitation programme in London. The sample was selected from significant others of individuals who had completed Element A and where attending Element B of vocational programme, during which they had attended a work experience placement of at least four weeks. Participants were included in the study only if the individual with ABI gave consent for them to be contacted and where the significant other had known the individual before their injury and had maintained close contact since the injury.

The sample included 6 individuals (5 females and 1 male). Three participants were related to the individual with ABI as wife or partner, two as mother and one as stepfather. Four people participated as individuals whereas one mother and stepfather participated together as a husband and wife couple. This parental couple did not live with their son at any point since his injury, another participant lived with her partner during the first year after injury but was not living with him at the time of participation in the study, due to work commitments. All other participants had lived with the person with ABI from the time of discharge from hospital to the time of data collection.

As regards the nature of the injury sustained by the individual with ABI, 2 had sustained a traumatic brain injury (1 as a result of a road traffic accident and 1 as a result of a fall); 2 had experienced a stroke and 1 had undergone surgery to remove a benign brain tumour. All had sustained a brain injury as an adult; the youngest age at which the injury had been sustained within this sample was 22 years and the oldest 44 years. Length of time since the injury had been sustained and starting vocational rehabilitation ranged between 10 months and 39 months (M=23 months). All had engaged well with the rehabilitation process and had attended regularly. They had all completed the key stages of vocational rehabilitation and had undertaken a work experience placement and were already, or were about to start, job seeking.

Three of the participants had been actively involved in the rehabilitation process and had regularly attended Individual Programme Planning meetings, held at the vocational rehabilitation centre, with the individual with brain injury. One of these participants had also attended a Family Educational Seminar delivered by the Rehab UK London Brain Injury Centre.

Procedure

Ethical approval was obtained from the local research ethics committee and all data was collected and retained in accordance with the Data Protection Act.

Initially, individuals attending Element B the London Brain Injury Vocational Centre who had completed, or had attended, at least four weeks of a work experience placement where approached in person, informed of the nature of the research and invited to nominate a significant other who may be interested in participating in the research interview. While I was aware that this could provide a sampling bias it was considered unethical, and a threat to positive therapeutic relationships, to invite significant others to participate in research without the consent of the individuals with whom I had a clinical relationship.

Nominated individuals were then contacted in writing and provided with an information leaflet detailing the purpose and nature of the study, the benefits and potential risks of taking part and confidentiality procedures. Contact details were given for anybody wishing to request further information before agreeing to participate. Written consent to participate was obtained by those willing take part and a convenient time for interview arranged.

Data Collection

Semi-structured interviews were chosen as the most appropriate source of data for this study. The use of semi-structured interviewing is a widely used method of data collection in qualitative research and is considered to offer advantages over more structured methods as 'responses to open-ended questions reflect an individual's personal reaction to the phenomenon under investigation, rather than one elicited by way of forced choice between predefined options' (Wilkson, Joffe & Yardley, 2004).

Willig (2001) however highlights that that this style of interviewing cannot be considered to be totally non-directive as the interviewer leads the interview toward the data relevant to the research questions and that the challenge for the interviewer is to find a balance between controlling the direction of the interview and 'allowing the interviewee space to re-define the topic under investigation and thus to generate novel insights for the researcher'.

All interviews were conducted at Rehab UK's London Brain Injury Centre and were carried out by the lead researcher following a semi-structured interview protocol (see Appendix B.2). Details relating to the nature of injury sustained by the individual with ABI and their rehabilitation since injury was available to the interviewer in terms of medical records obtained prior to the start of programme.

At the time of interview the nature of the research was reviewed and written consent to audio-tape the interview for transcription purposes was obtained. All participants agreed to for their interviews to be audiotaped and these tapes were later verbally transcribed. At the outset of interview the personal nature of the interview was acknowledged and participants were asked to inform the interviewer if they did not feel comfortable to respond to any of the questions asked. Participants were informed that the interview could be terminated at any time at their request. Interviews lasted between 45 minutes to 1 hour.

The interview aimed at investigating participants' perceptions of the following main issues:

1. the main areas of difficulty the individual with ABI has experienced since his/her brain injury?

2. the course of increased self-awareness of deficits by the individual with ABI, with emphasis on changes that have occurred during the vocational rehabilitation programme, factors that have promoted awareness and the individuals response to their developing insight.

3. any changes in mood observed in the individual with ABI since their injury, with emphasis on their time on the vocational programme, factors that may have contributed to these changes in mood and how the individual expressed them

4. the changes in mood the participant has experienced since the injury with emphasis on any changes that occurred during the vocational rehabilitation programme. Participants were asked what they felt contributed to these changes in mood, including how they responded to any changes in mood by the individual with ABI and any factors that helped them to cope with any difficulties encountered

5. any changes in health experienced by the participant since the injury, their understanding of the nature of these health changes and their connection with the status of the individual with ABI.

6. the participants evaluation of their current mood and health including any expectations or concerns for the future and feedback on the means by which their needs may have been better met.

As part of the interview schedule participants were asked about their current mood status and their need for any further support. Information regarding additional sources of support was available as required. At the end of each interview each participant was asked a debriefing question, relating to how they felt following the interview, to assess if it had resulted in any distress. It was noted that during several interviews participants were observed to become emotional when discussing some of the issues raised. However, no participants reported that the interview had caused them any distress and most indicted that they had found the interview process a positive one and had appreciated the opportunity to discuss their experiences.

For the purpose of transparency the nature of the relationship between the interviewer, participants and the individuals with ABI should be made explicit. The interviewer had been involved in some stage of the assessment process of three of the individuals with ABI prior to their start on the vocational programme and had been involved, in the role of psychologist, in the programme planning for these individuals during their rehabilitation and had attended their Individual Programme Planning (IPP) meetings. The interviewer had also had professional contact with all of the individuals with ABI in the delivery of group training sessions within the rehabilitation programme and informal contact on a day-to-day basis. The interviewer had previously met two of the significant other participants who had attended the IPP meetings with their family member. Three of the participants were unknown to the interviewer prior to the date of the interview.

Due to this relationship issues of confidentiality were emphasized. Participants were reassured that no information would be shared with the family member with a brain injury and that this interview was not part of the rehabilitation process, information would not be shared with the team and their responses would no way influence their family members future rehabilitation. It is acknowledged that the participant – interviewer relationship constitutes a dimension of the context within this study is set. However, it is felt that the participants responded in an open and candid manner and that the data represents an accurate account of their experience within this setting. Validation of this study's findings with existing literature, as reported later in the discussion section, supports this assertion.

Data Analysis

A grounded theory approach was adopted for the analysis (Strauss & Corbin, 1990) – See Study 2. In the full version of grounded theory data is systematically gathered and analysed throughout the research process. In this study the 'abbreviated' version of grounded theory (Willig, 2001) was applied; that is the data was collected before analysis began and interview transcripts were then analysed using the

principle of grounded theory. It was recognised that, due to the very specific context within the research was to be carried out, access to participants was limited and theoretical sampling (in which further data is collected to elaborate or challenge the categories that have emerged from earlier analysis) would not be practicable.

It is generally suggested that data collection and analysis is conducted before a detailed review of the literature is carried out. This is to avoid the researcher approaching the data with preconceived ideas and assumptions based on previously established theories. Only once the emerging theory is sufficiently developed is it suggested that the researcher reviews relevant literature in order to relate it to their work (Glaser and Strauss, 1967). In this study a preliminary review of current literature was necessary in order to develop a research proposal and to provide a cohesive rationale for carrying out the research when submitting an application for ethical approval. In addition, as a professional working with individuals who have sustained acquired brain injury, and their families, some knowledge of current research into the psychosocial impact of brain injury on significant others was unavoidable. However, in order to minimise any bias, attempts to independently verify the developing theory were made, including having a second researcher independently analyse sections of the data.

Open coding

The analysis began with 'open coding', which involves labelling basic concepts and categories in the data and identifying their properties and dimensions. Line-by-line analysis (Charmaz 2000) was carried out on all transcripts. While coding can be carried out on larger chunks of text, once initial codes have been established, it was felt that a more detailed analysis would be warranted to ensure that the theoretical formulations that would later emerge were truly grounded in the data. This decision was made partly due to the relatively small number of participants in this study and also because this has been recommended as the best method of analysis when the 'abbreviated version' of grounded theory is being used. Willig (2001) states that ' the depth of analysis generated by line-by-line coding is needed to compensate for the loss of breadth that accompanies the researcher's dependence upon the original data set'.

Initially the coding involved assigning largely descriptive labels for the discrete events or occurrences reported. Where possible 'in vivo' codes were used, that is words or phrases used by the participants were used as codes to ensure that the concepts derived remained true to the data. The code label was written in the margin of the transcript next to the line of text it was derived from. As analysis progressed these descriptive labels were collated in a database detailing the code name and the transcript and page number the code referred to. Code notes, indicating potential properties and

dimensions of that concept and initial thoughts on possible connections with other codes were also documented on this database. Colour coding was used to distinguish the codes derived from each transcript. At this stage a large number of codes were identified.

These codes began to be grouped together into categories using the 'constant comparative method'. This refers to the process in which the researcher compares incidents and looks for patterns or discrepancies in the data. By comparing similar incidents and grouping them together under the same conceptual label the more abstract categories on which theory can be developed begin to emerge. In grounded theory constant comparison analysis is carried out continually throughout all stages of analysis. In this study comparative analysis began during the early coding stage as relationships between codes, and suggestions for grouping categories, were indicated in the code notes. More detailed descriptions of these early emerging categories with explanations, references to other related incidents, questions raised and considerations for further analysis where developed through the use of memo writing. Strauss and Corbin (1990) stress the importance of memo writing as the means by which the researcher records 'the progress, thoughts, feeling and directions of the research process'.

When all transcripts had been open coded further analysis of the list of concepts was carried out to establish similarities and refine concepts for low-order categories. This involved constant cross checking of transcripts to identify whether any new categories that emerged were consistent with earlier themes or represented a new concept. This continued until saturation of themes was achieved and that the data had been analysed sufficiently 'to be sure that we have a full and detailed understanding of the phenomenon and can present a full account of it' (Chamberlain, 1999). It was established that concepts derived from the fifth interview concurred with concepts identified in previous analysis but did not reveal any new main themes suggesting that data saturation had been achieved.

A second researcher, a psychologist familiar with research methods, also analysed the first two transcripts. Consensus was found between the themes identified by both researchers and these were discussed to establish categories to be explored with further analysis. At this stage it was recognised that some of the themes emerging represented a shift from the original research questions. It was initially intended that the experience of participants, while their family member underwent vocational rehabilitation, would be main focus of the data collection. However, interview data indicated that participants' understanding of their adjustment, as a process following brain injury, could not be explained without reference to timescales and settings outside of this context. Participants gave accounts of the changes they had encountered since the injury and their responses to it.

Immediate responses to illness and injury have been well documented in the literature and so were not focused on here and the period from discharge from hospital, through any medical or outpatient followed by vocational rehabilitation to current time was identified as the temporal context for this study. Initially, these rehabilitative stages were considered as categories by which the data would be structured. However on further consideration participants' experience of adjustment after a brain injury in the family was found to relate more to the cognitive and emotional challenges faced than to these discrete stages. Although time did appear to be one property of adjustment other mediating factors were perceived to be more important.

Furthermore, one of the original research aims had been to investigate the relationship between emotional distress in the person with acquired brain injury psychological response in the significant other. While this relationship was indicated in the data it was identified that it was only one concept within a wider category of factors influencing the participants psychosocial adjustment to change after the brain injury.

Axial coding

Whereas open coding involves breaking down the data into concepts and categories the next stage of analysis involves putting the data back together again by identifying higher order categories based on more abstract conceptualisation of the emerging themes and identifying connections between these categories and the subcategories. This process is referred to as 'axial coding' by Strauss & Corbin (1990) who state that; 'Categories are higher level and more abstract that the concept they represent......Categories are the "cornerstones" of developing theory. They provide the means by which the theory can be integrated'.

Once open coding had been completed and initial categories had been established and agreed 'axial coding' began. The concepts and themes that had been identified in the early stages of coding where grouped together and main categories identified and labelled to describe the way in which their subcategories related to each other. Once all the emerging categories had been ordered by the lead researcher these were discussed with the second researcher to establish whether this constituted best fit. At this stage the coding was refined and by consensus further categories were merged to create fewer but more dense themes. For example the original codes of *dealing with issues of dependency, having to be strong for the brain injured other* and *managing multiple demands* were identified as sources of stress related to the changes of roles and responsibilities that occur when a family member sustains a

brain injury and were and grouped together under the category of *burden of care*. Other categories agreed at this stage related to factors that influenced the extent the significant other experienced burden or stress, labelled *mediators of the impact of change*, and the coping mechanisms reported to be used by participants to manage the psychosocial impact of change, labelled *strategies for maintaining health and well-being*.

Theoretical coding

In review with the second researcher the potential relationships between the high order categories were established and the core category of *coming to terms with change* when a close family member sustains a brain injury was identified as reflecting the main theme of the study. The core category is 'the one category which identifies what your research is about....the one which is abstract enough to encapsulate your storyline' (Bartlett & Payne, 1997). The relationships of the higher order categories to this 'core category', and to each other, was then discussed and agreed in order to form a theoretical framework.

In order to enable the researcher to think systematically about the data some authors propose the use of a 'coding paradigm' during this stage of analysis. Strauss and Corbin (1990) suggest that the use of such a paradigm provides researchers with a way of structuring their data and relating categories meaningfully by identifying a core category and then relating other categories in terms of the causal conditions, context, intervening conditions, interactional strategies and the consequences or the outcomes. Other authors (e.g. Glaser 1978) caution against the use of a formula that imposes specific constructs and structure on the data and rather argue that the most relevant theoretical codes are those that are indicated by the data.

In this study the 'coding paradigm' suggested by Strauss & Corbin (1990) was referred to as a useful framework for considering how these categories may link together but was not adhered to strictly. The structures of context, intervening factors and interactional strategies were found to be useful in relating three of the main categories around the core theme. Once this theoretical framework was agreed the transcripts were reread to ensure they provided a comprehensive account of the events reported in the original data. The second researcher also compared this coding with a further sample of transcripts and confirmed it's 'fit', thus supporting the validity of the analysis.

The importance of establishing validity and reliability in qualitative research has been discussed by a number of authors (Smith 1996; Willig 2001, Flick 2006). Osborne and Smith (1998) state that 'Validity, and the exercise of rigour to establish the credibility of qualitative study is considered to be no less essential that in any other form of research but it is important that the criteria by which it is judged are appropriate as qualitative inquiry has different epistemological roots to quantitative methodology'. Conrad (1990) suggests that when evaluating a qualitative study rather than looking at sample size, statistical power or participant selection the study should be evaluated by the applicability of the concepts.

In the analysis and reporting of this study the criteria that are suggested as characterizing good qualitative research by Henwood and Pidgeon (1992) were referred to. These are; the importance of fit, the integration of fit, reflexivity, documentation, theoretical sampling and negative case analysis, sensitivity to negotiated realities (participant feedback) and transferability. A detailed account of the analytic process and the way in which the categories emerged and were integrated has been given in order to illustrate the importance and integration of fit. Issues of reflexivity and the role of the researcher in shaping process of inquiry have been discussed in relation to the researcher – participant relationship. With regard to documentation, an audit trail was created at each stage of the coding process (Smith 1996) in the form of a database of codes and memos, diagrams and tables. The later stages of this documentation were discussed with the co-researcher to check that the interpretation was coherent.

Theoretical sampling was not conducted for reasons given earlier however attempts were made to seek out negative cases within the data collected. That is differences between cases and concepts were investigated in order to constantly adapt the emerging theory and to safeguard against initial formulations of theory influencing subsequent interpretations of data. In relation to transferability, the context within this grounded theory evolved and its applicability to other settings will be considered within the discussion.

Participant feedback was not established in this study. However, 'credibility checks' (Elliott, Fischer and Rennie, 1999) were carried out by the involvement of a co-researcher who independently analysed sections of the data to establish inter-rater reliability and by discussing the emerging categories with this co-researcher to ascertain consistency and by the second researcher checking the proposed theoretical framework against additional data to look for inconsistencies.

Elliot et al. (1999) also identify that qualitative research should involve 'grounding in examples' and that authors should illustrate their analysis with examples from the data so that the reader can assess the fit between data and the researcher's interpretations. In presenting the findings of this study I will present quotations to exemplify key themes. Within the results section all words, phrases or passages presented in quotation marks and italics represent verbatim examples of the original data.

Results

The core category that emerged from the interviews was the participants' experience of *coming to terms with change* following the impact of an acquired brain injury sustained by a close family member or partner. Following the immediate impact of what is often a sudden and traumatic injury or illness the significant other may be faced with a long period of recovery, which entails changes to roles, responsibilities and to their relationship with the person sustaining the injury and with other family members. Participants relate how 'traditional' spousal roles can be affected or reversed and how parents of adult children with ABI may be required to revert to a more protecting parental role. The significant other may be required to adopt additional responsibilities whilst attempting to maintain existing occupational, social and family roles.

Within these narratives a process of *coming to terms with change* is described in which the significant other goes through a process of adaptation and adjustment to the many challenges forced upon them. Through this journey the significant other moves from initial despair towards hope. Four stages, or tasks, are identified within this process; *letting go of the past, dealing with the here and now, regaining a sense of normality* and *refocusing on the future*. These are not suggested as discrete or linear stages but rather as tasks to be worked through.

Three further main themes were established. *Burden of care* describes the major sources of stress experienced by significant others as they attempt cope with change. *Mediators of the impact of change* describes the key factors reported by participants to influence or mediate their psychosocial response. *Strategies for maintaining health and well-being* describe the coping mechanisms and supports used by significant others to manage stress (See Table B.10).

Table B.10: Coming to terms with change: Main themes and sub-themes

Category	Subcategory
The tasks of coming to terms with change	Letting go of the past
	Dealing with the here and now
	Regaining a sense of normality
	Looking to the future
The burden of care	Managing multiple demands
	Balancing issues of independence
	Having to be strong
Mediators of the impact of change	Emotional response of person with ABI
	Access to support
	Vocational rehab
Strategies for maintaining health and well-being	Personal coping skills
	Open communication

Letting go of the past

Following the injury participants have to acknowledge changes and losses in their significant other and the reality that the person may not be the same again. Prior to the injury the individuals with brain injury had all been in employment or in the case of one individual had been a student in higher education. As result of the injury these vocational roles had to be abandoned resulting in significant change in family functioning and loss of status and confidence in the brain injury survivor.

Participants all described physical, cognitive, emotional and personality changes in their significant other. One participant described how the change in physical appearance of the family member with brain injury was symbolic of personality changes.

'physically he has changed enormously because before his brain injury he was a very big person. I mean he has lost a huge amount of weight and that has almost fed into a personality change. He is a smaller person than he used to be. He was a big ebullient, extravert type person .... he's gone from being almost over confident.....to being very withdrawn, very, very lacking in self-esteem.'

The emotional response to letting go of the past is characterised by grief, depression and anger. One participant described in detail the stages of shock, relief, questioning, anger and gradual acceptance following a brain injury in the family. This mourning process, in response to loss following illness or injury, has been thoroughly reviewed in previous literature and will not be reiterated here other than to note that both the person who sustains a brain injury and their close significant others may experience this sense of bereavement but may not progress through these stages at the same time.

Family members also have to adapt to changes to their lifestyle, at least in the immediate future, while the injured person continues through their recovery and rehabilitation. In the longer term the significant other may have to accept that plans and goals set before the brain injury have to be abandoned, or adapted to address the needs of the individual with ABI.

In the early stages of recovery it may be unclear to what extent future plans will need to be altered which brings uncertainty and anxiety as past lives are disrupted but new plans cannot yet be established. The significant other may find them self in a state of limbo as previously held ambitions are felt to be unattainable.

'you feel that you have come to a stop ...... you can't help but compare yourself to your friends and, and they're are all being promoted and buying lovely houses and all of this, and like you feel .... we've got nothing now, this is it, this is where you stop. ..... you can't see forward at all.....one of the main things for me was just feeling like you can't have any ambitions now, you can't have a five year, a ten year plan, or anything.'

The extent to which this sense of loss is experienced depends in part to the family members awareness of the deficits sustained by the person with brain injury and their understanding of the future implications of these. Where the family member has greater understanding than the person with brain injury they may experience frustration at having to let go of past goals that their family member is still aspiring to.

Alternatively, the family members recognition of the need to let go may be precipitated by the developing awareness of the person with the brain injury. One participant describes how she would try to avoid thinking about how things had changed since the injury until forced to do so by her partner's expression of frustration over his cognitive deficits.

> 'you just don't think about things too much and then when he actually would say "god, I can't remember ...whatever" ... then that brings it home to me and then it's like "god yeah things .... are a lot different from how they were before". '

Dealing with the here and now

This task relates to coping with the immediate demands involved in supporting an individual with ABI. On discharge from hospital significant others may busy themselves with the practical tasks of day to day life; caring for the individual with ABI, attending medical appointments, supporting other family members and attempting to maintain jobs, study or family roles. One participant described focusing on the physical needs of their family member by decorating and adapting the flat that he would be discharged to. Family members may face threats to well-being as they endeavour to cope with the physical and emotional strain of juggling multiple and possibly competing demands.

While dealing with the here and now generally refers to addressing *'the practical side of things'* this may be used as a psychological defense; where expectations of recovery are uncertain the significant other may focus their attention on *'existing day to day'* to avoid speculating on unfavourable outcomes. As one participant put it *'I think maybe we had put up a wall, I didn't want to think long term'.*

Regaining a sense of normality.

Participants attempted to find way of regaining some sense of normality by establishing pre-injury roles or routines. A sense of normality was also gained when the person with brain injury began to adopt some of their pre-injury functions such as undertaking tasks around the house, re-establishing social contacts and relationships, engaging in meaningful activity outside of the home (for example voluntary work) and by commencing vocational rehabilitation. On participant describes the 'normalizing' impact of the vocational rehabilitation programme for herself and the family.

'I think that for the children as well it was useful because suddenly daddy is living ...... what they saw as a much more normal life. ... he is getting up in the morning and he is going out and he is coming back and he has had a different experience instead of having being at home and not really having done anything all day and so it was quite reassuring to them, and I think for all of us.'

For another participant, who had taken on the role of primary caregiver for her partner when he sustained a brain injury, being able to return to her previous role as student when care giving duties where taken on by other family members enabled a return to normal life.

'It was great for me, I was really pleased, I mean I found it quite difficult because ...... we had a great time together at the beginning of University and then very much sort of nursing him through his accident and then he went away so....to begin with it was quite lonely. You know, suddenly you have all this freedom and you are a student again but ..... I needed that .... I had a lot of work so I could actually start concentrating on the work and go out with friends.'

Regaining a sense of normality may not necessarily refer to a return to previous routines. The significant other may find new ways of establishing a sense of 'normality'. One participant reported undergoing a training course following the brain injury to re-establish the structure, personal goals, time to herself and social contacts that were lost after her family members brain injury.

Looking to the future

This stage is characterized by a sense of 'moving on', gaining a sense of purpose and having something to look forward to. This may be experienced when the person with brain injury demonstrates progress in their recovery or moves into a new phase of rehabilitation. Initially this may be and as taking the next positive step resulting in positive affect for both the person with brain injury and their family member. One participant describes how the vocational rehabilitation programme had acted as a transition from dealing with the here and now to gaining a sense of purpose.

*'I think for all of us, and for (*the person with the brain injury*) as well there was that feeling that his was a step forward, we weren't just sort of existing day to day, this had a ... longer term purpose, and that we were moving on, that this was a bit of a phase that was coming to an end and something new was starting, which was very positive.'*

Initially, this phase may be a transitory one. As the individual with brain injury journeys through the awareness and adjustment process periods of positive gain may be followed by a plateau or even a *'set back'*, as they discover a new difficulty or gain greater understanding of an existing one. This may prompt the family member to adapt to newly recognised losses or to return to focusing on 'here and now' tasks.

All participants described how eventually they came to a more permanent sense of purpose and optimism as they saw their family member gaining independence and they regained hope that the person with brain injury would be able to return to some of their pre-injury roles, particularly in relation to gaining employment. The family is then able to focus again on the future and begin to make plans.
One participant describes how, at the time of the interview, she believed that the sense of *'possibilities'* she and her partner had held prior to his injury, but had let go of following the injury, were now achievable.

> '.....*and now I think that has come back because I am confident that he will get a job and a semi decent salary and we will be able to move forward and we will be able to have a nice life now... he is well in himself and even though things have changed we are still, you know, quite a strong unit together ..... we have still got a good future together.* '

The tasks of coming to terms with change are presented in the above order for the following rationale. Letting go of the past is largely an emotional task which may begin with the initial shock of finding out about the injury itself and the physical presentation of the injured person during hospitalisation. Dealing with the here and now relates to the practical demands of coping with the injured person; including change to routines while visiting and them in hospital and providing support on discharge. Regaining a sense of normality may be achieved when a routine begins to be established following discharge or when the person with brain injury regains a structure by undertaking further rehabilitation. Refocusing on the future generally occur when the person with brain injury begins to regain independence and when expectations of recovery are established. However, the journey from letting go of the past to being able to refocus on the future is not proposed as a model of discrete stages through which the individual progresses in a linear fashion. Rather it is an interactive, fluctuating process; the individual may tackle each task in varying order, may move backwards and forwards between tasks and may be attempting to work through more than one of these tasks at a time.

Burden of care

Participants described how they experience burden and stress as they came to terms with change after a brain injury of a significant other. They are often forced to *manage multiple demands* of caring for the individual with brain injury, carrying out additional roles within the family and adopting responsibilities previously carried out, or supported, by the person with brain injury. One parent describes how she had to help her adult daughter to dress herself in the initial stages after discharge ' *because it was just like having child back again'* and also took on a rehabilitative role, engaging her in activities to provide stimulation with the aim of improving cognitive function.

Having to adopt a parental role when the person requiring care is a spouse or partner can put strain on the relationship. One participant described how taking on the role of monitoring her partners lifestyle to ensure he stayed healthy meant that '*we are then not on equal terms, you know I am doing the parenting role which I don't like doing'*. The psychological impact of burden of care is experienced as fatigue, fluctuating mood, anxiety and guilt as additional responsibilities may leave less time for other members of the family.

The potential for emotional overload is described by another participant who describes the struggle of trying to maintain personal goals, manage a household with a partner with brain injury and two dependent children and attempting to provide support for the family. This participant describes the '*waring, frustrating'* nature of maintaining these multiple demands over time and how these can cumulate in '*flashpoints'* of being overwhelmed and unable to cope.

The strain of being supportive and *having to be strong* for the injured person and the family was a recurring theme. Feeling that the family member requires constant encouragement, always being there for them but not knowing when they may call on this support and having to put other persons needs and well-being before their own are all reported to be stressful. As one participant explained, '*constantly having to be the person who is the upbeat, chipper, optimistic person is very tiring.'*

Further stress may be experienced as the significant other attempts to *balance issues of independence*. Where the individual with brain injury has reduced independent functioning due to physical, cognitive or emotional deficits the significant other may seek to find a balance between encouraging regained independence in their family member with their desire to support and protect them.

'It's a very narrow line isn't it, you have got to encourage her and..... have confidence in her, but I don't want her to do too much because if she does too much it is one step forward two steps back isn't it really.'

This is associated with anxiety as the significant other understands the need for the family member to experience their abilities for themselves but worries how the person will cope and fears that they will encounter difficulties and experience distress. This anxiety often occurs when the person with the brain injury attempts new steps in their recovery, or rehabilitation, such as travelling unsupervised for the first time, starting the vocational rehabilitation programme or beginning the work placement. For parents particularly these issues are projected into the future as the parent experiences conflict between hoping for regained independent status and concern for their adult child should they experience barriers to achieving these goals in the future. One participant described this as having a *'a permanent lump in the pit of my stomach, 24 hours a day really, just hoping and praying nothing will happen and she will cope.'*

The burden of supporting someone with a brain injury is greater for significant others living with the injured person. Participants who did not have this level of proximity to the injured person reported less stress and indicated that they believed they would have been impacted to a greater degree had they lived with, or closer to, the injured person. One participant who lived with her partner initially reported being able to focus on her own lifestyle and goals when they later lived apart.

Mediators of the impact of change

Participants reported how the degree of stress and distress they experienced as they adapted to change and its resulting burden of care were influenced by key factors relating to the emotional adjustment of the family member with brain injury and their access to support.

Emotional response of the person with ABI

The psychosocial response of the significant other was influenced in part by the mood of the individual with brain injury. Generally, when the brain injury survivor expressed positive affect the significant other was more able to cope. When the significant others expressed distress the significant other also experienced distress. As one participant, describing her partner's mood, put it, *'when he has a bad day ... we all have a bad day because he brings it home and he is very open about it.'*

The person with brain injury was perceived by participants to experience deterioration in mood following their injury as a response to dealing with their sense of loss, a lack of meaningful activity, social isolation and uncertainty about the future. For all but one participant the period of lowest mood, or most severe mood disorder, occurred at some stage between discharge from hospital and start of the vocational programme. For one participant, whose family member started the vocational programme less than a year post injury, a period of significant depression was experienced whilst attending the vocational rehabilitation programme at the point when her awareness of her brain injury was increased and the *'reality of it...was hitting her'*.

Where the person with brain injury experienced mood change the severity of these mood issues and the duration over which they were experienced were all relevant in influencing the significant others mood. One participant described coping with severe mood disorder of her partner with brain injury over a 3 month period, which was characterised by mood swings and unpredictable behaviour. This participant experienced concern over their partner's safety, considerable burden of coping *'alone'* and ongoing sense of responsibility for managing the partner's health once mood had stabilised.

> *'I was totally and utterly exhausted, didn't have time to eat .... I would be always alert and I would say right ...we are going we are going to go to bed now and he would need a good two hours to wind down'*

When coping with depression in the person with brain injury the way in which the individual expresses their low mood can be a significant factor. Where the individual is openly upset, reports low confidence, expresses regret for the impact their injury has had on the family and requires constant emotional support this incurs significant emotional strain on the significant other. One participant describes the emotional strain of trying to be supportive of her partner during a period where his increased awareness into the impact of his brain injury resulted in a significant deterioration in mood.

> *'It was awful because it would happen every day so to begin with you know I could be supportive and say you know it is fine .... but when it happens again and again you're just like "aaaah what can I do or say next" I sort of run out of ideas of, you know, things I could say to him.......it was like a big turning point because that was when he could really see what had happened and how it affected his normal life, ... that was definitely the hardest part because you ....can't see a way forward really.'*

However, where the individual's behavioural response to their low mood was avoidance and withdrawal, the burden on the family member was also reported to be increased as they struggle to manage family roles alone and feel unsupported. Participants coped better with their family members depression when emotions were contained and the individual with brain injuries current level of activity and engagement was not significantly effected, where the period of depression was understood as a necessary stage in that persons awareness and adjustment process and when the is confident that the individual has the support or the coping skills to *'ride'* it out

One participant describes how she maintained optimism while her partner experienced difficulties during the work placement stage of his vocational rehabilitation programme.

> *'over the last few weeks, we have had to live with his lower mood again over this set back but you know I think that is being addressed and going forward so, no from my point of view it is a positive'.*

Access to support

The availability of social and professional support was an important factor in mediating the significant other's response to the stress of supporting an individual with acquired brain injury. After an acquired brain injury the families social networks often decline and the family may not get the practical support to deal with the additional burden of care or the social support recognised as important for buffering stress. When the injury is incurred by a spouse or partner the support previously received from the partner is often no longer available and the caregiver can be left feeling 'alone'. The close immediate family was reported to become the main source of support as extended family and friends return to their lives and may not recognise that support is required once the person with brain injury leaves hospital and returns home.

Where support is offered by those outside of the family this tended to be irregular and temporary, offering respite but not consistent or adequate ongoing support. As one participant reported, friends may want to help but not know how to support the injured person , *'I had great friends around but nobody else knows how to take it ..... their support is quite temporary and it was a question of just sort of handing him back to me. '* Having to explain the needs of the person with brain injury to family and friends was perceived as an additional demand. However, when the significant other received regular support from family or friends who understand their need the burden of care was reduced.

Professional services can play an important part in supporting the significant other in terms of both provision of information and emotional support. Participants reported being satisfied with the medical support received by their family member while in hospital. However, most participants reported being unprepared for some of the changes they experienced in their loved one and had not been adequately informed of what to expect after discharge from hospital. Participants reported being better informed regarding potential physical disabilities but were less aware of the potential cognitive effects and how these may affect future independent functioning and were often not informed of the emotional and behavioural changes the person with brain injury may go through. Most participants described learning about the needs of the person with acquired brain injury through a process of discovery once they had returned home.

Knowing what to expect regarding recovery was a key factor in the reported mood and adjustment of both the person with brain injury and the significant other. Whereas the person with brain injuries expectations of recovery were in part related to their level of awareness, significant others' expectations of recovery were reported to rely more on the provision of information which was reported by many to be an unmet, or inadequately met, need. Where information is available it can be contradictory and confusing.

> 'we did have a year kind of in the dark and the information after brain injury is really limited and that is something .. that we have all found quite difficult. There is nobody, nobody consistent, you see somebody from all different fields who can be telling you different things'

Participants who were able to attend support groups or use telephone support reported gaining benefit from these. However, family members do not always know what services are available and how to access these. When support services are identified there are often other barriers to access including having too far to travel, not being able to find the time due to other demands, not wanting to go alone and the service not being considered relevant for their need at that time. One participant reported that she had received counselling offered by her work place in the early stages after her partners injury but had that she may have benefited more from this support had she received it at a later stage. Participants also indicated that they may be reluctant to actively seek support but would value support if it were offered to them.

Feeling that the person with brain injury is supported was also a source of support and comfort for family members. The emotional demands of supporting the person with brain injury who may be experiencing distress were reported to be reduced if the injured person had access to counselling or psychological support.

Having confidence in the person with brain injury's social networks was also reported to reduce the sense of burden. The parents of an adult child who had experienced a stroke described how they felt reassured when they observed their son being supported by a new partner; ' *she took over my job .....a lot of that responsibility really had gone off my shoulders because I knew that she did care* '.

Vocational rehabilitation

Whilst the vocational rehabilitation programme can be described within the theme of access to professional support it will be reported as a category on its own as it is the context within which this study is set and one of the research aims was to identify how changes in awareness and mood associated with attending the vocational programme impacted on the significant other. Most participants described how the their family member had experienced low mood, little structured routine or activity and social isolation prior to attending the vocational rehabilitation programme. Participants reported experiencing a positive shift when their family member started to attend the programme. The regular routine and increased social contact promoted represented a regained sense of normality for the family while allowing the significant other time to themselves and respite from the demands of providing support. One participant describes how when her partner began the programme *'He suddenly had something else to talk about. It got him out of the house every day. That in itself was great, it was good for our relationship'*

The vocational rehabilitation programme was perceived by participants to promote independence in the person with brain injury by highlighting areas of retained strength, enabling favourable comparison with others and developing strategies for compensating for deficits and functional loss. As a consequence the brain injury survivor gained confidence and experienced improved mood.

> *'the first thing I saw was suddenly this realisation that, yes things had changed, but he could still hold his own..... he realised that, not only compared with other brain injured people but compared to ordinary people, if you like, he could still maintain a conversation, hold an argument, on level footing ......That gave him a lot more confidence and really sort of boosted his mood. '*

The vocational rehabilitation programme was also reported to provide a sense of support for the family member who felt that their family member was receiving consistent and relevant support and that by understanding the needs of the person with brain injury the family were no longer coping alone. Participants reported that during the vocational programme the individual with brain injury gained greater awareness of their limitations and the implications of these and were better able to identify realistic goals. By working toward a long term goal, in that the vocational rehabilitation programme aimed to achieve meaningful occupational goals (paid employment, further education or training or voluntary work) it was perceived by both the person with the brain injury and their significant other as providing a sense of purpose for the future.

All participants reported that generally their family members mood had improved during the time they had been attending the vocational programme and this was reflected in an increased sense of well-being for the significant other. As one participants states:

> 'the course generally has definitely been, has had a positive impact on my mood because I see this as a step forward for (him) ..... and it is looking toward the future which is... good'.

There were also some aspects of the vocational rehabilitation that were perceived by participants to be experienced negatively by their family member in that it highlighted to the individual the label of someone with a brain injury and some frustration was experienced when elements of the rehabilitation were perceived as not relevant. Participants reported experiencing periods of reduced confidence and emotional distress for their family member if they encountered 'set backs', for example when progress slowed, the individual experienced a new 'hurdle' or a limitation was highlighted. However, while participants reported some strain of having to support their family member through these low points they perceived these set backs as temporary and reported confidence in their ability to work through them.

Strategies for maintaining health and well-being

All participants reported generally feeling positive by the interview stage. They acknowledged some ongoing anxieties about the future and while it was accepted that further hurdles or set backs may be encountered by the person with brain injury participants expressed confidence in their abilities to cope with these.

Participants did not report significant physical health problems as a result adjusting to change and coping with the burden of caring for someone with acquired brain injury. Several participants reported temporary weight loss as an immediate response to stress at the time of the injury and the fatigue of coping with additional roles and demands was indicated in reducing general feelings of well-being. One participant reported an illness existing prior to the injury being exacerbated by periods of more intense stress following the injury. However, in relation to perceived vulnerability to illness most participants reported that their health had been good since the injury with several suggesting that they could not allow themselves to be ill. Participants reported maintaining their health and well-being by applying personal coping skills and by maintaining open communications within the family.

Personal coping skills

Participants described a number of coping strategies in order to maintain heath and well-being. These included religious support, personal coping style, setting personal goals, finding time for themselves, and stress management strategies

One participant benefited from religious faith and used prayer to cope with her initial emotional distress when faced with brain injury by her adult daughter. Another participant reported how having coped with earlier significant periods of stress including overcoming a significant health issue herself meant that she was a *'survivor'*, which had enabled her to cope with the *'devastating'* impact of a brain injury in the family. Another participant, explains how a problem-solving coping style and her outlook as *'quite a positive person'*, enabled her to focus on the positive aspects of her partner's recovery after brain injury.

> *'I lost quite a bit of weight when it first happened just because…… … you are at the hospital most of the day and everything but ….. I think because I am quite a positive person that's helped… …, I didn't sink into despair or anything I just look on the practical side of things'*

Participants attempted to find time for themselves as a break from the demands of supporting the person with brain injury. For some this involved taking a holiday, accessing support from family and friends to take over family responsibilities or engaging in activities that enabled them time outside of the home. This sense of respite was perceived as important for keeping stress to a manageable level and for promoting health.

Participants reported monitoring their health and one participant described how her health was used as an indictor of stress with symptoms of illness seen as *'a sign to step back and take a break.'*. Warning signs of deteriorating health were recognised and used as a cue to action to implement coping strategies.

Open Communication

The development of open communication and mutually supportive relationships were perceived to buffer the psychological impact of stress. Participants who felt able to discuss issues relating to the brain injury with the individual who had sustained injury reported experiencing less stress and feeling better supported. However, the use of communication to promote well-being was a less effective if the support was not mutual. Where the significant other discussed the concerns of the person with brain injury with them but did not feel able to express their own concerns in return, additional strain was experienced. Where families did not openly discuss issues relating to the injury the significant other reported greater burden of care.

Regardless of whether participants reported mutually supportive relationships with the person with brain injury, having somebody within the family network with whom they could communicate and share experience was perceived as supportive. Where the significant other is the parent of an adult child with brain injury the relationship with the other parent is important. The parents in this study reported some difference in the way in which they and their spouse responded to the needs of the person with brain injury. The male spouse was reported to offer the practical support within the family with the wife providing more emotionally based support.

One family who reported strong, mutually supportive relationships within the family also reported less stress and adjustment issues following the injury. Within this family the support provided by the significant others to the individual with brain injury was reported to be reciprocal with the person who had sustained the brain injury also acting as a significant source of support for other family members. These participants attended for interview together and described how they could *'talk things over together'*. They reported how by maintaining open communication the brain injury had improved family functioning by bringing the family closer together. On describing their relationship with their family member with brain injury one of these participants stated:

'I think it is better than normal. I think we have got a lot closer........I think we have got a lost closer to him. .... I think perhaps we need him as much as he needs us'.

Discussion

This research explored the experiences of significant others of adults with acquired brain injury, who were attending a vocational rehabilitation programme. It aimed to investigate the way in which family members cope with the, often considerable, disruption to relationships and family life following brain injury. It is established in study 2 of this thesis that the individual who sustains the brain injury undertakes their own process of adaptation and adjustment as they attempt to come to terms with changes and loss. In this study the accompanying journey of coming to terms with change, experienced by the close family members, is uncovered. Results indicate that the close family member faces four phases or tasks to be accomplished. Successful and healthy adaptation to these tasks requires the individual to a) let go of the past and come to terms with sense of loss, b) cope with the immediate often multiple demands of supporting the person with brain injury while adopting additional roles, c) re-establish a sense of normality and d) ultimately to regain a sense of purpose and be able to refocus on future aims and goals.

This is a dynamic, interactive model, which may be subject to individual differences. Furthermore, achieving a final stable state of adjustment is unlikely. Rather any of these phases may be revisited as new challenges are faced and the family deal with the changing nature of living with somebody with brain injury in a 'never-ending cycle of adaptation' (Verhaeghe, Defloor & Grypdonck, 2004). While this model of coming to terms with change incorporates traditional stage models of acceptance after brain injury these models of grieving tend to relate largely to the emotional demands of letting go of the past. The model proposed in this study goes beyond this phase and suggest that there are further tasks to be negotiated that involve considering not only the emotional acceptance of loss but at the same time dealing with the practical demands, role change and significant reorganisation of self, family and future lives.

There are similarities between the adaptation process undertaken by the individual with the brain injury and their close family members and dealing with loss is a key theme in both. Cagnetta & Cicognani (1999) in a grounded study of the adaptation strategies and quality of life of severely injured accident survivors indicate that the adaptation process follows a sequence of temporal phases characterised by different emotional reactions, needs and coping strategies. They describe a process of 'rebirth' as the accident survivor attempts to restore a sense of well-being and control over their lives. While there may be similarities in some of the psychosocial tasks faced by the individual with brain injury and their close family members there may be a mismatch between the phase of adjustment each person is in. The person with the brain injury may be protected from facing a sense of loss due to poor insight and awareness. This misalignment of adjustment can be an additional source of stress to the family member

who may recognise the considerable changes that will need to be made and experience frustration and resentment if the person with brain injury themselves do not. The family member may be facing the additional pressure from the demands of care giving, lack of support from the injured person, shrinking social worlds and financial strain.

One of the key initial aims of this study was to investigate the relationship between the adjustment of the brain injury survivor and the emotional response of their significant other. These results indicate that the emotional response of the person with brain injury was one factor influencing changes in mood in the significant other and the development of self-awareness by the individual with brain injury was one factor influencing their emotional response. While this supports a link between self-awareness and mood in the injured person and the psychological well-being of the significant other this association is situated within a more complex network of influencing factors. It is also noted that initially the emergent of awareness of deficits by the brain injury survivor may lead to low confidence, reduced self-worth and emotional distress resulting in additional psychological strain for the significant other. However, in the longer term, as the brain injured individual acknowledges and adjusts to their change in abilities and establishes more realistic expectations of the future, this may facilitate the process by which the significant other can begin to refocus on the future. The vocational rehabilitation programme was seen as an important facilitator of this process.

The availability, access to and satisfaction with information and support was identified as another key factor mediating the significant other's psychosocial response to change following the brain injury. However, this information and support is not always available. The findings of this study are consistent with existing literature that suggest that even soon after discharge from hospital carers want more information. In many cases the need for information is unrelated to the severity of injury or level of functional deficit and requests for information are often not made spontaneously but require prompting (McPherson, McNaughton & Pentland, 2000). Junque, Bruna & Mataro (1997) indicated that the perceived changes in behavioural and affective symptoms, and in the patient's quality of life, were most closely associated with the need expressed by family members for information regarding traumatic brain injury. These findings emphasise the importance of providing close family members of individuals with brain injury with information about the consequences of the injury particularly in relation to behavioural and emotional disturbances, in order that they might cope better with these difficulties.

The need for services to provide support to family members of survivors of brain injury, both in response to immediate needs and in the longer term is highlighted. The provision of written information, social work liaison programmes, long-term follow-up and peer support have all been indicated as beneficial supports in promoting coping for families of individuals with brain injury (Morris 2001; Albert, Im, Brenner, Smith & Waxman, 2002; Armstrong & Kerns 2002; Hibbard, Cantor, Charatz, Rosenthal, Ashman et al., 2002; Ergh, Hanks, Rapport & Coleman, 2003; Hawley, Ward, Magnay & Long, 2003). The provision of professional support to families after brain injury can promote effective coping skills that overtime can enable family members to cope with their situation better even after intervention (Cope & Wolfan 1994, Kreutzer, Serio & Bergquist, 1994c, Tyerman & Booth 2001).

Interventions that promote psychological health within the family may also promote recovery in the injured person. It has been found that the response of the family member can have a significant effect on the injured persons psychosocial adjustment. For example, rehabilitation after stroke proves to be less successful if the partner feels stressed or depressed (Carnworth and Johnson 1987). Effective use of problem solving and behavioural coping strategies by the family in response to traumatic brain injury was found to be significantly related to lower levels of depression in the person who sustained the injury (Leach, Frank, Bouman & Farmer, 1994). Sander, Caroselli, High, Becker, Neese & Scheibel (2002) found that persons with unhealthy family functioning showed less improvement over the course of a post-acute rehabilitation programme as measured on the Disability Rating Scale than those with healthy family functioning. The role of family functioning and family support in promoting successful outcome of vocational rehabilitation requires further investigation.

The findings of this research indicates that the family needs for information and support can be met by providing information to family members regarding the physical, cognitive and emotional and behavioural changes that may be encountered and that this information should be given before the brain injury survivor is discharged from hospital. Information about additional sources of support should also be given at this time. Access to an advisory service that can give guidance to family members and support when required may also be beneficial. Where family member are not able to travel to support groups telephone support or, as one participant suggested, email contact may be supportive. For families who experience dysfunction more intensive intervention to promote coping skills and problem solving may be required.

Significant others of individuals with acquired brain injury were found to use a range of personal coping skills to maintain health and well being. Coping strategies can generally be divided into those that are problem-focused, where the individual directs their efforts on dealing with the cause of stress,

and emotion- focused, where the aim is the reduction of the emotions provoked by the stressful situation. The most frequent emotion-oriented coping mechanisms reported to be used when a family member sustains a brain injury are denial and escape or avoidance in the form of the use of alcohol and medication. (Mauss-Clum & Ryan, 1981; Livingston 1987; Hall 1994). Malapdative coping mechanisms also include the ignoring of tasks, development of poor communication patterns, unrealistic thinking, projection of self anger onto professional carers and withdrawing from reality (Cope & Wolfan 1994).

Participants in this study reported the use of few maladaptive strategies although some avoidance was indicated by participants who reported focusing on practical considerations to avoid the anxieties of coping with uncertainty. Religious support was relied on by one participant who used prayer to cope with feelings of anger resulting from questioning 'why?' when her family member sustained a brain injury. Spiritual belief and faith has been reported as an emotion-oriented coping mechanism that can provide the basis for effective coping (Kasowsky 1994, Minnes et al. 2000). All but one participant in this study was female. Gender differences in the use of coping strategies have been identified with women tending to use more socially orientated coping mechanisms such as seeking self-help groups, while men tend be cope more individually and may be reluctant to discuss their needs (Giles 1994, Kreutzer et al. 1994b, Linn et al. 1994).

Families in which there was open communication and mutually supportive relationships reported feeling more supported and better able to cope with the burden of care. This was particularly evident in one family in which a strong reciprocal, supportive relationship with the family member with brain injury was reported with this family also reporting positive gains in family functioning following the injury. Existing research has highlighted the importance of reciprocal affective relationships with the brain injury survivor for effective family coping (Kreutzer et al. 1994b, Kolakowsky & Kishore 1999, Anderson et al. 2002). Montgomery and Evans, (1983) suggest that in supporting families after brain injury it is important to facilitate communication and help to develop skills in 'leveling, listening and validating'. Within this study all participants reported gaining a sense of purpose and retained optimism and physical and psychological health was generally maintained. Other studies have also indicated that generally family members do cope when an individual within the family sustains a brain injury (Boyle and Haines (2002). Kreutzer, Gervasio & Camplair (1994) compares adaptation to traumatic brain injury with that of other disorders and found that the process of dealing with TBI is 'less healthy' than that of dealing with other illness conditions, such as multiple sclerosis but that families of people with brain injury function 'more healthily' than families of psychiatric patients.

Further research to investigate the experience of significant others of individuals with brain injury who do not find a way through the process of coming to terms with change after the brain injury is warranted to identify how family members may become stuck within the adjustment trajectory and how they can be supported. It is noted that the individuals with brain injury attending the vocational rehabilitation programme to whom the experiences in this research are related all progressed to achieve successful employment outcomes. Further qualitative study of significant others of individuals who attend the vocational rehabilitation programme but do not achieve positive outcomes or individuals who are not accepted onto the vocational rehabilitation programme because they are not considered to have vocational potential would be useful additions to this research.

In grounded theory research, context is embedded in the phenomenon that is being studied, and consequently an individual's experience cannot be understood outside of the context in which it occurs (Caron & Bowers, 2000). The specificity of the context of this study, that is the experience of close family members of an individual who has acquired a brain injury and has attended vocational rehabilitation programme, which included attending a work experience placement, and subsequently achieved a positive employment outcome and where the family member was willing to attend for interview, is noted. Generalization of these findings to other contexts should be made with caution and further research is required.

Conclusions.

In a literature review of stress and coping among families of patients with traumatic brain injury Verhaeghe, Defloor & Grypdonck, (2005) conclude that there is not much information available about the 'process whereby family members some to terms with having a brain injured patient in the family'. The findings of this study indicate the process and adaptations family members make as they adjust to the many changes to relationships and family life forced upon them by an acquired brain injury. The participants in this study generally reported healthy adaptation and found their own methods of coping with stress. Significant others were found to experience less psychosocial dysfunction following a brain injury when the individual who has the injury experiences, or expresses, less emotional change following their injury, adequate information and support is available enabling a realistic expectation of recovery, there is open communication and mutually supportive relationships within the family and the significant other is able to utilize adaptive coping strategies.

Vocational rehabilitation can play a role in meeting the support needs of the family members and in facilitation a sense of purpose for the future. However, access to adequate, timely support is often reported as an unmet need and the implication for support and intervention needs are discussed. It is noted that the transferability of these findings are limited by a relatively small sample size drawn from a specific population of individuals who successfully completed vocational rehabilitation and later achieved occupational outcomes. Further qualitative research is called for to compare these findings with the experience of families of individuals with acquired brain injuries who do not achieve positive vocational outcomes. An investigation into the experience of families who display maladaptive coping following brain injury would also be beneficial in order to identify their specific support needs.

Research Summary and Recommendations

Following and acquired brain injury individuals may have limited understanding of the nature, degree or impact of their impairments. Individuals who lack this awareness tend to overestimate their abilities, may be resistant to therapy and reluctant to learn strategies to compensate for their limitations. More accurate awareness of deficit following an acquired brain injury may also be related to rehabilitation gains and increased functional outcome. However, greater self-awareness may also be associated with greater psychological distress.

There is some evidence that unawareness of deficits in the individual with brain injury may predict emotional distress in significant others, especially in those who lack social support. It is also suggested that emotional and behavioural changes in the individual with brain injury is related to lower mood and higher levels of perceive burden in their significant others. It is important to understand the emotional and psychological impact of increased awareness on both the individual and their significant other in order to develop a therapeutic rehabilitation programme and provide appropriate support in response to changes in mood.

Research Aims:

This series of studies aimed to investigate the process of increased awareness, acceptance and adjustment in adults with acquired brain injury attending vocational rehabilitation and their significant others.

Study 1 examined the relationship between awareness, mood and quality of life in adults attending rehabilitation less than two years after injury, and more than two years after injury, to investigate changes in this relationship with time.

Study 2 aimed to develop a model of the psychological impact of increased awareness, acceptance and adjustment in adults with acquired brain injury undertaking a vocational rehabilitation programme.

Study 3 aimed to gain in depth understanding of the changes in mood and health experienced by significant others of adults when a close family member or partner sustains a brain injury. Initially, the experiences of the significant other as the individual with acquired brain injury progressed through the stages of increased awareness, acceptance and adjustment, while undertaking a vocational rehabilitation programme, was the focus for this research.

Methodology:

A mixed design, which included both quantitative and qualitative methods, was used to answer different questions and progress understanding of the research topic on different levels. The use of 'mixed methodology' (Tashakkori & Teddlie 1998) is being more widely used in social science research, within the concept of 'pragmatism', which calls for compatibility between the previously opposing paradigms of 'positivism', underlying quantitative methods, and 'constructivism', underlying qualitative methods. Tashakkori and Teddlie (1998) refer to 'paradigm relativism' to describe 'the use of whatever philosophical and/or methodological approach works for the particular research problem under study'. Quantitative methods and statistical analysis was used to answer the research questions on Study 1. Qualitative methods of semi-structured interviews and grounded theory analysis were used to explore the experiences of participants in Study 2 and Study 3.

Conclusions:

Anxiety, depression and lower quality of life are common in adults accepted for vocational rehabilitation. The incidence of depression was found to increase with time since injury, up to two years post injury however no relationship was found between awareness and time since injury. Increases in depression over this time may be facilitated by other factors such as reduction in contact with professional support, not having returned to employment and increased social isolation. Qualitative data supports these conclusions and indicates that while emotional distress can be experienced as a response to increased awareness of deficit and the experience of functional loss, additional factors act to moderate these mood changes.

For participants starting vocational rehabilitation less than two years after their injury, higher levels of anxiety and depression were found in those who indicated greater awareness of their deficits than in those who indicated lower levels of awareness. This suggests that reduced awareness continues to protect against mood disorder in the longer term, up to at least two years post injury. However, it may be that the contributing factors indicated in maintaining low mood in individuals with greater awareness over time may also lead to a deterioration in mood in those who lack such awareness. There is evidence that long-term unemployment is detrimental to mental health and given that individuals who attend for vocational rehabilitation are those who have not made a successful return to work it may be expected that those who have been out of work for some time will present with poor psychological health regardless of their degree of self-awareness.

A theoretical model of achieving adjustment to the impact of brain injury through a process of increased self-awareness of deficits and subsequent adaptation to functional loss was developed. It is suggested during vocational rehabilitation individuals with acquired brain injury develop greater self- awareness by experiencing limitations through activities that are meaningful and relevant to their perceived goals and that the work experience placement is important in offering these experiential opportunities. Changes in mood and health that accompanied this adjustment process were identified. Mood and health are perceived as interrelated by many individuals following brain injury and the promotion of healthy behaviours are perceived as promoting well-being.

The experience of significant other's of individuals with brain injury was identified as process of coming to terms with change that required the close family member to undertake the following four cognitive and emotional tasks: letting go of the past, which includes coming to terms with sense of loss; coping with the immediate often multiple demands of supporting the person with brain injury; re-establishing a sense of normality and, ultimately, regaining a sense of purpose which enables the significant other to refocus on future aims and goals. The demands of adjusting to considerable change to roles and responsibilities, when a brain injury is sustained by a close family member, was perceived to produce burden of care. The emotional response of the brain injury survivor and the degree of social support available mediated the degree of psychological stress reported. Significant others use a range of personal coping skills and utilize reciprocal communication networks within the family in order to maintain a sense of health and well-being.

Significant others were found to experience less psychosocial dysfunction following a brain injury when the individual who has the injury experiences, or expresses, less emotional change following their injury, adequate information and support is available enabling a realistic expectation of recovery, there is open communication and mutually supportive relationships within the family and the significant other is able to utilize adaptive coping strategies. Vocational rehabilitation can play a role in meeting the support needs of the family members and in facilitation a sense of purpose the future.

Recommendations:

The following recommendations are derived from the clinical implications of these studies.

1. An assessment of mood, including indications of anxiety and depression should be conducted at the outset of vocational rehabilitation with all individuals accepted onto such rehabilitation programmes. Where standardized assessment methods are used to identify those scoring within at clinical levels of mood disorder further investigation should be carried out with the individual to ascertain the nature of these emotional issues and identify appropriate sources of support. Referral may be required to outside therapeutic service were the emotional support needs of the individual cannot be met within the rehabilitation services. The individual's mood should be monitored during the course of the vocational rehabilitation programme to identify when further psychological support may be required.

2. The importance of structure provided by rehabilitation in improving mood was highlighted and the relevance of activity and structure for well-being has been indicated in studies of the psychosocial benefits of employment. These benefits should be considered by professionals of inpatient services when preparing the individual for discharge. The individual should be encouraged to plan daily activities which could include domestic tasks, leisure activities or where appropriate vocational options such as voluntary work.

3. Information should be provided to family members prior to the person with brain injury being discharged from hospital. This information should include not only information on the medical and physical needs of the individual but also about any cognitive, emotional and behavioural changes that may be expected. Significant others should be informed of the sources of support available for both the brain injury survivor and themselves. Family members should be included in discharge planning which should include an investigation into the social support networks of the individual with brain injury and the family. If there is an identified lack of social support for the significant other this may signpost the need for additional professional support or intervention to prevent a deterioration in psychosocial health.

4. Family support service should consider issues of accessibility and identify means for delivering support remotely and telephone advise services can be beneficial. The use of formally run email support groups or video conferencing has yet to be explored.

5. Many rehabilitation services engage family member in the planning and delivery of programmes for the individual with brain injury. However, the introduction of interventions for family members is recommended particularly for family members who present with high levels of burden, utilize largely emotion focused coping skills, such as denial or avoidance, who have little social support and who do not report open communication within the family. Interventions to promote these coping skills may not only improve psychological well-being in the family member but may also promote recovery and rehabilitation gains in the individual with brain injury.

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SECTION C

Professional Practice

AREA OF COMPETENCE: Teaching And Training

Approaches To Managing Deficits Of Awareness: In-House Staff Workshop

SETTING: Rehab UK (not for profit organisation)

TARGET GROUP: Rehab UK's London Brain Injury Service's vocational rehabilitation staff team

DESCRIPTION OF WORK: To teach vocational rehabilitation staff about managing issues of awareness in adults with acquired brain injury.

PLANNING AND DESIGNING TRAINING PROGRAMMES THAT ENABLE STUDENTS TO LEARN ABOUT PSYCHOLOGICAL KNOWLEDGE, SKILLS AND PRACTICES

In February 2005, it was agreed by Rehab UK's London Brain Injury Services' Operations Manager and Senior Psychologist that a series of in-house staff workshops would be arranged to develop skills within the rehabilitation team. These would be delivered once a month by the Senior Psychologist or other relevant staff and would be reviewed after three months to assess their value to the team. The Senior Psychologist contacted all staff by email to ask for feedback on their training needs. She provided suggestions of key topics and asked staff to highlight the main areas they would like training in. 'Approaches to managing deficits of awareness' was identified as one of the three preferred topics and a training session was proposed for 7th April 2005. I was asked by the Senior Psychologist to present this training, as it was an area in which I was conducting research.

A training needs assessment questionnaire was designed (see Appendix C.1) and distributed to all staff to identify the extent of learners current knowledge, areas for further development and preferred style of delivery. The responses were collated and reviewed (see Appendix C.2 for summary of training needs). Most trainees reported that they would prefer some interactive methods of training, in addition to didactic teaching, and this was incorporated into the proposed training plan (see practice log for draft training plan). This training plan was presented for feedback to the Senior Psychologist, who suggested that, due to limited time, it may be necessary to shorten the group work session. The training plan was amended in light of this recommendation and the final plan distributed to the rehabilitation team (see Appendix C.3 for Training Plan).

The aims and objective of the training were identified and included in the training presentation. Teaching materials were designed based on key literature and resources available from colleagues within the organisation who had attended external training of a similar nature. Additional research was carried out to address the questions identified by learners in the training needs questionnaires.

DELIVERING THE TRAINING PROGRAMME

It was identified that the equipment required for a PowerPoint presentation was available within the centre and this equipment was checked to ensure working order.

Prior to this training I had experience in providing training presentations (to referring agents, at family information evenings and in training with clients). I had been observed training and received feedback by Rehab UK's Education Co-ordinator, (see practice log for observation report) and have attended Stage 2 workshops on teaching and training and received feedback on my training skills from my Supervisor. I implemented this feedback in this training by carefully considering the learning needs of the audience, identifying and stating the aims and learning objectives and including interactive teaching methods.

On 7th April 2005 the training was delivered to 14 members of the rehabilitation team. The training plan was generally adhered to in terms of content and time scales. Two slides were omitted toward the end of the training due to time pressure. However, it was identified while designing the training what information was optional and which slides could be missed out or skimmed over if necessary.

Learners where encouraged to ask questions during the training and to share knowledge with each other. Learners were also informed that further requests for information could be addressed outside of the training.

PLANNING AND IMPLEMENTING ASSESSMENT PROCEDURES FOR THE TRAINING PROGRAMME

During the training session the learning objectives were assessed by asking questions to check learners understanding of the material provided and by the case study exercise; which provided opportunity for learners to apply the knowledge presented to a clinical example.

It was planned that the extent to which the training met the learning outcome would also be assessed informally via an evaluation questionnaire, which asked learners to rate the degree to which they agreed

that their knowledge and skills in the areas relevant to the training objectives had increased as a result of the training (see Appendix C.8 for evaluation questionnaire).

Given the nature of the work and that a key aim of the training was for learners 'to be able to apply this knowledge appropriately when working with clients with deficits of awareness' a naturalistic rather than academic, knowledge based, assessment was planned. This assessment involved a sample of learners completing a questionnaire at 6 week follow up to give feedback on the extent to which the skills they had gained in the training had been applied within their work practice.

EVALUATING THE TRAINING PROGRAMME

The evaluation questionnaire was designed and distributed to all learners following the training. Responses were reviewed and collated (see Appendix C.5 for evaluation summary). This evaluation highlighted that most learners agreed that, as a result of the training, they were more aware of models of awareness after brain injury, the causes of lack of awareness, the range of methods for assessing awareness, different treatment approaches and techniques for facilitating awareness and felt more confident to apply these approaches when working with clients with deficits of awareness. However, one learner disagreed with the statement that that they were more able to identify different treatment approaches and another learner disagreed with the statements that they understood more about different techniques for facilitating awareness or that they felt more confident to apply them.

Feedback on the style of the training showed that learners would have liked a longer training session with more interaction and case studies. The evaluation summary was sent to the Operations Manager and Senior Psychologist to be included in the overall appraisal of the staff training workshops.

Six weeks after the training the follow-up evaluation questionnaire was designed and circulated to staff (see Appendix C.6 for follow up questionnaire). The responses were reviewed and it was noted that one member of staff had referred to the training materials for reference and one member of staff reported applying some of the approaches introduced in the training into their work practice.

The training and feedback was discussed with the Operations Manager in my performance review meeting. Opportunities for further training were discussed and viability of providing training to external professionals considered. The training session had been video taped and this tape was reviewed together with the evaluation feedback in order to identify ways in which the training programme could be modified for future use.

The following areas for improvement were identified and agreed with the Senior Psychologist.

- Less presentation of theory about the causes, models and assessment methods of deficits of awareness. This training was delivered to experienced rehabilitation staff who had some understanding of the issues of awareness that arose in clinical practice and an in-depth knowledge of theoretical issues is not necessary in order to develop rehabilitation approaches for managing deficits of awareness.

- More focus on approaches and techniques for managing deficits of awareness and consideration of these methods in relation to the clinical issues the rehabilitation staff have experienced.

- A more interactive style, interspersing short periods of presentation with short sessions of group work, brainstorming, or discussion of relevant clinical problems. It would have been useful to present of a real of case example and for the group to develop an awareness management plan relevant to this case which can then be implemented in the rehabilitation setting.

SUMMARY AND REFLECTION

Overall the feedback from the training event was positive and a training package has been developed which could be delivered to new members of staff, to other Rehab UK Brain injury Centres and to other professional groups working with clients who have had a brain injury. Key learning points from this experience have been developing the skill of obtaining the right balance of information to suit the audience needs. In this case, I had to provide sufficient and relevant information but not too much theory. I encouraged those who wanted additional information to request it.

This training erred toward a presentation style delivery at the beginning of the training followed by an interactive group exercise at the end. On reflection I would have used a more interactive style of delivery from the beginning in order to engage the audience. This could have been done by starting the training with a brainstorm of what the audience understood by 'deficits of awareness' or to identify the difficulties they experience when working with clients with lack of awareness.

Following this training I identified that I tended to feel more comfortable with a presentation style of teaching. I have since developed and practiced more interactive training methods and adapted the stress management training programme, delivered in the centre, to include a wider range of training approaches (see Case Study 2). I have also given greater consideration to assessment and evaluation methods and have developed an evaluation protocol for the Awareness training sessions delivered to clients.

AREA OF COMPETENCE: TEACHING AND TRAINING

STRESS MANAGEMENT TRAINING

SETTING: Rehab UK (not for profit organisation)

TARGET GROUP: Adults with acquired brain injury

DESCRIPTION OF WORK: To teach adults with acquired brain injury attending Rehab UK's vocational rehabilitation programme about the nature of stress and to train them in the application of stress management strategies.

PLANNING AND DESIGNING TRAINING PROGRAMMES THAT ENABLE STUDENTS TO LEARN ABOUT PSYCHOLOGICAL KNOWLEDGE, SKILLS AND PRACTICES

Training in stress management skills is a core element of Rehab UK's vocational rehabilitation programme. The training incorporates understanding the nature of stress, an introduction to anxiety and anger responses and an explanation of why changes in anxiety or anger may occur after a brain injury. The training then progresses to introduce stress management strategies and to provide practice and feedback to support learners to adopt these strategies when appropriate. The training is delivered by a member of the psychology team to each intake of clients beginning the vocational programme. Training sessions are delivered over a period of 12 weeks in Element A with a further 12 week training, focusing on cognitive restructuring strategies and assertiveness skills, in the second element of the programme.

Feedback from clients, both verbally and via regular client satisfaction surveys, suggested that these training sessions tended to be too theory based and presented in a taught 'chalk and talk' rather than interactive manner, which did not motivate or facilitate learning. Similar feedback was provided by the Rehab UK Education Co-ordinator who observed one of the stress management training sessions I facilitated in October 2004 (see practice log for observation feedback report).

In discussion within the psychology team it was recognized that changes were required to the stress management module. Due to workload it has not yet been possible to systematically revise the training curriculum and content but it was agreed that revisions to the existing curriculum would be developed as the training was implemented. Updating of this curriculum was also required as a result of timetabling changes in which the stress management module was extended from one 45-minute session to two consecutive 45-minute sessions a week.

The need for training in stress management for this learning group is indicated by the literature. Problems in controlling anger are often experienced after a brain injury and may persist for many years after injury[1]. It is suggested that anxiety is most common 6 – 12 months after brain injury[2] but may continue to be experienced for some time with a study of individuals within 2 years of injury indicating that 26% were clinically anxious[3].

The individual needs of this group of learners were first assessed in an initial interview attended before they began the programme as part of their referral process. Of the ten learners attending this training four reported issues with stress and frustration (related to the limitations resulting from their brain injury), one reported issues with anger control, another reported feelings of anger leading to withdrawal and another reported significant issues of anxiety. At the outset of the stress management training a formal assessment of anxiety was undertaken using the Hospital Anxiety and Depression Scale[4], on this assessment 3 clients were assessed as within the borderline caseness range for anxiety.

DELIVERING THE TRAINING PROGRAMME

The training was delivered to a group of ten learners between April 2005 and July 2005 using a mixture of tutor led presentations, group discussion and small group work. Emphasis was placed on making the training as interactive as possible with learners encouraged to share experiences, ask questions and to comment of the information presented. The aims of each session were identified and session plans were updated prior to each session. Session materials and handouts were either collated from previously used material, materials used in other Rehab UK brain injury centres or designed specifically for the session (see practice log for training materials).

As a result of their brain injury some learners experienced language difficulties and required additional support to read handouts or to complete written worksheets. A learning support worker was allocated to the sessions to address these additional learning needs. An attempt was made to use teaching models to match individual learning styles. Within the centre various methods of assessing learning styles had been piloted. A short questionnaire assessment had been used to identify whether learners were a visual, auditory, tactile or kinaesthetic learners. Later a more comprehensive Learning Styles Inventory was

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[1] Lezak, M. (1987) Relationships between personality disorders, social disorders, social disturbances, and physical disability following traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 2(1), 57-69.

[2] Ibid

[3] Kinsella, G., Moran, C., Ford, b., & Ponsford, J. (1988). Emotional disorder and its assessment within the severe head injured population. *Psychological Medicine*, 18, 57-63.

[4] Zigmond, A.S. & Snaith, R.P. (1983) The Hospital Anxiety and Depression Scale. *Acta Psychiatr Scand.* 67:361-370

used to identify whether learners where 'activist', 'reflector', 'theorist' or 'pragmatist'[5]. However, these assessments relied on learners self-report and learners themselves indicated that they found it difficult to answer the assessment questions accurately in relation to their current preferences and that their responses may reflect their pre-injury learning styles.

At the time of this training, learning preference was inferred from any neuro-psychological assessment reports available and other assessment records indicating the client's cognitive strengths and weaknesses. Within the training, materials were presented in different ways to accommodate a variety of learning styles. For example a handout may include written and visual information and be read out by the tutor to promote auditory learning and group work activities included to promote interactive learning.

PLANNING AND IMPLEMENTING ASSESSMENT PROCEDURES FOR THE TRAINING PROGRAMME

Informal assessment was carried out during the training sessions by asking learners questions to clarify their understanding of the material presented. The training also required learners to complete worksheets to demonstrate their ability to apply the information to their personal situation. A record of each learner's progress was logged in session notes written after each session. At the end of the training module each learner was asked to complete an assessment quiz (see Appendix C.7). These questions were then discussed in the group to provide a review of the programme.

The stress management training is incorporated within an educational programme that enables learners to work toward National Skills Profile (NSP) certificates, awarded under contract with a local college. The Element A stress management training provides a background to some of the skills required for the NSP Personal Development Module 4 'Developing Relationships' and Module 5 'Demonstrating Personal Rights and Responsibilities'. These skills are formally assessed in the Stress Management Training delivered in Element B of the vocational programme (see practice log for assessment materials).

EVALUATING THE TRAINING PROGRAMME

At the end of the training learners were asked to complete an evaluation questionnaire, to identify the extent to which they had benefited from the training and to comment on the training content and delivery (see Appendix C.8). The feedback indicated that on the whole learners agreed that they

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[5] Honey, P. & Mumford, A. (1992) *The Manual of Learning Styles.* Peter Honey Publications. Maidenhead.

understood more about the factors that cause and maintain anger, anxiety and stress and the impact that these response could have on their lives and were more aware of a range of stress management techniques. However, not all learners agreed that they were more motivated to tackle their stress, could identify their early signs of stress or were able to apply stress management techniques effectively. This suggests that while learners are gaining knowledge the training is not as successful at developing skills that can be applied outside of the training setting.

SUMMARY AND REFLECTION

The stress management programme is a core element of the vocational skills developed by clients attending the centre and feedback from learners suggests that most find the training beneficial. It is recognised that the training curriculum requires further revision in order to develop skills that can be transferred to other settings. The development of the training programme will continue to be reviewed within the psychology team. From my experience of delivering this training I will be recommending the following adjustments.

- To reduce the amount of theory presented at the beginning of the programme. The introduction of practical strategies at an earlier stage may enable learners to practice and implement these more effectively.

- To introduce more creative approaches such as peer assisted learning in which learners investigate an aspect of stress management and deliver this to the group. 'Reciprocal peer tutoring'[6] is suggested to promote more active learning, greater ownership of the learning process and better transfer of knowledge and skills to new situations[7]

- Further consideration of different learning styles. In addition to reviewing information gained from previous formal assessments, a discussion with learners, about their preferred learning, style during the induction stage of the programme could be useful.

I delivered stress management training to a further group of learners in August 2005. The third session of this training was observed by my Stage 2 supervisor and was videotaped. (See Appendix C.9 for video clip and reflective commentary).

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[6] Fantuzzo, J., Riggio, R.E. & Connelly, S. (1989) Effects of reciprocal peer tutoring on academic achievement and psychological adjustment. A component analysis. *Journal of Educational Psychology*. 81(2), 173-177.
[7] Greenwood, C.R., Carta, J.J. & Kamps. D. (1990) Teacher-mediated versus Peer-mediated Instruction. A review of educational advantages and disadvantages, in Foot, H.C., Morgan, M.J. & Shute, R.H. (eds.) Children Helping Children. London & New York: John Wiley.

AREA OF COMPETENCE: Consultancy

Arts Project For Adults With Acquired Brain Injury

SETTING: Social Services

TARGET GROUP: Adults with acquired brain injury identified by an Adult Disability Team.

AIMS OF CONSULTANCY:

- To provide consultancy service for a pilot project to evaluate the functional, psychological and health gains of adults with acquired brain injury receiving a package of arts based therapeutic support.
- To provide education and information to families and guidance and feedback to service users.
- To provide assessment and goal setting, advice and supervision to arts therapists.

ASSESSING REQUESTS FOR CONSULTANCY

In November 2003 Rehab UK was contacted by the client, a Care Manager within the Adult Disabilities Team of local Social Services, who had secured funding for a pilot project to provide art-based intervention to people with acquired brain injury. Following discussion with my work place supervisor (a Consultant Clinical Psychologist) and line manager I contacted the client for further details of the project and to discuss the possibility of providing this input myself, as a Trainee Health Psychologist on behalf of Rehab UK.

Other psychologists had also shown interest in this role and I was asked to submit my CV with references and Criminal Records Bureau (CRB) check documentation for consideration. The client was keen for Rehab UK to be involved in the project as the organization is reputable within brain injury rehabilitation. A dialogue began regarding the service required, contracted hours and fees.

The project aimed to engage and motivate adults with acquired brain injury through a programme of crafts such as pottery, creative writing and drama. A review of relevant literature identified a variety of reports on the impact of arts in health and a small body of research investigating the use of art with people with acquired brain injury. (See Introduction of Evaluation Report – Appendix C.14 for literature review).

The project was planned to begin in January 2004 and was to run one day a week for a period of 12 weeks. The consultancy request was for both the delivery of psychological intervention, in terms of brain injury education to service users and families and working with service users to set individual goals, and evaluation of the project as a whole.

The client expected the following input:

- a 'psycho-educational' session for service users and families
- a session to assess and identify service users needs and set goals with the therapists
- a supervision session in week 6
- an evaluation meeting
- report write up
- regular supervision of tutors by telephone

The time commitment was a particular consideration to my line manager, in terms of releasing me from current duties at a time of heavy workload. It was agreed that further negotiations would be held with my line manager who requested written confirmation from the client of the planned input, time commitment and fees.

The contract was formally agreed by email on 22nd December 2004. It was established that I would provide 20 hours of input at an overall fee of £1000.

The client recruited two art facilitators, one to provide drama work and creative writing and another to provide visual arts and crafts, and a planning meeting was arranged for 19th January 2004. However I was not able to attend this meeting due to prior work commitments.

Reflection

The main challenge at this stage in the consultancy was developing a working relationship and establishing the service needs of the project. The exact aims and requirements of the consultancy were initially unclear, which in part reflected the novelty of the service being developed. As the consultancy developed I was able to discuss any ambiguities more openly with the client. However, it would have been helpful to confirm my understanding of these discussions and verbal agreements in writing to prevent misunderstanding. While time pressures did not allow for the development of a formal written proposal at the time, for training purposes a proposal was written retrospectively and presented to the client for feedback. (See Appendix C.16 for example proposal)

Another learning point at the contracting stage involved developing competency in negotiating payment for consultancy services, which I was previously unfamiliar with. I took guidance from my work place supervisor and was involved in the initial discussion of fees with the client, with the details negotiated by my line manager. For future reference I reviewed this process with my manager who provided advice on contracting skills.

PLANNING CONSULTANCY

Prior to the start of the project, telephone discussions took place with the client relating to the aims of the project and appropriate methods for assessment and evaluation. Together we brainstormed aspects of service user functioning the project could potentially impact on and identified the following: motivation and engagement in activities, development of compensatory strategies for cognitive difficulties, increased functioning in terms of activities of daily living and improved sense of autonomy, confidence and quality of life. It was agreed that due to the limited, short-term nature of the project quantitative evaluation methods would not be suitable. Alternative methodologies, e.g. observational, dairy and self-monitoring techniques and monitoring of motivation by reviewing attendance and completion of homework tasks were considered.

A number of practical issues were also resolved during these telephone contacts. For example we agreed that that a very open inclusion criteria would be used and that any service user living in the borough known to the Adult Disabilities Team who had had an acquired brain injury would be invited to attend.

We also discussed whether carers should be invited to the initial brain injury awareness sessions. We agreed that while it would be useful for carers to be aware of issues raised and to support work done in subsequent sessions it was also important that service users be empowered to identify their individual needs and set their own goals. It was agreed that carers would be invited with the service users prior informed consent.

A 'user led' approach was adopted for the project. This model has a history within mental health services (it is embedded within the NHS National Service Framework for Mental Health 1999) and the self-advocacy movement within services for people with learning difficulties.

It has more recently been introduced within the NHS as a means to empower people with chronic long-term medical conditions to become key decision makers in their own care. A report published by the Department of Health in 2001[8] refers to the 'expert patient' and to pilot programmes whereby the 'user led' model had been shown to enhance relationships between patients and healthcare professionals and lead to improved outcomes and patients' self-confidence. This framework has also been applied within brain injury rehabilitation as a means of identify the needs of this client group[9].

It was proposed that in applying this approach participants would be encouraged to discuss and identify their current barriers to daily functioning and in doing so be active participants in developing the nature and aims of further intervention. It was also hoped that this involvement would increase motivation and engagement in the group. Due to this evolving nature of the consultancy only the first session was planned in detail before the start of the project. The aims, objectives and session plans of subsequent workshops were devised following feedback from service users and arts facilitators (See Appendix C.10 for Aims, Objectives and Session Plans).

An 'expert model' of consultancy was used (Schein 1999)[10]. In this model the client defines the need or problem, and then purchases from the consultant information or an expert service they unable to provide them self. In this case the client was requesting input from a psychologist with experience in brain injury to provide brain injury education, assessment, intervention and evaluation. Schein points out that this model 'assumes that the manager knows what kind of nformation or service she or he is looking for and that the consultant is able to provide the information'[11].

An alternative model of consultancy, as proposed by Schein, is 'process consultation'. In this model both the client and consultant engage in a period of joint diagnosis, 'reflecting the reality that neither the client or the consultant knows enough at the point of initial contact to define the kind of expertise that might be relevant in the situation'[12].

[8] 'The Expert Patient: A New Approach to Chronic Disease Management in the 21st Century' (2001) Department of Health. http://www.doh.gov.uk/healthinequalities

[9] DARE Report - Review of Brain Injury Services. Part of the Best Value Review of Independent Living Services. The DARE Foundation Workshop Programme Aug 2003 to Jan 2004

[10] Schein. E.H. (1999) Process Consultation Revisited: Building the Helping Relationship. Addison-Wesley Publishing Company Inc. USA. pg 7

[11] Ibid pg 7

[12] Ibid pg 9

The goal of the consultant in this model is not only to help the client diagnosis the problem but also to help the client learn how to address the issue them self. Schein suggests that a consultancy should 'always begin in the PC (*process consultancy*) mode'[13] to undertake an initial inquiry before deciding whether it is desirable to move into another consultancy model.

Reflection

In this consultancy two services were being contracted for; the provision of information and training *and* the evaluation of the overall service. Planning for these required different approaches.

The intervention stage was consistent with an 'expert' led approach and was planned based on models of neuro-psychological rehabilitation. However, the 'user led' framework for working with the service users required a flexible, adaptive approach and changes were made to the initial plan based on feedback and expressed need. On reflection, an earlier assessment of the needs and expectations of the service users, possibly via focus group before beginning the project, or using the first meeting of the group as an informal discussion would have enabled the training element of the project to be more geared toward an audience-centred perspective.

The client was actively involved in the evaluation stage of the consultancy. The planning of the evaluation was conducted as a joint enquiry with the client to establish the aims and goals of the project and the desired outcomes. The client wished to have input into the evaluation methods and attended the focus group discussion with service users and facilitated the final evaluation meeting.

ESTABLISHING, DEVELOPING AND MAINTAINING WORKING RELATIONSHIPS WITH CLIENTS

Initially working relationships with the client was carried out via telephone and email contact. The client attended the first two session of the art group. This provided an opportunity to meet with her, and the two arts facilitators, to discuss the project and clarify expectations. Following this session the client gave positive feedback on the usefulness of the input, which reassured me that we were working toward the same aims.

I met briefly with the arts facilitators at the start and end of the sessions I attended, in order to receive their feedback on the development of the group and to review the previous session. This enabled us to develop a common perspective and to discuss future developments.

[13] Schein. E.H. (1999) Process Consultation Revisited: Building the Helping Relationship. Addison-Wesley Publishing Company Inc. USA. Pg 19

While planning the evaluation phase of the consultancy I discussed the evaluation needs with the client on the telephone, as she had expressed some concern that my evaluation needs may be different from hers. I ensured that she was kept informed of the methods and aims of the evaluation and she was sent drafts of the focus group protocol and evaluation questionnaires for her approval.

It was planned as part of the consultancy that the arts facilitators could call me if they had any concerns or needed any advice. However, they did not utilize this service and at the final review meeting expressed a wish for a more formal supervision method.

Reflection

Due to the tight deadline to begin the project, all people involved did not meet until the first session with service users. While a positive working relationship was developed throughout the course of the consultancy, the opportunity to meet and plan prior to the start of the project may have helped to clarify roles, build relationships and establish common working approaches earlier in the project.

The client established her main role as to identify funding and recruit professionals to provide the service. Following this she took a more 'backseat role' which resulted in a lack of identified 'leadership' within the project. However, the transfer of responsibility from client to consultant is consistent with the 'expert model 'of consultancy and in hindsight I would have taken a more boundaried approach to support the facilitators to keep the project within its remit. A learning point from this is the necessity to identify leadership and a point of contact within the consultancy proposal.

At the final review of the project it was apparent that the facilitators would have appreciated greater support, supervision and direction. More ongoing evaluation of working relationships throughout the consultancy may have identified this need earlier.

CONDUCTING CONSULTANCY

The project began on 2nd February 2004 (a few weeks later than originally planned due to the availability of all the people involved) and ran each Monday for a period of 12 weeks.

The client attended this session to give an over view of the purpose of the group. In this first session I provided brain injury awareness training and facilitated group discussion of the compensatory strategies the service users were currently using.

Following the first group it was agreed that I would attend a further session 3 weeks later to continue the assessment of need and facilitate goal setting. This took the form of an interactive workshop in which service users worked with each other to identify their own areas of strength and need. Individual goals were then identified by the service users and common issues identified as group goals, to be worked towards throughout the rest of the project. (See Appendix C.11 for Individual and Group Goals established in this goal setting session).

The therapists reported that the group goals identified in this session would be helpful for development of future sessions and I agreed to attend two further sessions, at 3-week intervals, to deliver workshops on memory strategies and assertiveness skills. While this would involve attending one more session than initially agreed it was established that this would be possible without exceeding the maximum hours of input agreed in the contract (See Appendix C.12 for revised timetable for consultancy).

On 10th May 2004 I attended the final meeting with the group. This involved a focus group with the service users for evaluation purposes and a final review meeting with the client and arts facilitators. It was agreed at this meeting that any further contact for review, evaluation or recommendation purposes would be carried out between the members of the team by telephone or email. (See Appendix C13 for minutes from final review meeting). The outcomes of the consultancy were documented in an evaluation report (See Appendix C.14).

Reflection

It was initially planned that I would work with the facilitators to develop methods for introducing cognitive strategies into their arts work. However, this was not developed fully due to lack of time to plan this. This highlighted the difficulty of implementing theory into practice in a consultancy setting. A learning point gained from this was the need to estimate the time available for others to be involved in a consultancy.

In addition the group began to take on a more social nature and the focus moved away from a cognitive retraining model. The facilitators reported that they had experienced some resistance from group members to both the art based work and the psychology input. They had found it hard to motivate the group and to find activities that engaged a group so diverse in interests and abilities. In response the group became less formal and a format for service users to discuss interests and issues. As the project progressed different expectations became apparent between the remit established by the client, the skills and experience implemented by the facilitators and the wishes of the service users.

MONITORING THE PROCESS OF CONSULTANCY

During the delivery phase of the project, progress was reviewed briefly with facilitators at the beginning and end of each session. However, these meetings were often interrupted or lacked focus due to competing practical demands, for example the room needing to be prepared for the session or equipment or resources needing to be returned to another part of the building.

I made notes following any contact with the client, and at the end of each training session summarising the input provided, any changes made compared with the input planned, observations of the group and feedback from the facilitators. These notes allowed reflection of the consultancy process and informed planning for the next stage. Care was taken to maintain confidentiality for the service users; initials were used instead of full names in notes and transcription of focus group evaluation. Materials relating to service users were kept in a locked drawer and notes kept on computer were password protected.

A final review meeting was attended by the client, the two arts facilitators and myself. The aim of this meeting was to review the perceived strengths and weaknesses of the project and to consolidate the service user and facilitator feedback into an action plan. The feedback from this review was incorporated into the evaluation of the project. (See Appendix C.14 – Evaluation Report)

Reflection

Again a more formal process of monitoring and review would have been preferred and would be consistent with an 'expert model' approach. Within this approach it would be the consultant's responsibility to initiate these processes and I could have taken a more proactive role in setting up more rigorous monitoring systems.

It was agreed at the review meeting that the art based work and the psychology input did not integrate as well as planned. This may have been partly due to the group developing into a support based group because of the emotional nature of the issues being raised. This led the arts work away from being a tool for assessing service user's cognitive needs and developing compensatory strategies. The psychological intervention continued to involve a more traditional training style and some conflict became apparent between the less formal facilitated 'arts' sessions and the psycho-educational approach.

In hindsight an emphasis on working through the facilitators may have been more effective. This could have been achieved by focusing the training on developing the facilitators' knowledge and skills in brain injury rehabilitation. They could then have used their skills to incorporate this training into the creative arts work using the relationship and rapport they had built with the service users.

EVALUATING THE IMPACT OF CONSULTANCY

The project was evaluated using a range of qualitative evaluation methods. This evaluation identified the following perceived benefits for some participants

- increased engagement and motivation
- a sense of social and emotional support
- increased independent functioning

The benefits reported in this evaluation broadly reflect those reported in the literature on the health and social impact of arts based interventions. While participants did not identify the psycho-educational workshops as directly relevant to these benefits they did report progress toward the agreed group goals.

The evaluation report was sent to the client for review and submitted by her to the funding body with the aim of applying for further funding to continue the project based on the recommendations of the evaluation. (see Appendix C.14 - Evaluation Report for full review of evaluation methods and findings; see Appendix C.15 for consent procedures)

Reflection

The evaluation stage of the consultancy allowed for a great deal of new learning on my part and I undertook research into qualitative evaluation methods including focus group and thematic analysis. The process of evaluation was useful in terms of linking the consultancy process and conclusions to the arts for health literature and gave reassurance of the validity and usefulness of the input provided. It was at this stage that I felt most confident. While the earlier process of consultancy had felt very much exploratory the evaluation stage could be planned in advance and utilized established methodology.

SUMMARY

On reflection, I can identify that at present I prefer to be involved in consultancy that is well structured and planned. The 'expert model' of consultancy meets these criteria as long as there is a clear remit and roles and expectations are clarified. I can identify that areas for professional development as a consultant are to build confidence and skill in establishing needs and developing systems with a client, if these are not initially clear, and in managing the needs and expectations of the different parties involved in a consultancy.

AREA OF COMPETENCE: OPTIONAL

5.1 Implement interventions to change health-related behaviour

SETTING: Rehab UK (not for profit organisation)

TARGET GROUP: Adults with acquired brain injury.

DESCRIPTION OF WORK: To design and implement a stress management intervention to address the needs of adults with acquired brain injury attending a vocational rehabilitation programme.

ASSESSING THE SUITABILITY OF CLIENT FOR HEALTH-RELATED BEHAVIOUR INTERVENTION

B is a 49 year old man who suffered a stroke in 2001 and who began Rehab UK's vocational rehabilitation programme in January 2004. At the initial assessment stage of the programme B expressed some issues with increased irritability (anger control issues are often observed following brain injury[1]). B attended a group anger and anxiety programme as part of the core curriculum of the rehabilitation programme for one 45 minute session a week for the first twelve weeks.

In July 2004 B began to experience regular headaches and consulted his GP. He underwent a medical assessment but no health changes were revealed. At this point B discussed with his Keyworker the possibility that these headaches may be stress related and he requested advice on managing this.

In accordance with Rehab UK procedures this request was discussed with the Senior Psychologist who identified that B may benefit from additional stress management training and he was referred to me to for intervention.

Reflection

B had previously been diagnosed with hypertension, Type 2 diabetes and angina all of which were being treated pharmacologically. Before beginning the intervention a literature review was carried out to identify the appropriateness of stress management training for an individual with these health issues.

Literature relating to the use of stress management techniques with adults with acquired brain injury identified some evidence for the benefit of relaxation in reducing anxiety[2] and a number of case studies that suggest that cognitive behavioural methods may be useful in reducing anger problems[3] in this client group.

A systematic review of literature relating to stress management in the prevention and control of hypertension identified that multi-component individualised cognitive behavioural interventions were effective, and comparable in some studies to weight loss or medication[4]. Cognitive behavioural stress management training was also found to reduce blood pressure reactivity in response to stress in individuals who showed enhanced blood pressure reactivity[5].

There is evidence that short-term group stress management training can improve long-term glycemic control in type 2 diabetes[6] and can reduce chest pain in men with angina[7]. It was therefore identified that a stress management training using cognitive behavioural techniques was appropriate for this client and could have significant health benefits.

IDENTIFYING AND NEGOTIATING THE BEHAVIOUR CHANGE GOALS OF THE CLIENTS

The first session of the intervention involved a contracting stage in which B's expectations of the stress management intervention were discussed and aims agreed. The long terms aims identified were to reduce the incidence of headache, reduce the need for painkillers and additional medication and in the long term reduce health risks. The immediate goals for the intervention where for B to gain understanding of the nature of stress, to recognise personal triggers and indicators of stress, to learn appropriate stress management techniques and to be able to apply these in the early stages of stress escalation.

ASSESSING THE COGNITIVE, BEHAVIOURAL AND SITUATIONAL DETERMINANTS OF, AND INFLUENCE ON, RELEVANT CURRENT BEHAVIOUR

Triggers for B's reported stress were discussed in the assessment session. B initially reported very specific non-personal situational determinants of his current behaviour and stated that he would respond to these withdrawing from the situation. B also indicated a reliance on medication as a method of reducing the headache and high blood pressure and reported taking these as a precaution when he anticipated stress rather than focussing on techniques for mastering the situation.

Physical and behavioural signs of stress were discussed with B. He reported not being aware of his physical escalation of stress and described it as an 'all or nothing' event. In order to identify early signs of stress an exploration was carried out in which B was asked to describe a 'stressful situation' in the session and observed changes in body cues were fed back to him. B also agreed to ask a close family member for additional feedback and further indicators were identified.

Initial concerns that B may have negative cognitions relating to discussing stressful situations or reporting occasions of anger expression were not realised. However, as the sessions progressed B reported a wider range of trigger situations for stress and it was observed that these tended to relate to situations in which B experienced, or anticipated, some set back to a planned course of action, which he tended to interpret in relation to the cognitive, visual or language difficulties he experiences as a result of his brain injury.

DEVELOPING A BEHAVIOUR CHANGE PLAN BASED ON COGNITIVE BEHAVIOURAL PRINCIPLES

In the initial assessment session potential barriers to behaviour change were identified as B's lack of knowledge of psychological stress management techniques (he reported that he had not successfully adopted the strategies suggested in the earlier group training and was unable to recall these) and an apparent reluctance to discuss his experience of stress other than in relation to very specific situations (this was later understood within the context of B not being able to recognise his own stress response and therefore only being able to report this in terms of health indicators i.e. increased blood pressure or headache).

Further exploration of B's motivation to learn strategies to manage his stress was carried out as the intervention developed. He was asked about his reasons for requesting intervention, how confident he was that he would be able learn and apply stress management techniques, what he believed were the consequences of not managing his stress better, how severe and how likely he saw these consequences and the perceived benefits of making a behaviour change. This enquiry was based on models of health belief and health behaviour (i.e. Health Belief Model[8] and Protection Motivation Theory[9]). The social support available to facilitate B's behaviour change and his 'social outcome expectancies', as emphasised in the motivation stage of the Health Action Process Approach,[10] were also explored.

B stated that his motivation for behaviour change was primarily concern about his health, his increasing use of medication and reported feelings of 'not being in control'. He identified the consequences of not learning to manage his stress as high risk of a second stroke or heart failure; he believed that people of his ethnicity and health issues were particularly susceptible to heart problems; a view supported by research literature[11].

Other facilitators of behaviour change identified were B's reported increase in confidence to manage his stress effectively and 'not accepting it' as the intervention progressed. Vocational benefits were also emphasised in that he would need to manage his stress in a work place if he is to return to employment.

A plan was established and agreed my with work place supervisor (see Appendix C.16). It was acknowledged that this plan may need to be flexible to allow B to work through the programme at a pace which enables him to master the strategies and allow for any 'detours' into more cognitive techniques.

The intervention was developed based on Stress Inoculation Training techniques[12]. In accordance with this model the intervention began with a 'conceptualization phase' in which B was educated about the nature and impact of stress. Initially B was introduced to the concept of a 'transactional model' of stress[13] and the physical response to stress discussed with reference to the 'fight or flight' model[14]. B's feeling of anger and stress were discussed in relation to this model and his physical signs of stress explored. B was encouraged to identify a cue term as a prompt to use stress management techniques when he noticed these signs.

He was guided through a 'skills acquisition and rehearsal stage', which included instruction in the following stress management techniques; progressive muscle relaxation, deep abdominal breathing, visual imagery and cognitive restructuring, followed by 'application and follow-through', which included practicing techniques and monitoring their effectiveness.

A graded introduction to each technique was applied. First the technique was described and demonstrated, B then practiced the strategy while it was modelled with him. Once he was able to apply the technique correctly he was asked to describe a stressful situation (this 'stressful scenario' was produced as a script to be used during these live practice session) and to monitor and report changes in physical stress levels. He was then prompted to use the cue term followed by stress management technique. Verbal cues were given to encourage attention to the changes in physical response before and after applying the technique. When a technique had been mastered B was encouraged to apply this method in real situations outside of the sessions.

Cognitive restructuring techniques were introduced throughout the intervention. While monitoring his stress response behaviour each week B was encouraged to identify the cognitions relating to the experiences he reported. Any irrational or negative thoughts were gently challenged and evidence for B's coping skills explored. One training session focused on teaching B to apply cognitive restructuring independently. He was asked to identify a situation in which his negative thoughts had resulted in an increase in anxiety or stress. This negative self-statement was then worked through, using self-talk and questioning techniques, and an alternative positive coping statement was established. B later described applying this technique successfully in a situation outside of the training setting.

Reflection

Following the initial assessment session I did not feel that I fully understood B's determinants of behaviour change and was unsure about his motivation to engage in the training. I discussed this with my work place supervisor who recommended motivational interviewing[15] as a useful technique to adopt if client does not indicate strong motivation to change. This method has been used successfully with people with brain injury[16]. In order to carry out a more comprehensive assessment of B's motivation to change I devised a series of questions and prompts based on models of health behaviour. These areas were then explored with B and a strong motivation to develop skills and confidence in applying stress management techniques was established. In addition to developing a clearer understanding of B's perspective of his health behaviours this process of deeper exploration also established a closer rapport with B, which appeared to facilitate trust and progress.

It was noted during the practice sessions that some techniques were more effective than others. B reported difficulty 'settling' on a visual image while practising the visualization technique. This may be related to neuropsychological factors as, following his stroke, B experiences visual neglect on one side of his visual field. There is some evidence that people with unilateral visual neglect may also neglect objects in their mental images and experience difficulty with visual imagery[17].

B also reported that he had not attempted the physical muscle relaxation techniques outside of the session as he had found this too lengthy and complicated to remember. While he had been given a handout his language difficulties meant that this was not a useful prompt. An attempt was made to simplify this strategy by prompting B to identify one muscle group in which he is able to recognise the most significant difference in physical tension when tensing then relaxing these muscles. He was able to use this single exercise as a quick physical relaxation strategy. However, it was concluded that the deep abdominal breathing was B's overall preferred stress management technique.

The association made by B between his health beliefs and ethnicity as well as his behaviour change choices highlighted the need to consider cultural factors. Some exploration of B's cultural, including religious, beliefs was carried out. However, greater use could have been made of culturally specific material to support the intervention.

ENSURE MONITORING AND SUPPORT FOR BEHAVIOUR CHANGE

Monitoring was carried out within the training sessions by repeated recapping at the beginning of each session to assess B's recall and understanding of the intervention so far. B was also informed that I was available on an informal basis for support between sessions if required.

In accordance with Rehab UK's procedure the vocational rehabilitation staff team were informed of the techniques developed with B during the intervention so that they could support him to use these in other settings. A stress-monitoring chart (see Appendix C.17) was selected as the most appropriate method of monitoring behaviour change over the course of the intervention and to assess B's ability to transfer the strategies outside of the training environment.

Reflection

The self-monitoring form was reviewed with B at the beginning of each session. B has moderate aphasia as a result of his stroke and has some difficulty writing. While he was able to write brief detail of his experiences of stress I encouraged him to expand on these and noted this additional information on the record form (taking care to use the clients own words and to check my understanding of his explanations). B was encouraged to give a full explanation of all aspects of his stress response (situational, physical and behavioural). It was hoped that going through this process would model to B the way in which to reflect on and report his responses during the self-monitoring process. The examples given on the stress log were then used in the practice sessions in order to make these relevant to the client.

EVALUATING OUTCOME

Continuous evaluation was carried out throughout the intervention by appraising progress at each session. Key indicators of learning and behaviour change were noted. For example at week four B reported having applied the cue phrase and breathing technique in a situation outside of the centre in which he anticipated stress. B also began to report some physical indicators. He reported a noticeable increase in heart rate while describing a 'stressful scenario' during a practice session. He then demonstrated the use of his preferred relaxation technique (abdominal breathing) until he felt his heart rate return to resting levels.

The stress-monitoring chart log was consistently reviewed to evaluate the extent to which the training was transferred to real life situations. Following the intervention the self-monitoring data was collated and analysed. No baseline data was available prior to outset of intervention. However, a comparison between data recorded at the beginning and end of intervention was used to assess any change in frequency of reported 'stressful incidents' and any change of behaviour in terms of strategy use. It was noted that 50% of incidents reported took place between the initial assessment meeting and the second session following B's leave of absence four weeks later. One incident was recorded for each for the subsequent 2 weeks and no incidents reported after week four.

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At week four B began to report using the stress management techniques he had learned in the sessions as his behavioural response in anticipation of a stressful situation, indicating behaviour change. This indicates that the immediate goals of identifying and effectively adopting stress management techniques had been achieved. Health benefits were also indicated in that B reported that he had not used painkillers or additional medication in the final four weeks of the intervention and no longer reported headaches.

Following the intervention B was asked to complete an evaluation questionnaire (Appendix C.18) to assess the extent of new learning, behaviour change and the appropriateness of the design and delivery of the course to meet B's needs. B rated himself as 'agreeing' or 'strongly agreeing' on all items relating to an increase in understanding and ability to apply stress management techniques and on all but one item relating to delivery (he did not agree that the handouts and course material had been helpful).

Reflection

A more comprehensive evaluation would have been obtained by asking B to complete a version of the evaluation questionnaire at the start of the intervention. This would have given an indication of his understanding of stress and stress management strategies at baseline and would have enabled a comparison to be made with his understanding at the end. It would also have been useful to repeat the evaluation at for example 6 weeks follow up in order to assess the sustained benefits of the intervention.

NEGOTIATE COMPLETION, FOLLOW-UP OR REFERRAL AS APPROPRIATE

The final session of the intervention included a review of the intervention and discussion of any additional support needs and follow up. B reported that he felt that he had benefited from the intervention and did not need any addition support at this time. Follow up support was offered and it was agreed with B that he could request this by speaking to his Keyworker or arrange this with me directly. Ongoing regular review by his Keyworker indicated that B was maintaining his behaviour change.

Reflection

This intervention highlighted that additional issues need to be considered in order to provide effective stress management intervention with adults with brain injury. Neuropsychological factors may be reported as a source of stress leading to increased anxiety or anger expression. Cognitive difficulties (e.g. memory, attention, information processing, planning or initiation difficulties) and language impairments may influence the individuals ability to attend to, understand and recall the information

given, adopt particular strategies or implement strategies independently. This highlights the importance of establishing a clear understanding of an individuals needs when designing the intervention in order to anticipate and plan for any of these issues.

In this intervention cognitive difficulties were addressed by continuous recapping of information and checking of B's recall and comprehension. As B also had some difficulty with verbal expression I took care to clarify issues with him, using paraphrasing to check my understanding. Handouts and summary notes of each session were given but it was recognised that these were of limited value due to reading difficulties. The production of audio taped summaries were considered but it was agreed that these would not be necessary as a memory aid at this point given that B demonstrated that he was able to identify and apply strategies effectively without reference material.

In adapting to these needs the process took slightly longer than may have done with a non-brain injured client. I reviewed the intervention plan on a week by week basis and discussed this regularly with my work place supervisor in order to deliver the intervention at a pace and level that met B's needs.

Summary

In implementing this intervention I gained understanding of the potential impact of stress management training on health outcomes and of the importance of understanding an individuals motivators and barriers to behaviour change, particularly in relation to individuals who have had an acquired brain injury. I gained experience of designing an intervention based on health behaviour models and of implementing cognitive behavioural techniques. Ares for further development are the skills to assess and adapt a stress management programme to meet a range of individual needs.

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AREA OF COMPETENCE: Optional

5.2 Direct the implementation of interventions

SETTING: Rehab UK (not for profit organisation)

TARGET GROUP: Adults with acquired brain injury

DESCRIPTION OF WORK: To direct the implementation of a pain management intervention designed to address the needs of adults with acquired brain injury who experience chronic pain.

ESTABLISHING NEEDS AND IMPLEMENTING STRATEGIES FOR THE PROCUREMENT OF INTERVENTION RESOURCES

In October 2004 I discussed the potential for developing a pain management intervention for clients attending the vocational rehabilitation programme with the Senior Psychologist responsible for overseeing the rehabilitation programme.

A literature review was carried out to investigate the reported benefit of psychological pain management interventions, and the extent to which these had been used successfully with a brain injury population. Meta-analysis of randomised controlled trials of cognitive behaviour therapy (CBT) for chronic pain have concluded that these methods are effective[1] and there is some evidence of the benefit of these interventions with individuals with post traumatic headache[2] and with post stroke pain[3] (see Appendix C.20 'Needs Assessment Report' for literature review).

A pain management intervention was then developed based on an identified need for some clients on the vocational rehabilitation programme to develop strategies to manage pain experienced subsequent to their brain injury. This six-week pilot intervention was based on psychological pain management techniques reported in the literature, specifically those documented in A Treatment Manual for

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[1] Morley, S., Eccleston, C. & Williams, A. (1999) Systematic review and meta-analysis of randomized controlled trials of cognitive behaviour therapy and behaviour therapy for chronic pain in adults, excluding headache. *Pain* 80: 1-13.

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Attention Management in Chronic Pain[4] (see practice log for pilot intervention plan, aims, session plans and materials). This programme was offered to clients attending Element B of the rehabilitation programme, as these clients had already attended a group stress management training and therefore had a basic understanding of relaxation and cognitive restructuring techniques.

The pilot programme was delivered by myself to a group of 3 male clients between January and March 2005. Following each session of the intervention I reviewed the appropriateness of the resources and the extent to which the intervention appeared to meet the programme aims, and evaluation notes were made. At the end of the 6 weeks the intervention was evaluated to establish it's relevance and benefit to this client group (see Appendix C.20 for Needs Assessment Report).

In summary, the pilot evaluation identified that the pain management intervention was effective for at least one client, indicating that it can be of benefit. The pilot highlighted the importance of assessing motivation and availability to attend when identifying suitable clients for this service.

It was agreed that the intervention would continue to be offered to clients beginning the Element B programme. It was acknowledged that the delivery of this intervention should be by a member of the psychology team with knowledge and experience of cognitive behavioural approaches and it was agreed that the intervention would be provided to the next group of clients by the Assistant Psychologist (RP). A 45-minute session was timetabled into the weekly rehabilitation programme by the Senior Psychologist in line with RP's availability and a training room identified for use at this time. It was decided that I would direct RP's implementation of this intervention.

Based on the evaluation of the pilot, I made changes to the intervention plan and reviewed and updated materials to ensure that appropriate resources were available to RP (see practice log for updated intervention plan, aims, session plans and materials).

Reflection

The design and implementation of a pain management intervention was a new area of skill development for me. I had some previous knowledge of theory of pain and had attended training in the application of pain management during Stage 2 training workshops. However, I felt that further training was needed to be confident to direct others to implement intervention in this area.

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[4] Treatment Manual for Attention Management in Chronic Pain. (2003) Stephen Morley, David Shapiro & Jonathon Biggs. www.leeds.ac.uk/medicine/psvchiatrv/attman.htm

I investigated training opportunities and identified an annual conference of the Faculty of Clinical Health Psychology 'Challenging the Way we Work in Chronic Pain Management'. However, places on this conference were full. I contacted the Pain Management Unit of a local hospital who offered workshops and professional visits but they were not able to offer these at this time (see practice log for details of training opportunities explored). I also contacted the author of the 'Treatment Manual for Attention Management in Chronic Pain' for feedback on whether these methods had previously been applied with people with brain injury but was not able to find any further information on this. These training needs were not therefore fully met. However, after carrying out research I was able to develop an intervention based on established practices. The pilot intervention provided a learning experience through which I was able to develop the intervention and the confidence to direct RP to implement it.

ASSESSING THE CAPABILITIES OF THE PEOPLE REQUIRED TO CONDUCT AND MONITOR A PLANNED INTERVENTION

It was identified that as an Assistant Psychologist RP had sufficient competence, experience, knowledge and qualifications to implement the intervention. He has a degree in psychology, has previous experience of working with adults with acquired brain injury, is experienced within the vocational rehabilitation team and has delivered training to clients within the centre based on cognitive behavioural principles (CBT), e.g. anger and anxiety management. Although he was not familiar with pain management techniques it was agreed that this knowledge gap could be developed through regular supervision.

An initial meeting was held with RP and myself to discuss his supervision needs. I presented an overview of the psychological factors in pain, the 'gate control' theory[5] and the principles of CBT based pain management techniques. A supervision plan was agreed which included weekly meetings between RP and myself in order to prepare for each session of the intervention (see Appendix C.21 for Supervision Plan).

In each of these supervision meetings RP's ability to implement the intervention was assessed informally by asking him questions about the material and asking him to recap the session plan; focusing on any techniques he was unfamiliar with. Opportunity was provided for RP to raise concerns or issues about his competence or confidence to deliver the intervention. It was also established that informal supervision could take place in between arranged meetings if additional issues arose. This could be easily provided given that myself and RP were based in the same shared office.

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Staffing issues were discussed in relation to the delivery of the intervention if RP was unavailable due to unexpected absence. Ideally, I would provide cover in such circumstances however due to other commitments I would not be available at the required time for the duration on the intervention. It was agreed that if RP could not deliver any session of the intervention the session would be postponed to the following week.

Reflection

It was initially planned that prior to the delivery of the intervention I would present a training session on pain management to him and other members of the team. However, due to time pressures and resources this was not possible and the training was delivered individually to RP through supervision. If this had been anticipated it would have been beneficial to have included RP in the implementation of the pilot intervention for example by having him shadow one of the pain management training sessions or including him as a co-trainer.

ADVISING AND GUIDING THE ACTIVITIES OF DESIGNATED OTHERS

Roles and responsibilities within the intervention where discussed in my initial meeting with RP. It was established that I would provide the information and materials required to deliver the training, including an overall intervention plan, plans for each of the weekly session, detailed tutor notes and handouts for clients. RP would deliver the intervention in 6 weekly, 45-minute sessions. RP would give feedback from the previous intervention in weekly supervision and would discuss any potential difficulties. Based on this feedback adjustments to the intervention plan would be made and discussed with RP as appropriate.

It was agreed that RP would oversee the completion and scoring of the evaluation materials, which we would review together. I would then collate this information and write an evaluation report. Any complaints arising during the intervention would be dealt with under Rehab UK's complaints procedures. However, no formal complaints were made during the course of the intervention.

Methods for assessment of clients needs were presented to RP prior to the intervention. I suggested he use the McGill Pain Questionnaire and a brief interview with each client to assess the nature and severity of their pain and that clients complete the Pain Coping Strategies Questionnaire (PCSQ) to indicate the ways in which they were currently coping with their pain.

RP implemented this assessment with two of the three potential clients. One client was unavailable at the time of the assessment and was later assessed by myself. I reviewed the assessment information

with RP: one client reported regular headache; another client reported chronic pain in his leg, back and neck as well as post-traumatic headache; the third client reported occasional headache and also stated that situations in which she incurred any moderate acute pain could result in a loss of anger control. RP scored the PCSQ to give an overview of each clients profile of strategy use pre- training.

Reflection

In directing the implementation of this intervention I took a training approach while supervising RP to deliver the intervention. I took and a more hands-on approach to the assessment of clients and evaluation of the intervention, carrying out some of these tasks myself with the aim that through modelling. RP would develop the skills to carry out all aspects of the intervention independently in future.

A formal supervision role was new to me in this setting, although my job involves providing support and advice to staff on a less formal basis. I felt confident within this role but learned from this experience in terms of the establishing roles and responsibilities and setting up formal supervision procedures.

ENSURING TECHNICAL SUPPORT FOR A PLANNED INTERVENTION

No specific technical support was identified as being required. Materials were presented in handout format and a whiteboard and flipchart were available for use during the intervention. An overhead projector was available and could have been used for presenting information visually. However, it was not considered appropriate, as a less formal style of presentation was preferred for this small group setting.

RP has access to his own office based PC for any further research or reading. Any technical advice or support while using this equipment was via standard Rehab UK policy in that the IT tutor within the centre provided in- house support to all staff on any IT based issues.

OVERSEEING AND DIRECTING THE CONDUCT OF A PLANNED INTERVENTION

Systems for ensuring confidentiality and security of sensitive information were carried out in line with Rehab UK's policy and the Data Protection Act. Any data relating to individual clients obtained during the intervention was stored in client files kept in a locked file room accessible only to Rehab UK staff. Any client information kept on PC, e.g. for evaluation purposes, was password protected.

Consideration was given to ensure that the intervention would not sustain any negative impact. Clients were informed of the nature of the programme at the outset and expectations discussed in order to avoid any unrealistic expectations, which would not be met. Clients were informed to consult their GP if they experienced any increase or changes in pattern of their pain. Within sessions clients where given the option to take part in practice exercises only to the extent they felt comfortable (e.g. clients may not feel comfortable closing their eyes during relaxation exercises).

As the intervention was still in it's early stages of development when delivered by RP it was identified that further changes may be needed. RP was encouraged to make notes after each session to record his impression of the extent to which the content and training materials met the aims and needs of the clients and the accuracy of the timescales set. RP's impressions were regularly fedback through supervision sessions. It was agreed that the first session included too much presentation of theory and that it was not possible to deliver this within the timescale. It was agreed that in future relevant theory would be delivered in short sections interspersed within the more practical based training.

In the final week of the intervention RP carried out an evaluation. Clients were asked to complete the Pain Coping Strategies Questionnaire so that a comparison could be made with their pre-intervention ratings. Clients were also asked to complete an evaluation questionnaire designed for the pilot stage (see practice log for evaluation materials). Two of the three clients completed these evaluations. RP collated the pre-and post PCSQ scores and we reviewed these together to evaluate the degree to which clients appeared to have benefited from the intervention.

In summary one client demonstrated some mild changes in terms of a decrease in catastrophising responses to pain and increase in use of positive coping statements. This client reported understanding more about the psychological factors in pain and about the range of pain management strategies but did not report being more motivated to use pain management strategies or that he was more able to use these effectively.

Another client reported more noticeable changes in terms of an increase in a range of positive responses including diverting attention, reinterpreting the pain sensation, ignoring the pain sensation and increased behavioural activities. It is noted that this client did indicate an increase in catastrophising in response to her pain. It may be that this represents an increase in awareness of her catastrophic responses to pain rather than a change in her response as it is noted that she also reported an increased use of coping self-statements. This client reported she was more aware of pain management strategies and was more able to use these effectively. She also gave positive feedback about the delivery and content of the intervention.

In the evaluation meeting RP gave feedback on his experience of implementing the intervention, including what he felt had worked well, any problems that had arisen and made suggestions for future changes. It was agreed in this discussion that in order to meet the needs of a number of different clients it was necessary to include a wide range of approaches and strategies in the intervention. In this group setting it would be expected that each client would benefit from some aspect of the overall programme but may not benefit from all pain management methods or sessions. It was suggested that the programme may be more effective if implemented on one-to-one basis in a shorter intervention specifically targeted to that individuals need. This approach may also help to overcome some of the issues of motivation evident in both the pilot and intervention.

The evaluation materials and RP's feedback was collated in report format which was presented to the Senior Psychologist and centre's Operations Manager to discuss the development of the pain management service within the rehabilitation programme (see Appendix C.22 for evaluation report). It was concluded that the pain management programme would continue to be offered to clients on the programme on an individual needs basis. A timetabled session would not be formalised within the rehabilitation programme but potential clients for this service would be referred to the psychology team for input and allocated for individual intervention by myself or RP depending on availability. The intervention may be offered to more than one client at the same time if after assessment of their pain management issues their needs are identified as suitably similar.

Reflection

During the delivery of the intervention issues of ethical practice were considered and discussed with RP. For example, during the problem solving and planning session clients tended to set goals relating to physical activity. During the pilot, care was taken not to agree plans with clients which involved an increase or change in activity without agreement with their GP. These considerations where emphasised to RP when delivering the intervention and he was encouraged to set goals with clients which focused on assessing or pacing rather than increasing their activity levels.

Any problems arising during the intervention were discussed and addressed during the regular supervision meetings. One issue raised was that due to client absence there were some sessions when only one or two clients could attend. As the intervention took place in the afternoon it was possible to identify which clients would be attending and it was suggested to RP that some flexibility be applied to adapt the intervention to focus more specifically on the strategies relevant to those clients. This approach appeared to work well and feedback during the evaluation process was that at least one client reported benefiting from a more individual approach.

Another potential problem was the reluctance of one client to continue the pain management intervention. They reported to their Keyworker (a member of staff responsible for overseeing their rehabilitation programme) that they already used pain management strategies and did not feel that they would benefit from further input.

This was fed back to the team by the Keyworker and discussed with myself and RP. This issue was addressed by myself and the Keyworker in a previously planned review meeting with the client. As the client had already attended 3 of the intervention sessions it was suggested that he complete the 6 sessions as, although it was recognised that he had developed his own methods of coping with pain, he may be introduced to alternative methods which could also be helpful. The client was willing to complete the intervention on the agreement that other appropriate changes were made to his timetable and this issue was resolved effectively

SUMMARY

A pain management intervention was developed and its effectiveness evaluated within a brain injury rehabilitation setting. This evaluation suggested that the intervention could benefit some rehabilitation clients with chronic pain issues. The importance of assessing individual client need and exploring individuals' motivation to address pain management issues was highlighted. This intervention could be effectively implemented by an experienced Assistant Psychologist under supervision. In directing this intervention I developed new skills in implementing pain management as well as supervisory and training skills.

SECTION D

Systematic Review of

Literature

Psychosocial interventions for caregivers of survivors of stroke: A systematic review

Background

At any one time in the UK there are an estimated 250,000 people who are disabled stroke survivors dependent on the help of a carer (Bonita, Solomon & Broad, 1997). Most stroke survivors are cared for at home by informal carers, usually their partners or children. Stroke caregivers often have to deal with a wide range of care needs including mobility, self-care and communication difficulties as well as cognitive impairment, depression and personality changes in the stroke survivor (Kelly & Winograd, 1985) The role of a carer of a disabled stroke survivor can therefore include physical activities, nursing responsibilities and communication, psychological, emotional and social support (Hankey, 2004).

The chronic burden of meeting these needs can have a significant impact on the psychological well-being of the caregiver. Depression has been reported as one of the most common symptoms of caregiver strain with estimates of prevalence ranging between 39% and 52% (Han & Haley, 1999). The experience of depression by the caregiver has been associated with physical abuse of the patient (Joslin, Coyne & Johnson, 1991) and greater likelihood of nursing home placement (Stephens, Kinney & Ogrocki, 1991).

Caregiver burden can also contribute to anxiety (Kitze, von Cramon & Wilz, 2002), decline in quality of life (Coughlan & Humphrey, 1982) and social isolation. It can lead to physical health problems and subsequent increase in the use of health services and self-administration of medication by the carer (Lichtenberg & Gibbons, 1992). Financial burden can also be incurred, with up to 14% of employed caregivers reported to leave their jobs to undertake the caregiver role (Brocklehurst, Morris, Andrews, Richards & Laycock, 1981).

The expected rise in the number of survivors of stroke and the focus on community rather then hospital care is likely to increase the demands made on caregivers. To address this issue attempts have been made to develop and evaluate interventions for reducing the burden of the informal care giving for dependent stroke survivors. These include the provision of information and education and access to services such as psychological, counseling and emotional support.

Reviews of the effectiveness of information and education provision to stroke patients and their carers have been inconclusive. The provision of information alone has not been found to have any effect on mood, perceived health status or quality of life for patients or carers (Forster, Smith, Young, Knapp,

House, & Wright, 2001). Investigations into the potential benefit of Family Support Workers, to provide information, support and liaison with other services for families affected by stroke, have also proved inconclusive. While Mant, Carter, Wade, & Winner (2000) indicate that the involvement of a family support worker significantly increases social activities and improves quality of life for carers, other studies did not find such an effect (Lincoln, Francis, Lilley, Sharma & Summerfield, 2003) and earlier studies indicate that any benefits may be offset by adverse effects on mental health and social adjustment of patients (Dennis, O'Rourke, Slattery, Stainforth, & Warlow, 1997).

However, systematic reviews of a wider range of interventions with caregivers indicate that some interventions can promote psychosocial gains. Bohgal, Teasall, Foley & Speechley (2003) evaluated 10 randomized controlled trials of family education or intervention programmes. They identified that among the seven studies reporting positive outcomes six were those that included some element of counseling or social support. Two of the three studies not reporting significant outcomes used information packages and workbooks only. More recently Visser-Meily, van Heugten, Post, Schepers, & Linderman (2005) reviewed 22 studies examining a range of interventions including the provision of specialist services, education, counseling and social support by peers. They identified 10 studies that reported positive results, in one or more outcome measure, and concluded that counseling programmes appeared to have the most positive outcomes. The finding that interventions with a psychosocial element are most likely to result in positive outcome is consistent with the results of systematic reviews of interventions with caregivers of dementia (Cooke, McNally, Mulligan, Harrison, & Newman, 2001; Pusey & Richards, 2001) and family caregivers of older adults (Sörensen, Pinquart, Habilb, & Duberstein, 2002).

One potential mechanism by which these interventions promote well-being is by reducing stress and increasing coping skills in accordance with the stress coping model. Gatz, Bengston, & Blum (1990) summarize a model of caregiver stress with the following features: a stressor (the onset of a disabling event prompting care); appraisal of the experience of caring; mediators (the coping skills utilized); and outcome (successful caring or abandonment of role). According to this model, intervention can promote coping and reduce caregiver distress by influencing the caregivers appraisal of their self and situation and develop positive mediators such care skills and knowledge of disability.

This hypothesis is consistent with evidence that psychological factors relating to the carer, such as coping style, influence the level of distress experienced. Caregivers who use positive coping strategies report fewer psychiatric symptoms than those using passive avoidance strategies (Hodgson, Wood & Langton-Hewer, 1996). Problem solving style has been found to be predictive of caregiver distress and problem solving ability found to be a moderator between disability of the stroke survivor and negative

affect in their caregivers (Shanmugham 2001). Caregivers of stroke survivors who have higher perceived self-efficacy, are satisfied with social support and use the coping strategy of confrontation are found to experience less strain, higher mental well-being and greater vitality (van den Heuval, de Witte, Schure, Sanderman, Meyboom-de Jong, 2001). It may be then that interventions that promote social support and develop coping and problem solving skills reduce the risk of caregiver burden.

The role of problem solving training for caregivers of patients with chronic illnesses has been recognized and several models for such training have been developed (Houts, Nezu, Nezu, & Bucher, 1996; Kurylo, Elliott & Shewchuk, 2001). While these models are yet to be evaluated there is evidence that individual social problem solving interventions positively influence physical and psychological well-being in family caregivers of the frail elderly (Toseland, Rossiter, Peak and Smith, 1990) spouses caring for aging veterans (Toseland, Labrecque, Goebal and Whitney, 1992) spouses of cancer patients (Toseland, Blanchard and McCallion, 1995) and caregivers of people with dementia (Pusey et al 2001).

The aim of this review is to analyze systematically those interventions that intentionally target psychosocial functioning in caregivers of stroke survivors. Psychosocial interventions are defined as those that provide support other than, or in addition to, education or information alone, where this support is based on psychological principles and where the theoretical framework is clearly stated. Within this narrowly defined remit a number of studies included in earlier systematic reviews are excluded. For example, Family Support Worker and stroke support group studies are not included as the nature and extent of emotional support provided is not specified.

Methods

A systematic review of the literature on psychosocial interventions for caregivers of survivors of stroke was carried out based on the method suggested by the NHS Centre for Reviews and Dissemination Report 4, 2nd Edition (CRD 2001).

The objectives of this systematic review were:
- To identify which psychosocial interventions have been tested for effectiveness in informal caregivers of survivors of stroke.
- To evaluate the success of psychosocial interventions in reducing the burden of caring for a stroke survivor.
- To identify which psychosocial approaches (e.g. counseling, cognitive behaviour therapy, problem solving training) are most effective in producing positive outcome for these carers.

Inclusion Criteria

Participants: Informal adult carers (age 16+) of a survivor of stroke living in the community where the intervention is provided to the carer or to the patient and their carer.

Interventions: Psychosocial interventions that provide counseling, support or training designed to address specific health and social care outcomes, where the interventions is based on psychological principles and the theoretical model is specified. Interventions that involved education or information alone, that focused on system or service change or included a counseling or support element but the nature of which is not specified, were excluded.

Outcomes: Measures of psychological health (e.g. depression, anger, stress, anxiety), physical health, quality of life or perceived burden. Where these are measured using established and validated assessment tools

Setting: The stroke survivor receiving care either in hospital or the community and the intervention delivered to the caregiver mainly outside of the hospital setting. Interventions that begin in hospital, prior to the stroke survivor's discharge, but continue after discharge were included.

Study design: Randomized controlled trials only.

Search strategy

The following databases were searched for published literature: Medline, Psychinfo, Embase, Cumulative Index to Nursing and Allied Health Literature, Cochrane Controlled Trials Register. The following databases were searched for unpublished literature: Conference Papers Index, Dissertation Abstracts, National Research Register.

The following journals were searched by Internet or by hand: Brain Injury, Journal of Neuropsychological Rehabilitation, Archives of Physical Medicine and Rehabilitation, Stroke, Topics in Stroke Research, Cerebrovascular Diseases, Gerontology, BMJ.
Key researchers and practitioners in the field were approached for work recently completed. Reference lists of relevant primary and review articles were searched for studies not identified by the original search.

The following search terms were used: *stroke* and *carer*, *caregiver* or *family* combined with, *counseling*, *psych**, *cognitive behaviour (behavior)*, *cognitive behavioural (behavioral)*, *problem solving*, *behaviour (behavior) management*, *psychotherapy*, *support* and *intervention* or *randomized controlled trial.*

The initial search yielded 80 papers for review. The abstracts of these were checked and those not meeting the inclusion criteria eliminated. The remaining articles were studied further and, where the abstract lacked sufficient data, the full text was read. A final selection of 7 articles where considered relevant to this review.

The sensitivity of the search strategy was evaluated in relation to previous relevant systematic reviews (Bohgal et al, 2003; Visser-Meily et al, 2005). This search identified all relevant papers reported in these reviews and included a further two titles not previously reviewed.

Quality Assessment Procedures

The quality of the studies selected for inclusion where assessed using a Quality Assessment Tool designed for this review (See Appendix 2a). Each study was assessed independently by two reviewers and these ratings compared. Difference in rating scores between both reviewers varied by no more than 2 points on all but one study, where there was a difference of 6 points. The two reviewers met to discuss these discrepancies and consensus was reached in all cases. The quality assessment scores were amended accordingly. A quality score of 10 was agreed as the cut off point for inclusion in the review. This eliminated studies that did not meet at least half of the quality criteria or where insufficient information was available to accurately assess these quality measures. Three studies were eliminated at this stage: Grant (1999) included a sample of only 30 caregivers assigned to three treatment groups and did not indicate method of randomization, attempt to compare groups at baseline, check for confounding variables or state rate of loss to follow up. In two studies by van den Heuval, de Witte, Nooyen-Haazen, Sanderman & Meyboom-de Jong, 2000 and van den Heuval, de Witte, Stewart, Schure, Sanderman & Meyboom-de Jong, 2002 (both reported on an intervention with the same group of participants over different timescales) loss to follow up was reported at over 25%, sample size was disproportionate between groups and no indication is given of method of randomization, definition of control, checks for confounding variables or whether data was collected blind.

Results

Four studies were included in the review (see Table D.1 for study characteristics and outcomes). The interventions evaluated in these studies included education with family counseling, education with

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individual counseling, individual telephone support and a group teleconference intervention. The psychological models underpinning these interventions were family systems theory, cognitive behavior therapy, social problem solving training and stress coping model.

Methodological Critique

Only randomized controlled trials were included in this review. However, only two studies indicate their method of randomization; computer generated allocation system (Clarke, Rubenach & Winsor, 2003) and Method of Taves (Evans, Matlock, Bishop, Stranahan & Pederson, 1988). All studies included a control group that received routine care including usual discharge planning services. Sample sizes were relatively small. Only one study reported that they had established sample size using power analysis (Clarke et al, 2003). However this was powered to detect a difference previously reported in family functioning of stroke patients and was not directly related to caregiver data.

Three studies used statistical analysis to test for equivalence of groups on a range of demographic variables at baseline (Evans et al, 1988; Grant, Elliot, Weaver, Bartolucci. & Newman Giger, 2002; Hartke & King, 2003). Hartke and King (2003) identified that their intervention group had spouses who were significantly more functionally impaired in terms of motor skills and were receiving more help to care for their spouses. Clarke et al (2000) controlled for age and estimated stroke severity by including these as covariates in their analysis. Attempts to check for confounding interventions are not adequately reported in any of these studies. Although Hartke and King (2003) state that, at 6 month follow up, their control group participants were asked about any counseling sought during the interim period, the results of this data are not given.

Three studies reported a loss to follow up rate of less that 25%. Hartke & King (2003) had an estimated attrition rate of 29% with significantly more participants in the intervention group dropping out than in the control group.

Different methods of analysis were used. Evans et al (1988) used univariate analysis of variance to determine if conditions differed before treatment and at follow up and Sheffe's test to assess differences between conditions 6 months after stroke. Hartke and King (2000) report that within group comparisons for the treatment condition were tested with repeated measures analysis of covariance over three time intervals. Competence scores were not evenly distributed and differences in this variable was tested with Friedman's' ANOVA. It is also noted that despite randomization the two groups were not matched on outcome variables at baseline with the intervention group showing significantly higher levels of depression, burden, loneliness and stress and lower sense of competence. To account for this lack of homogeneity between groups comparisons were performed by calculating difference scores for each of

the dependent variables between first assessment and follow up, which were then analyzed using independent t tests (except for the variable competence; as change scores were not normally distributed a Mann-Whitney U statistic was used). Grant et al (2002) used hierarchical linear models to estimate time regression weights for each group. Chi squared statistics were then used to test the significance of differences for those dependent variables for which their were dissimilar changes over time between groups. Clarke et al (2003) tested within group differences in family functioning using repeated measures analysis of variance at admission, discharge and 6 months. SF-36 data was analyzed using one-way analysis of variance.

Outcomes

The outcomes measurements varied between studies (see Table 1.1 for key of assessment tools). Three outcomes were measured using the same tool across two separate studies; family functioning measured be the FAD (Clarke et al, 2002; Evans et al, 1988); perceived health status measured by the SF-36 (Clarke et al 2002; Grant et al 2002); depression measured by the CES-D (Grant et al ,2002; Hartke and King, 2000). A further outcome was measured in two different studies but using different measures; caregiver burden (Grant et al, 2002; Hartke and King, 2000) measured by the CGBS and BI respectively. Other outcome measurements were particular to one study only; Loneliness (UCLA Loneliness Scale); Stress (PPI); Competence (CCS); Problem solving (SPSI); Preparedness (PCGS) and Personal adjustment (PARS). All assessment tools included are reported to have adequate construct validity and internal consistency.

Three of the four studies (Clarke et al, 2002; Evans et al, 1988; Hartke and King, 2000) report results at 6 months. Evans et al (1988) also included measurement at 1-year follow up. Grant et al (2002) measured outcome at 5-9 weeks and 13 weeks post discharge.

A brief review of each intervention and the results reported is given below. It should be noted that some original studies also included additional data relating to patient outcomes, or to caregiver outcomes considered outside of the scope of this review (such as caregiver knowledge and satisfaction), which is not reported here.

Family counseling

Clarke et al (2003) aimed to determine whether an intervention that involved education plus counseling, based on family systems theory, would prevent an otherwise probable decline in family functioning in the six months after discharge from rehabilitation from stroke. This hypothesis was supported in that the family functioning of spouses in the control group declined slightly while that of the intervention spouses improved. However, there was no evidence for better general health, as measured on the SF-36

physical health and mental health dimensions, at six months for spouses receiving the intervention. Change in family functioning, as perceived by spouses between discharge and six months, was significantly associated to changes in functional status of the stroke survivor (as measured by the Barthel Index) with significantly better patient functioning found in the intervention group at follow up.

Individual counseling based

Evans et al (1988) compared an intervention that involved education plus counseling, based on cognitive behaviour therapy, with an education only and a control group of primary caregivers living with a stroke survivor. They hypothesized that caregiver education would positively affect family functioning and would promote patient adjustment and that counseling would foster greater gains than education alone. Their results indicate that all three conditions showed worsening family functioning after stroke but that both the education and counseling conditions deteriorated significantly less than controls on the subscales of problem solving, communication and global family functioning. Only the counseling condition significantly improved patient adjustment relative to control.

A further follow up at one year post stroke indicated that these initial effect were maintained and additional benefits of the intervention groups were indicated in that both the educational and counseling group scored significantly better on measures of affective involvement and behaviour control. The hypothesized long-term benefits of counseling over education alone were observed on the variables of family functions problem solving, communication, behaviour control, global family functions and patient adjustment.

Table D.1: Characteristics, methodology, effect size and results of studies investigating the impact of psychosocial interventions for caregivers of survivors of stroke

Author	Participants 1. Definition of caregiver 2. Time since stroke 3. Setting	Sample 1. Number of participants 2. Demographic details	Intervention 1. Nature (theoretical model) 2. Duration 3. Delivered by.	Time to follow up (T)	Outcome (measures)	Effect Size		Test used	p		QA Score
1. Clarke et al (2003) *Australia*	1. Spouses of stroke survivor 2. <6wks 3. At patient discharge	1.Sample size N=62. Intervention (32); Control (30) 2. Mean age: Intervention 71.3 years; Control 69.3 years.	1. Education package plus family counseling (family systems theory) 2. Information package given on discharge & three one-hour sessions (1st at three weeks post discharge, 2nd two months post discharge, 3rd five months post discharge) 3. Social worker	6 months post discharge	Family functioning (FAD global functioning) Perceived health status (SF-36 physical) (SF-36 mental)	0.23 -0.09 -0.32		repeated measures anova one-way anova	<0.05 NS		17
2. Evans, et al (1988) *USA*	1. Principal supportive person with whom stroke survivor lives 2. < 3 months 3. Patient in hospital and after discharge.	1. intervention (N=61); control (N=63) 2. intervention (male 8.2%; female 91.8%; age 47..9 +/- 15.4) control (male 11.1%; female 88.9%, age50.7 +/-15.2)	1. Education package plus counseling (cognitive behaviour therapy) 2. two 1-hour sessions of education (1st within 3rd week of hospitalization, 2nd within 3 working days later) followed by seven 1-hour counseling sessions (1st session during 3rd week of hospitalization and six biweekly sessions post discharge) 3. Social worker	T1. 6 month post stroke T2. 1 year post stroke	T1 & T2. Family Functioning (FAD problem solving) (FAD role assignments) (FAD communication) (FAD behaviour control) (FAD affective involvement) (FAD affective responsiveness) (FAD global functioning) Personal Adjustment (PARS)	T1 0.46 0.02 0.49 0.03 0.05 0.03 0.38 2.21	T2 0.7 0.05 0.47 0.34 0.34 0.02 0.94 1.88	Sheffe's test	T1 <0.01 NS <0.01 NS NS NS <0.01 <0.01	T2 <0.01 NS <0.01 <0.01 <0.01 NS <0.01 <0.01	13
3. Grant et al (2002) *USA*	1. Primary family caregiver of stroke survivor 2. 3-4 weeks (not limited to first incidence of stroke) 3. At patient discharge	1. Sample size N=74. 2. Male (N=7; age 58 years+/ -12); Female (N=67; age 56 +/- 12).	1. Social problem solving telephone partnerships (social problem solving training) 2. Three hour training session in SPSP at discharge followed by telephone contacts over 12 weeks post discharge (month 1 weekly, month 2 & 3 biweekly) 3. Research nurse	T1. 5-9 wks post discharge T2. 13 weeks post discharge	Perceived health status (SF-36 social functioning) (SF-36 vitality) (SF-36 role limitation emotional) (SF-36 mental health) Depression (CES-D) Burden (CGBS) Problem solving (SPSI) Preparedness (PCGS)	Mean and SD data not available to calculate effect size		χ2 χ2 χ2 χ2 χ2	<0.05 <0.05 <0.01 <0.001 <0.001 NS <0.01 <0.001		13 ½
4. Hartke & King (2003) *USA*	1. Spouses 2. 1month – 3years 3. Patient living at home	1. Sample size N=86. Intervention (N=43); Control (N=43) 2. Intervention (male 26%; female 74%; mean age 69.74yrs. Control (male 22%; female 78%; mean age 68.69yrs	1. Telephone psycho-educational group support (stress coping model). 2. 8 weekly 1 hour sessions 3. Psychologist, social worker or nurse	6months from start of study.	Loneliness (UCLA Loneliness Scale) Depression (CES-D) Burden (BI) Stress (PPI) Competence (CCS)	-0.38* -0.54 -0.1 -0.18 -0.38		t test t test t test t test Mann-Whitney U	NS NS <0.05 NS <0.05		12

* The authors note that despite randomization the treatment and control group were not equivalent on outcome measures prior to intervention. Between group comparisons where therefore made using difference scores between each outcome measure taken prior to intervention and at 6 months. Hence, negative effect sizes do not represent significance of results.

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Key to measures: FAD = McMaster Family Assessment Device; SF-36 = Short Form Health Survey; CES-D = Center for Epidemiological Studies Depression Scale; UCLA Loneliness Scale; CCS = Caregiver Competence Scale; BI = The Burden Interview; PPI = The Pressing Problem Index; SPSI = Social Problem Solving Inventory; PCGS = Preparedness for Caregiving Scale ; CGBS = The Caregiver Burden Scale; PARS = Personal Adjustment and Role Skills Scale

Psycho-educational group support delivered via teleconference

Hartke & King (2000) devised an intervention tailored toward managing the stress of providing care to a stroke survivor according to the stress coping model. All participants were given a manual including a relaxation audiotape and a publication on stress management. Participants in the intervention group also took part in group sessions conducted by telephone conference, facilitated by two clinicians, with each session focused around a specified topic. Hartke and King (2000) hypothesized that those in the treatment group would show a significant improvement in depression, loneliness, burden, competence and stress between entrance into the study and at completion of the intervention and would maintain gains at 6 month follow up.

The results did not indicate a significant difference in degree of change between intervention and control group for depression, loneliness or stress. Group differences in change scores were significant for burden and competence. Compared with the intervention group the control participants showed a significant increase in reported burden between outset and 6 month follow up. The treatment group showed a significant gain in their sense of competence between outset and follow up.

Social Problem-Solving Telephone Partnerships

Grant et al (2002) compared primary family caregivers of a stroke survivor receiving a telephone based problem solving intervention with a sham group receiving telephone contact which did not involve the intervention and a routine care control group. Results indicated that at 13-week post discharge the intervention group had significantly better social functioning and caregivers in the intervention group showed significant improvements in vitality, mental health and role limitations related to emotional problems. Caregivers in the control group had decreased levels of mental health over time. The intervention group showed greater caregiver preparedness and less depression and also had significantly better social problem solving skills, (in terms of less negative orientation and impulsivity/ carelessness and more rational problem solving skills) than either the sham or the control group. Positive problem orientation did not change significantly over time for the intervention or sham group but the control group participants were found to deteriorate. No significant difference between groups was found regarding caregiver burden.

Effect size

Effect size was computed from observed means and standard deviations of the treatment and control conditions using Cohen's d (Cohen, 1988) for three of the four studies. In the study by Grant et al (2002) insufficient data was available to enable an effect size calculation. Negative effect sizes were indicated in Hartke and King (2003) however it is noted that there were significant differences between intervention group and control group as measured prior to the intervention. (See Table 1.1 for details of study characteristics, methodology, effect size and results).

Results at six months indicate a small effect size (ES= 0.23) of family counseling on family functioning as measured by the global functioning subscales of the FAD (Clarke et al, 2003). At six months, individualized counseling based on cognitive behavioral principles was found to have a moderate effect size on family functioning as measured by the global functioning (ES=0.38), problem solving (ES=0.46) and communication subscales (ES=0.49) of the FAD (Evans et al ,1988)). This study also indicated a large effect size of this intervention on the personal adjustment of the stroke survivor as perceived by the caregiver (ES=2.21). These results are indicated to be sustained at one year post stroke. At long term follow up this study indicated a large effect size of the intervention on global family functioning (ES =0.94); a moderate (but larger than at 6 months) effect size in relation to problem solving (ES=0.7); a moderate effect size on communication (ES=0.47) and a continued large effect size on patient adjustment (ES=1.88). At one year post stoke moderate effect sizes of the intervention on behavior control (ES=0.34) and affective involvement were also found (ES=0.34).

Due to the inconsistency of outcome measures used across studies, and insufficient data to estimate accurate effect sizes in two of these studies, it is only possible to combine the effect size of one measure, the global functioning subscale of the FAD, across two studies (see Table D.2). This indicates that an intervention that includes both an educational and a counseling element has a moderate effect size (ES=0.305) on global family functioning of primary caregivers married to or living with a stroke survivor. It is noted that the intervention reported in Evans et al (1988) is longer in duration than that in Clarke et al (2003). It is possible that duration of intervention has some implication for the size of the effect of the intervention on outcome.

Table D.2: Combined effect size for FAD global functioning subscale at 6 months follow up

	Effect Size	
Clarke et al (2003)	0.23	small
Evans et al (1988)	0.38	moderate
Combined effect size	**0.305**	**moderate**

Discussion

This review aimed to evaluate psychosocial interventions for reducing the burden of caring for a stroke survivor and to identify the approaches that are most effective in producing a positive outcome. An educational intervention that includes family counseling was found to prevent a decline in family functioning at 6months post stroke. An educational intervention that includes individual counseling based on cognitive behaviour therapy also promotes family functioning and significantly improves the personal adjustment of the stroke survivor at 6 months and shows greater gains at one year follow up. Group telephone support based on social problem solving training was found to improve problem solving skills, improve some aspects of perceived health status and prevent a decline in mental health at 13 week follow up. This intervention also promoted caregiver preparedness and protected against depression. An individual telephone support intervention based on a stress coping model was found to prevent against an increase in burden and to increase competence at 6 months follow up.

Due to the different approaches and theoretical models underpinning each study direct comparison is difficult. However some marked differences in results are apparent. Most noticeably, some of the outcomes reported by Grant et al (2002) differ from those reported in other studies. Grant et al reports that their intervention has a significant positive impact on some aspects of perceived health status, which is not consistent with the findings of Clarke et al (2003). Grant et al (2002) also indicates that their intervention prevented a decline in depression but did not prevent an increase in burden in the intervention group. This is contrary to the results reported by Hartke and King (2003) who found that that their intervention prevented an increase in perceived burden in the intervention group but did not have any significant effect on depression. It may be that these disparities can be accounted for by differences in the nature of the intervention, or quality of study. Alternatively, this may be the product of the different length of time to follow up. Grant et al (2002) included a 13-week follow up but unlike other studies did not measure outcomes at 6 months. It may be that psychosocial interventions promote improvements in perceived health status and protect against an increase in depression in the short term but that these benefits are not sustained over time.

It is noted that despite Hartke and King (2003) tailoring their intervention to support spouses of stroke survivors to manage the stress of care giving the intervention group did not significantly differ from the control group on a measure designed to assess stress (PPI). They point out that the initial assessment on the stress measure involved identifying and rating personal experiences of stress. They suggest that control participants may have found this therapeutic in itself and experienced a beneficial effect from the administration process. Hartke and King (2003) also note that a significant difference in loneliness was not reported between their intervention and control group despite the results of an earlier study

indicating less reported loneliness amongst housebound recipients of telephone support (Evans, Kleinman, Haler & Herzer, 1985). They note that lack of social involvement was one of the most frequently mentioned sources of stress on the initial stress inventory and that the time limited phone contact may not be sufficient to counter this sense of isolation. Despite encouraging group members to have informal contact with each other outside of the telephone conferences they note that few did so.

Method of delivery

Group interventions: Hartke and King (2003) indicate that an intervention delivered to a group of caregivers of stroke survivors at the same time, via telephone conferencing, can have some positive psychosocial outcomes. In a study excluded from this review van den Heuval (2002) indicate that both individual and group interventions, based on active coping training, significantly increase the use of the active coping strategies of 'confronting' and 'seeking support' at 1 month and 6 months follow up. The potential benefits of providing group support to caregivers has clinical implications, in that group delivery makes less demand on resources. However, there are practical issues involved in delivering a group intervention as the demands of providing extensive care to an individual with stroke may prevent a caregiver from accessing this support.

Telephone interventions: Grant et al (2002) and Hartke & King (2003) both evaluate interventions delivered by telephone and, despite variations in their results, both indicate some positive outcomes for caregivers. In an earlier study Grant (1999) suggests that a social problem solving intervention may be more effective when delivered by telephone than delivered by a home visit. Grant (1999) suggests that, compared with personal contact, the distance provided by telephone contact may enable caregivers to appraise their care giving experience more objectively and subsequently be more consistent in their use of problem solving skills. While it should be noted that this study was excluded from this review as it did not meet the quality criteria, telephone interventions with older adults have been found to be as effective as home visits in reducing depressive symptoms (Hanser and Thompson, 1994), with higher retention of subjects in the telephone group compared to home visit controls. There is no evidence then that telephone interventions are less beneficial than home visit support and they may encourage access to the support available.

Problem solving and coping

Most of the studies in this review promote problem-solving skills in the caregiver. Two studies measure problem solving directly as an outcome (Evans et al, 1988; Grant et al, 2002) and both report that problem-solving skills among those receiving the intervention are significantly better at follow up than

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those of the control group. This significant difference in problem solving skills may be a moderating factor in other psychosocial outcomes reported.

Evans et al (1988) suggest that effective problem solving may have an impact on family integration by improving the way in which family members handle stressful situations and deal with the rehabilitation process and may facilitate lifestyle change. They also indicate that development of problem solving skills may offer some explanation for the better personal adjustment of the stroke survivor reported by caregivers in the intervention group. In earlier studies they demonstrate the importance of family problem solving to patient adjustment to stroke at one year (Evans, Bishop, Matlock, Stranahan, Haler & Noonan, 1987a) and to adherence to treatment after stroke (Evans, Bishop, Matlock, Stranahan, Smith & Haler, 1987b). Evans et al (1988) suggest that patient adjustment may also have been promoted by the development affective involvement and communication within families; poor affective involvement is associated with deterioration after stroke (Steidl, Finkelstein, Wexler, Feigenbaum, Kitsen, Kliger & Quinlan, 1980)) and communication is identified as a central factor in recovery from depression after stroke (Robinson, Bolduc, Kubos, Starr & Price, 1985).

Conclusions

The findings of this review indicates that interventions designed to target psychosocial outcomes in informal caregivers of survivors of stroke can lead to better family functioning and promote problem solving and may protect against the negative psychosocial impact of caring for someone with stroke. Such interventions may also improve independent functioning and prevent a decline in personal adjustment in the care receiver. There is some support for the hypothesis that increased problem solving skills and positive appraisal of coping skills act as mechanisms by which other measures of health and psychological well-being are moderated. However, it is not proposed that these mechanisms are exclusive and other factors may also be involved.

It is noted that there are relatively few studies investigating the impact of psychologically based interventions for caregivers of stroke survivors and of those that exist are not all of a high standard of quality. Of the studies identified for review direct comparison is difficult given the different outcome measures, assessment tools, time to follow up, design and methods of analysis used. Most studies did not consider outcome longer than six months post intervention. However findings at one year suggest that psychosocial interventions may provide a protection against caregiver stresses over a longer period of time.

More research, including long-term studies, is clearly needed to substantiate the findings of this review. Further investigation should also consider how caregiver characteristics, such as age, gender, type of caregiver-care receiver relationship and initial burden, may influence observed results; these factors have been found to be relevant to the response to interventions for caregivers of individual with dementia (Sörensen, Pinquart, Habilb & Duberstein, 2002).

The clinical implications of this review would suggest that those working with survivors of stroke and their families should consider providing interventions for primary caregivers. Positive benefits can be produced by relatively short interventions that can be provided via the telephone and to more than one caregiver at a time. It is recommended that any intervention should be designed with consideration to the specific needs of the carer group and be delivered close to the time of the stroke.

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APPENDICES

APPENDIX B1: Interview Schedule

Interviewee ID _____ **Date**_____

Duration of interview _____

Background questions: When did you start the programme? What rehabilitation did you have before coming here?

1. What have been the main areas of difficulty you have been working on while on the vocational rehabilitation programme?

Prompt interviewee to identify all main areas of difficulty. Response may relate to physical, cognitive, emotional, behavioural difficulties. Prompt for general nature of these difficulties e.g. physical weakness, memory, anxiety, but these do not need to be explored beyond this in detail.

2. When did you first realise you had these (insert deficits identified) difficulties?

Probe for specific events or experiences e.g. what was it that made you aware of this problem? Was it something somebody said to them or something they did? Was there one specific thing that brought these difficulties to your attention/ was is a gradual discovery?

3. How did the realisation that you had these difficulties make you feel?

Prompt for changes in mood. If interviewee expresses mood issues probe regarding support received, (e.g. consulting GP, referred to psychologist) and their satisfaction of the support received. Did they benefit from it? What was the impact of the changes in mood? E.g. did it affect engagement in other activities? What helped them to cope at this time? Did mood change (improve or deteriorate) after that time?

4. What kinds of things do you do to help you with these (insert deficits identified) difficulties?

If interviewee identifies strategies probe for the extent the client finds them useful. Does this make tasks easier for you? How do these strategies help you (at home / in the centre / in the workplace)?

5. When did you begin using these 'compensatory strategies' (insert strategies identified by interviewee)?

6. What made you start using compensatory strategies for these difficulties (insert strategies and limitations as identified by the interviewee)?

Probe for specific examples and experiences? If client indicates and experience relating to increased awareness ask how this event made them feel?

7. In what way did activities within the vocational programme help you to understand the limitations you experience?

Probe regarding particular sessions or experiences within the centre and at work placement. How beneficial were the awareness training sessions? Did these help the interviewee gain awareness. What would have helped more? Did any other sessions help to raise awareness? In what way? How did the work placement help to raise awareness?

8. How did the this development of awareness of these limtations make you feel?

Prompt for changes in mood. If interviewee expresses mood issues probe regarding support received, (e.g. consulting GP, referred to psychologist) and their satisfaction of the support received. Did they benefit from it? What was the impact of the changes in mood? E.g. did it affect attendance at centre, engagement in other activities? What helped them to cope at this time? Did mood change (improve or deteriorate) after that time? Prompt for each change in mood.

9. What might have helped you to have understood these difficulties or made you aware of the need to use compensatory strategies sooner? (insert limitations and strategies as identified by the interviewee)

10. Did anything else affect your mood during your time on the programme?

11. What changes have you experienced in general health while on the programme?

12. What do you think contributed to these health changes?

13. How do you think that the limitations you have described will impact on you in the future?
Probe for impact on work, social, personal goals?

14. How is your mood / general health now?
If interviewee has reported poor or deterioration in mood has this improved? If improvement in mood / general health is reported probe client for the reason for this change? If client reports fluctuating mood probe for high and low points?

15. Is there anything else relating to what we have talked about you would like to add?

Appendix B2. Interview Schedule (Significant Other)

"Thank you for agreeing to be interviewed today. I am _____ (Introduce self if not known to interviewee).

Complete consent procedure.

I'm now going to ask you some questions about the changes that in your view X has gone through since her brain injury and particularly while on the programme here and how these changes have affected you. There are no right or wrong answers. I am interested in your personal views. The interview should last about 45 minutes."

Allow interviewee to ask any questions about the procedure before beginning.

Switch on tape recorder

Interviewee ID _____ **Date** _____

Location of interview _____

Duration of interview _____

What are the main areas of difficulty you feel X has experienced since his/her brain injury?

When did you think X first become aware of these (insert deficits identified) difficulties? Probe for specific events or experiences

What changes in awareness of these (insert deficits identified) difficulties have you noticed while X has been on the programme? *Probe for patterns of change (i.e. fluctuating or consistent increased awareness?) and timescales. If interviewee does not report changes explore changes in awareness prior to the programme.*

What do you think contributed to these changes? *How did the significant other become aware of these changes (through observation, being told)? Probe regarding particular sessions or experiences within the centre and at work placement.*

In your opinion how did X feel during these changes in awareness?
Probe what changes in mood has been observed during time on programme. Prompt for the impact of any changes in mood and how for changes in general health of the client).

Tell me about your mood during the time X has been on the programme?
Prompt for changes in mood. Prompt for patterns and timescales. If interviewee expresses mood issues probe regarding support received, (e.g. consulting GP, referred to psychologist) and their satisfaction and benefits of the support received. What helped them to cope at this time? If interviewee does not report changes explore changes in mood prior to the programme.

What do you think contributed to these feelings / changes in mood? *Probe for factors relating to the changes in clients while on the programme and also for external factors.*

Tell me about your general health while X has been on the programme?
Clarify general health if necessary e.g. increase in medical complaints, feeling 'under the weather'. If interviewee does not report changes explore changes in mood prior to the programme.

What do you think contributed to these changes in health?

How do you think your mood or health were affected by the changes that X was experiencing while on the programme?

How is your mood and general health now? *If interviewee has reported poor or deterioration in mood has this improved? If improvement in mood / general health is reported probe client for the reason for this change?*

Is there anything else relating to what we have talked about that you would like to add?

That is the end of the interview. Thank your for taking part. **(Switch off tape recorder)**

Allow interviewee to ask questions?

Debrief: If client has reported current mood issues discuss sources of support e.g. suggest talking to GP, referral for counselling and support via Headway.
Give all interviewees family support information sheet.

APPENDIX C.1: Training Needs Questionnaire

Approaches to managing deficits of awareness

Proposed learning outcomes for trainees:

- to gain greater understanding of the potential causes and models of self-awareness and the interventions and approaches to managing it
- to be able to apply this knowledge appropriately when working with clients with deficits of awareness.

Topics	Please tick your level of current knowledge				*Please tick below all topics you would like to learn more about in the training*
	None	Basic	Moderate	Advanced	
What do we mean by awareness?					
Reasons for lack of awareness					
How do we assess awareness?					
Treatment models for awareness issues					
Approaches to working with clients with lack of awareness					

Please add any other topics relating to awareness you would like covered or any specific questions you would like to be answered during the training

_____

_____

_____

What style of training best suits your learning style? Please tick all that apply

- Information presented verbally by trainer ____
- Full group discussion ____
- Small group tasks ____
- Role play ____
- Case study ____

Evaluation:

In order to assess the extent to which the training achieves it's learning outcomes I would like to ask trainees to complete a short evaluation questionnaire following the training.

In order to evaluate the extent to which knowledge gained in the training is later used to inform practice I would like to ask a sample of staff to give feedback at 6 week follow up. Would you be willing to take part in this? Y / N

APPENDIX C.2: Summary of Training Needs

Approaches to managing deficits of awareness

Proposed learning outcomes for trainees:
- to gain greater understanding of the potential causes and models of self-awareness and the interventions and approaches to managing it
- to be able to apply this knowledge appropriately when working with clients with deficits of awareness.

Topics	Please tick your level of current knowledge				*Please tick below all topics you would like to learn more about in the training*
	None	Basic	Moderate	Advanced	
What do we mean by awareness?			5	2	1
Reasons for lack of awareness		2	3	2	1
How do we assess awareness?		3	3	1	4
Programmes and interventions for developing awareness		5	1	1	5
Approaches to working with clients with lack of awareness		2	4	1	5

Please add any other topics relating to awareness you would like covered or any specific questions you would like to be answered during the training

- *How do you differentiate between lack of awareness and denial?*
- *How do you deal with a client who lacks awareness and is defensive with feedback?*
- *Current debates on models of causes and therapies for awareness difficulties*
- *In some of the more subtle cases, how can we define the lack of awareness that is attributable to ABI as opposed to a general lack of awareness.*
- *Does pre-injury personality affect awareness*

What style of training best suits your learning style? Please tick all that apply
- Information presented verbally by trainer _6__
- Full group discussion ___5
- Small group tasks ___4
- Role play _4__
- Case study ___6

Evaluation:

In order to assess the extent to which the training achieves its learning outcomes I would like to ask trainees to complete a short evaluation questionnaire following the training.

In order to evaluate the extent to which knowledge gained in the training is later used to inform practice I would like to ask a sample of staff to give feedback at 6 week follow up. Would you be willing to take part in this? Y = 7 N = 0

APPENDIX C.3: Training Plan

Approaches To Managing Deficits Of Awareness

Date of training: 7th April 2005

Time of training: 3.45 – 5pm (1 ¼ hours)

Attendees: Rehabilitation staff at the Rehab UK's London Brain Injury Centre

Workshop aims: The aims of this workshop are for rehabilitation staff

- to gain greater understanding of the potential causes and models of self-awareness and the interventions and approaches to managing it
- to be able to apply this knowledge appropriately when working with clients with deficits of awareness.

Teaching session: 3.45 – 4.45pm
1. What do we mean by awareness (10 mins) • Defining awareness • Hierarchical model (3 levels of awareness) • Increased awareness – the benefits and risks
2. Reasons for poor self-awareness (5 mins) • *Organic v denial debate*
3. Assessing awareness (5 mins) • General approaches to assessing awareness • Assessment measures
4. Therapies and interventions – different approaches (15 mins) • *Individual Awareness-Enhancing Programmes* • *Caregiver training and education* • *Procedural training and Environmental Support*
5. Techniques for facilitating awareness (15 mins) • *Facilitating 3 levels of awareness* • *Compensatory strategies for those who continue to lack awareness* • *Confrontational v non-confrontational approaches*
7. Q & A: (10 mins) • Addressing the issues raised in the training needs assessment and any questions arising
Practice session: Case Study 4.45 – 5.00
1. As a group review and discuss case study 'Tim' (adapted from Sohlberg and Mateer) and to agree an awareness management approach. (10 mins)
2. Brief review of suggestions given by Sohlberg and Mateer and give trainees copies of full case study describing awareness intervention. Final questions and comments. (5 mins)

APPENDIX C.4: Training Evaluation Questionnaire

For each statement below, tick the box that best describes the extent to which you agree or disagree with the statement.

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
As a result of attending the Approaches to Managing Deficits of Awareness Training…					
I understand more about models of awareness after brain injury					
I am more aware of the causes of lack of awareness					
I am more aware of a range of methods for assessing awareness					
I am more able to identify different treatment approaches for lack of awareness					
I understand more about different techniques for facilitating awareness and when to apply them					
I feel more confident to apply these approaches when working with clients with deficits of awareness					
Please comment on the presentation style					
The training had the right balance between the teaching, group discussion and case study exercise					
The content of the training was pitched at the right level (not too basic or too complex)					
Which aspect of the training did you find most useful?					
Which aspect of the training did you find least useful?					
What improvements would you make to the training?					
Any other comments					

APPENDIX C.5: Summary of Training Evaluation

Approaches to Managing Deficits of Awareness: Training Evaluation

For each statement below, tick the box that best describes the extent to which you agree or disagree with the statement.

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
As a result of attending the Approaches to Managing Deficits of Awareness Training...					
I understand more about models of awareness after brain injury				67%	33%
I am more aware of the causes of lack of awareness			17%	50%	33%
I am more aware of a range of methods for assessing awareness			8%	59%	33%
I am more able to identify different treatment approaches for lack of awareness		9%	18%	36.5%	36.5%
I understand more about different techniques for facilitating awareness and when to apply them		8%		67%	25%
I feel more confident to apply these approaches when working with clients with deficits of awareness		8%	8%	76%	8%
Please comment on the presentation style					
The training had the right balance between the teaching, group discussion and case study exercise		8%	25%	50%	17%
The content of the training was pitched at the right level (not too basic or too complex)				54.5%	45.5%

Which aspect of the training did you find most useful?
- 'Information about techniques for facilitating awareness, including confrontational vs. non-confrontational approaches'
- 'The training was about one particular topic and I find it all relevant and useful'
- 'The breakdown of different approaches to use at the different stages / types of unawareness'
- 'The reasons for poor awareness'
- 'Evaluating the case study'
- 'Non acceptance'
- 'Theory behind what we do and understating why we approach different clients differently to address deficits of awareness'
- 'The case study enables us to apply the training, very useful'
- 'Reinforcement that I am addressing needs and using best practice'
- 'Reasons for lack of awareness and how to manage it'
- 'organic vs psychologiscal'

Which aspect of the training did you find least useful?

- 'The beginning, but only because I already knew about theories of awareness and why lack of awareness occurs'
- 'None, it was all useful'
- 'All useful, but see improvements'
- 'Found all the session useful'
- 'I honestly found it all useful – packed with interesting / relevant information'
- 'Some of the theories were discussed too much in depth'
- 'Add more time for case study and to try and practice strategies for dealing with awareness – and could be more interactive'

What improvements would you make to the training?

- 'Adjust the balance between the teaching, group discussion and case study exercise'
- 'Perhaps the allotted time was a bit tight for the amount of training delivered'
- ' longer training event that left more time for both the information content and also some more interactive stuff'
- 'More time for group discussion, a longer session with a break'
- 'The training was excellent only minimal change would be to have had more time'
- 'Longer to include more case studies'
- 'Try to add a few more models'
- 'Given the broad background of the audience and the time allowed it would be difficult to say'
- 'None, but would allow extra time to allow opening up more discussion'

Any other comments

- 'Well presented, very clear and logical format'
- 'That was a very well done job and than you for your time and effort'
- 'A very interesting and useful event'
- 'More case studies'
- 'Presentation was flexible given time constraints, well managed and ended on time'
- 'Overall extremely useful'

APPENDIX C.6: FOLLOW-UP EVALUATION QUESTIONNAIRE

Approaches to Managing Deficits of Awareness:
Follow-up Evaluation

1. Following the training have you read or referred to any of the handouts provided in the training.   Y / N

2. If yes was this: For general reference ☐

            To recap a specific area of interest ☐

            For guidance on managing a particular client issue ☐

3. Since the training session have you applied any of the theory, models or approaches presented in the training to your work with clients. Y / N

4. If yes please give details:

_____

_____

_____

_____

_____

_____

Thank you for your time.

Appendix C.7: Stress Management Training Assessment Quiz: Anxiety

1. Which one of the following graphs is correct?
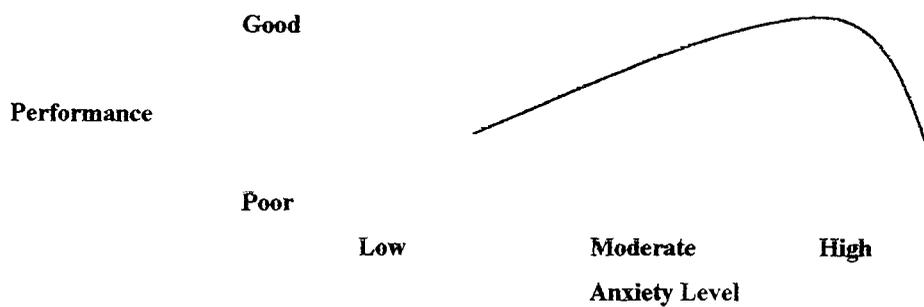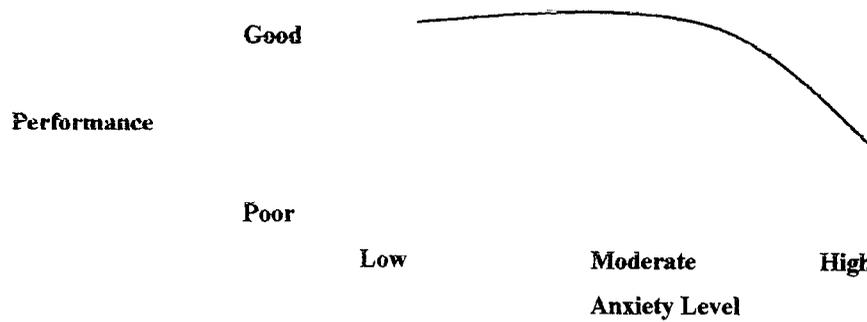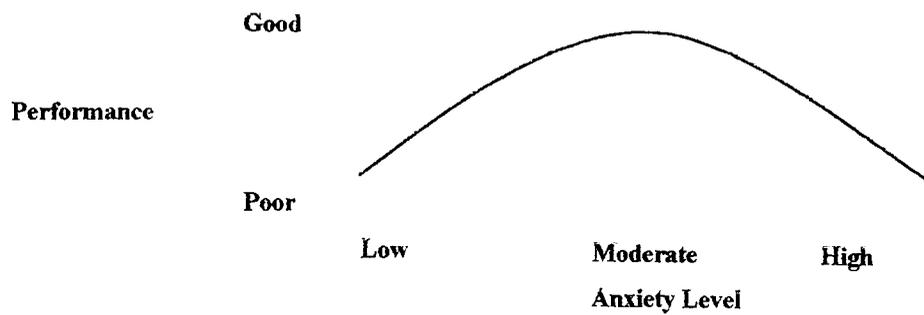
2. Which of the following words best finishes the sentence below?

a) Pleasure   b) Hunger   c) Tiredness   d) Anger

"The physical responses to anxiety are very much like those produced by other feelings such as _____."

3. Give three changes that happen to the body when you get anxious

1)

2)

3)

4. Which one of the following sentences about the nervous system is false?

a)   the **somatic system** is largely under our control and is used for tensing and relaxing muscles

b)   the **autonomic system** is used to regulate activities such as breathing, heart rate and blood pressure

c)   the **somatic** system is divided into two parts: the **sympathetic** and the **parasympathetic** system

d)   the **sympathetic** and the **parasympathetic** system can't work both at the same time

Appendix C.7: Stress Management Training Assessment Quiz: Anger

1. Give a reason why anger control problems can occur after a brain injury.

_____

_____

_____

_____

2. What are anger triggers? Give an example of a trigger for your own anger.

_____

_____

_____

_____

3. What are body cues?

_____

_____

_____

_____

4. Why is it important to be aware of your body cues?

_____

_____

_____

_____

5. Give an example of a word or phrase you can use when you are becoming angry to prevent the situation getting worse.

_____

_____

_____

_____

Appendix C.7: Stress Management Training Assessment Quiz: Relaxation
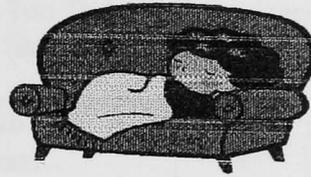
1) In order to relax and feel in control, it is best to breathe

(a)   Quickly

(b)   Slowly & Deeply

(c)   Standing on your head

2) If you think you might lose control and hurt or offend someone, it's a good idea to

(a)   Walk away from the situation

(b)   Try and fight back the urge to lose it

(c)   Have a go at the person anyway: better out than in!

3) If you can't avoid the person that's making you stressed, you should

(a)   Ignore anything they say or do

(b)   Tell them to get out of your face

(c)   Count to ten before you say or do anything

4) When using the visualisation technique, it's best to imagine

(a)   Yourself punching the person annoying you in the face

(b)   Yourself somewhere pleasant like a beach

(c)   Previous times when people have wound you up

5) Which of these are not true about the negative images people have about themselves

(a)   They increase stress and anxiety

(b)   They are normally true

(c)   They can become a self-fulfilling prophecy

Appendix C.8: Stress management training evaluation

Firstly, we would like to know what you feel you have learned from the course. For each statement below, tick the box that best describes the extent to which you agree or disagree with the statement.

As a result of attending the Rehab UK stress management training course...	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1. I understand more about what factors cause and maintain anger, anxiety and stress reactions.					
Give two reasons why people can be more prone to anger, anxiety and stress following an acquired brain injury.					
2. I am more aware of the impact that anger, anxiety and stress can have on my life.					
Give an example of how anger, anxiety or stress have affected your life.					
3. I feel more motivated to tackle my anger, anxiety or stress issues.					
4. I can identify more easily when I am starting to become angry, anxious or stressed.					
What are the signs that you are becoming angry, anxious or stressed?					
5. I am more aware of the situations, thinking errors and other factors that tend to make me angry, anxious or stressed.					
What situations tend to make you angry, anxious or stressed?					
What are the thinking errors that tend to make you angry, anxious or stressed?					
6. I am aware of a range of anger, anxiety and stress management techniques, understand the rationale behind them, the situations in which they are appropriate and their limitations.					

As a result of attending the Rehab UK stress management training course...	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
7, I apply a range of anger, anxiety or stress management techniques effectively in a variety of settings.					
What anger, anxiety or stress management strategies do you regularly use?					
8. I am now less likely to view situations as being anger-provoking, anxiety-inducing or stressful.					
9. I am now better able to control my feelings of anger, anxiety or stress.					
10 I am now better able to resolve the underlying causes of my anger, anxiety and stress.					
Next, we would like to know what you feel about how the course was designed and delivered. For each statement below, tick the box that best describes the extent to which you agree or disagree with the statement.					
11. The course had a good balance between formal teaching, group discussion and practical exercises					
12. The content and pace of the course were pitched at the right level for me, being neither to easy nor too difficult.					
13. I could easily see how what was being taught in the sessions related to my own situation.					
14. I found the handouts and other course materials useful.					

APPENDIX C.9: Reflective commentary on video recording of stress management training session.

This video recording shows edited clips from a 45 minute session of the stress management training provided to a group of clients with acquired brain injury attending rehab UK's brain injury vocational centre.

The beginning of the tape shows the start of the session in which I give an overview of the topics to be covered in the training session in order to set the context and prepare learners for the training tasks. In preparing the session plan (see case study Appendix A) the aims of the training session are defined. I did not present these to the learners at the start of the session and in hindsight it would have been useful to have done so and to have had these written, on a flip chart or handout, for learners to refer to.

I ask learners to recap some of the information delivered in previous sessions in order to establish and reinforce what had been learned during the training programme so far. In hindsight, and it is noted in feedback from my University supervisor who was observing this session, that I could have focused more on encouraging learners to explain in their own words what they had learnt about responses to stress rather than on their recall of psychological terms such as 'fight and flight'.

The next stage of the training involved a group exercise where learners where asked to work in pairs to generate ideas to the following questions: 'Why do we need to control anger?', 'What can trigger anger?' and 'How do people display their anger?'. They were asked to write their responses on flipchart paper and later feedback to the group for discussion. The aim of this exercise was to encourage interactive learning by working together and sharing ideas. Feedback from previous groups attending the stress management training was that it had been too theory based and tutor led and so I attempted throughout this training programme to include some interactive, group work into each session. While working on this exercise I visited each group to offer support, give prompts to generate ideas if needed and to give positive feedback (this is not shown on the video clip).

Each pair fedback to the group and I facilitated further discussion and suggestions. The feedback session from one group is shown on the video clip (What can trigger anger?). Following the feedback of the group exercise one learner described a situation in which she had expressed anger. The video clip shows me responding to this learner example in order to illustrate the importance of identifying personal signs of anger and stress and to recognise when to adapt an appropriate strategy to manage the stress response.

In the next stage of the training I present the reasons why people may experience issues with anger after brain injury. This presentation is theory based and I attempted to encourage learners to relate this theory to their own experience. During this discussion a learner made a suggestion which was not accurate and I attempted to address his misunderstanding in a way which was supportive.

The final clip shows the end of the first half of the session (the training continued after a short break. The second half of the training is was not video taped). At the end of the session I recapped what had been discussed and explained the purpose for presenting this information in that it was to support learners to understand their own sources and responses to stress and anger in order to develop strategies for managing this. I informed clients what would be covered in the next session. Handouts were prepared to highlight the information provided in this session and these were given out at the end of the session. I chose not to give out the hand out at the beginning in order to encourage more active learning, which may be avoided if learners focus on reading the handouts rather than engaging into the sessions.

During the training there is a degree of repetition of information and a structured approach is used in which I explain to learners what will be delivered, deliver the information and training and then review what has been delivered. This structure was adopted to meet the needs of the learner group who as a result of an acquired brain injury may experience difficulties of attention, memory or information processing. Repetition and reinforcement of material is therefore beneficial.

Throughout the training, and as can be seen at times within the clip, I attempt to clarify what learners mean when they make a comment by paraphrasing and checking. The nature of brain in injury is such that some clients have difficulty expressing themselves verbally, may take longer to organise and express their thoughts and may have word finding difficulties. When responding to learner questions and comments I tried to listen carefully, give them time to express themselves and finish, ask for clarification myself if I am not sure what they mean. I try to think before responding to ensure I have understood the learners point as it can be discouraging or frustrating if they feel they have been misunderstood and have to repeat themselves or state that was understood what not what they meant. This can be seen in the clip where I at times take time before responding to a comment.

APPENDIX C.10:   Session Plans For Training Workshops

Brain Injury Awareness

Aims:

- To educate attendees about the range of effects of brain injury
- To provide examples of different strategies that can be used to compensate for cognitive difficulties
- To support clients to analyze their own areas of strength and weakness and to begin to set goals
- To support therapists to identify areas of work with clients

Objectives:

- Clients to demonstrate understanding of brain injury and its effects
- Clients to be able to identify appropriate strategies to compensate for cognitive difficulties
- Clients to begin to set goals to develop over course of therapy
- Therapists to be able to identify some therapy tasks and goals

Materials

- Handouts: The brain and it's functions.

    Hierarchy of cognitive functions

    Attention, memory, executive functions

- Flipchart paper
- Pens
- Blue tack

Appendix C.10   Session plan: Brain Injury Awareness

1. **Introduction and aims (15 mins)**

   Ice breaker and introductions

   State purpose of project and of this session

2. **Brain injury awareness (30 mins)**

   Describe functions of different areas of brain (2 diagrams)

   Hierarchy of cognitive functions

Explain -	4 elements of attention
	Short-term memory
	Executive functions

3. **Group work (15 mins)**

   In groups identify and list areas of need and how they impact on daily functioning.

   List strategies for attention for compensating for these difficulties (either that clients already use or that hey know of)

<div align="center">

BREAK 20 mins

</div>

4. **Overview of strategies (20 mins)**

   Brief review of strategies for

   - attentional management
   - memory internal / external
   - planning / organizing
   - mood

5. **Goal setting exercise (20 mins)**

   (if appropriate) strength and needs analysis

   Or

   List of areas to develop

Appendix C.10   Goal setting

Aims:

- To support clients to analyse their own areas of strength and weakness and to begin to set personal goals.
- To identify areas of need to provide a focus for future sessions.
- To support therapists to identify strategies and cognitive tasks which can be introduced in their sessions.

Objectives:

- Clients to analyse their own areas of strength and weakness and to have set personal goals to be worked on within the group.
- The group to have identified common areas for development to be addressed in future sessions.
- Therapists to have identified relevant therapy tasks and goals.

Materials:

- Strengths and needs analysis sheet
- Pens
- Flipchart paper

Session Plan: Goal Setting

1. Recap previous session (15 mins)

Brain injury awareness / needs and strategies

2. Introduce Strengths and needs analysis form (30mins)

Group to work in pairs to complete form with support

BREAK 20 mins

3. Feedback from pairs and goal setting (20 mins)

4. Cognitive strategy task (if time allows) (15 mins)

e.g. review notebook use, use dairy to record events over the week and to monitor progress toward goal.

Appendix C.10   Session Plan: Memory Strategies

Aims:

- To present a range of external and internal memory strategies
- To demonstrate the importance of strategies and their effective use
- To support each client to identify strategies appropriate to them and to facilitate their implementation
- To develop diary or time planner as a memory and organisation strategy

Objectives:

- Clients to have better understanding of a range of different memory strategies and to have identified those which would be useful to them
- Clients to practice using some of the strategies discussed
- Clients to keep a log of strategies used for homework
- Clients to use an appropriate strategy for remembering to bring the goals and log each session
- Clients to bring a diary (if they have one to the next session) or to use time planner sheet if they do not have one.

Materials

- Handouts: A model of memory

                      External and internal memory strategies
- Word list and Kim's game picture
- Memo note and paper
- Strategy log record from
- Time planner sheets.
- Flip chart paper and pens

Appendix C.10   Session plan: Memory Strategies

1. Recap of previous session (10mins)

Ask clients if they remember the areas of need they identified last week (individually/ or as a group).

Give out individual lists and copy of group list

Inform the group that I will attend two more training sessions and then a review session, this session to practice memory strategies and the next to practice assertiveness (as these were identified as group goals)

2. Give overview of memory process (20 mins)

Stage model (demonstrate on flipchart)

3. Review of strategies (20 mins)

Brainstorm and present External memory strategies –discuss briefly as covered in first session

Brainstorm and present Internal memory strategies

BREAK (20 mins) (use strategy to be back on time)

4. Memory games(40 mins)

Verbal memory - Word list exercise

Demonstrate Storytelling strategy and ask clients to practice this by repeating word list exercise

Visual memory – give Kim's game exercise, discuss strategies used.

'Chinese whispers' note taking exercise – In group of 3 clients practice taking notes and passing on a message

5. Homework (10 mins)

Ask each person to bring a dairy or notebook to the session (give out time planner if people do not have one)

Appendix C.10   Session Plan: Assertiveness

Aims:

- To identify difficulties members of the group may have with being assertive
- To educate clients about different communicating behaviours (passive, passive aggressive, aggressive and assertive)
- To provide clients with a framework for communicating assertively
- To support clients to practice communicating assertively and to give constructive feedback

Objectives:

- Clients to identify their own communication goals
- Clients to demonstrate an understanding of the 4 behaviour types and to be able to recognize an assertive way of responding.
- Clients to demonstrate, through role-play, an understanding of how communicating assertively

Materials:

- Handouts: The four behaviour types

                Assertiveness
- Role play scenarios
- Flip chart paper and pens

Appendix C.10   Session Plan: Assertiveness

1.Recap previous session. (10mins)

Ask if anyone has used any of the memory strategies discussed last week

2. Introduction to assertiveness (15mins)

What do people find difficult in communicating effectively?

What is assertiveness?

3. Presentation of different behaviour types (15 mins)

Give handout C (4 behaviour types)

On flipchart identify the body language etc. related to each behaviour type.

4. pairs exercise (20 mins)

In pairs have a conversation e.g. what you did at the weekend, favourite TV

programme? One person uses one type of 'bad' body language. The other person

identifies it. Repeat with the other person using 'bad' body language.

Repeat a third time trying to avoid all body language bad habits.

Break 20 mins

5. Assertiveness definition and tool kit. (15mins)

Discuss how to communicate effectively.

Work through an example e.g. a friend has borrowed money and you have to ask

for it back. Aggressive, passive, passive aggressive and assertive response.

6. Role play (20 mins)

Give scenarios (or ask clients to pick their own situation) and role play in

threes. Third person give feedback as observer. If time practice 2 role

plays and play back to group.

7. Feedback and Home work (5mins)

Ask clients to try using this skills in a real

situation

APPENDIX C11: Individual and Group Goals established in goal setting workshop

Individual strengths and areas of need

Client 1:

Strengths

- Cognitive:' Waking up and planning week'
- Social: 'Sociable, chats a lot'
- Skills / abilities: 'Artistic, assertive – speaks up'
- Independent living: 'Cooking Washing'

Needs

- Cognitive: 'To develop memory strategies'
- Mood: 'To try to be cheerful'
- Social: 'To be able to ask to talk to somebody in private, to not have other people listening in'
- Communication: 'To be heard'

Personal goals:

1. To develop memory strategies.
2. To develop assertiveness skills

Client 2:

Strengths

- Cognitive: 'Good long term memory about how I was when I was young'
- Social: 'Talks to old people who have many things working with them, using our brain'
- Communication: 'Sense of humour, honest'
- Skills / abilities: 'Crane, JCB, Lorry, Handtools, Bricks, Plaster, temperatures' (skills before injury)
- Independent living: 'Independent, does things own way'

Needs

- Cognitive: 'Short term memory e.g. someone's name'
- Mood:'I panic at times (e.g. when going out on own). When I talk I am more relaxed'
- Independent living: 'Frozen food – I can't be bothered to cook'

Personal goals:

1. To develop memory strategies
2. To develop anxiety management strategies

Client 3:

Strengths

- Cognitive: 'following instructions, getting orders and following it'
- Mood: 'Very happy that I am still living and working and very pleased that I am in top job '
- Social: 'Chat a lot. Down the pub, to the cinema with friends'
- Communication: 'Talking to people on the phone, face to face'.
- Skills / abilities: 'Computer games, collecting stamps, playing football, staying in watching TV and DVD, going to concerts.'
- Independent living: 'Making cup of coffee, getting up in the morning'

Needs

- Mood: 'I feel very down'
- Communication: 'Getting orders – saying it once not a hundred times.'
- Independent living: 'Living in America and work there and earn millions'

Personal goals:

1. To develop ways of managing mood.
2. To develop assertiveness skills (i.e. 'to deal with work colleagues who are always telling people what to do')

Client 4:

Strengths

- Cognitive: 'Long term memory very good'
- Social: 'respect other people, organizing parties, role model, sharing own experiences, good mother'
- Communication: 'Friendly, chatty, good, listener, flirting'
- Skills / abilities: 'Doing household skills, singing, artistic'
- Independent living: 'Personal hygiene, dusting, making drinks, washing up, cooking, ironing, shopping, arranging transport, going to the pub, eating out, going out with my children'

Needs

- Cognitive: 'Short term memory not so good'
- Social: 'Being more positive'
- Independent living: 'Motivation, praise, determination to move on'

Personal goals:

1. I believe I will walk again
2. To learn more and be a singer
3. To develop memory strategies
4. To develop confidence

APPENDIX C11: Individual and Group Goals established in goal setting workshop

Group Goals

1. To develop communication skills - assertiveness, 'being heard', expressing self positively

2. To increase self-confidence (belief in self)

3. To develop memory strategies

4. To improve motivation

APPENDIX C12: Final Implementation Plan (Amended during consultancy in discussion with client and arts facilitators)

Implementation plan	Date of input	Time allocated (including travel)
Week 1: Brain injury awareness session with client, participants, carers and arts facilitators	2nd February 2004	3 hours
Week 3: Group session to identify needs and set goals with client, participants and arts facilitators	23rd February 2004 (no session 16th Feb 04 due to school holidays)	3 hours
Week 6: Memory strategy training session with participants and arts facilitators	15th March 2004	3hours
Week 9: Assertiveness training session with participants and arts facilitators	5th April 2004	3hours
Week 12: Evaluation meeting	10th May 2004 (12th April, 3rd May Bank Holidays)	3 hours
Evaluation report completed	21st May 2004	5 hours
Accessible to arts facilitators for supervision by phone / email	Ongoing	As required

APPENDIX C13: Minutes of evaluation meeting   10th May 2004

Present: Client, Clare Eldred (Health Psychologist in training), Arts facilitator – visual arts and crafts, Arts Facilitator – drama and creative writing

Aim of meeting was to review the project so far and to develop an action plan to take the ideas of the service users forward.

Feedback from arts facilitators

It was observed that there had been some positive changes during the group in that service users had shown improved communication skills and improved their attention on tasks throughout the project. The group appeared to bond and support each other. However, the four regular attendees developed a group cohesiveness and appeared resistant to new members or non regular attendees of the group. This led to some underlying conflict in some of the group sessions.

Service users often raised emotional issues. The arts facilitators did not feel they had sufficient training or supervision to adequately address these issues. They advised that the continuation of this project should include further training on the emotional effects of brain injury and how to manage these. They commented that they had spent some time after each session debriefing each other but felt they would have benefited more from formal professional supervision.

They advised that two 2-hour sessions on one day was to long. They did not feel they had an adequate break as they often spent break times and lunch times talking to clients. These sessions also required a great deal of preparation. They would need to plan for several activities as group members were not able to attend to one task for long or could be reluctant to engage in a particular activity.

They reported that the group members had expressed resistance to the psycho-educational elements of the project. The arts facilitators felt that they had benefited personally from these sessions but that the group members had not.

Recommendations for the continuation of the group

It was agreed that future groups should include elements of a craft activity, social outings and social support. It was suggested that the group meet monthly and be client led but include a facilitator who was a professional with experience of brain injury. The focus of these meeting groups would be to plan an activity or outing to take place after the meeting or at a later date.

Action points

- Client to investigate funding for the continuation of the group and address transport issues.
- Arts Facilitators to consider if they wish to continue to facilitate the group activities.
- Arts facilitators to send Clare Eldred a list of the activities the service users have identified they would like the group to engage in.
- Clare Eldred to send the arts facilitators an evaluation questionnaire by email.
- Clare Eldred to complete evaluation report and send to client by 21st May 2004. This will then be submitted by the client to the funding body.

Arts Project For Adults With Acquired Brain Injury: Evaluation Report

Acknowledgments:

Summary

Background

The Bromley Arts Project was set up to provide an arts and crafts based activities group, with a psycho-educational approach, to adults with an acquired brain injury, living in Bromley and receiving support from the Adult Disabilities Team within Bromley Social Services.

This project aimed to provide psycho-social benefits for it's participants. The impact of the project was evaluated using qualitative evaluation methods and recommendations are made for future development of the group and for the implementation of similar arts interventions for people with brain injury

Scope

The Bromley Arts Project was implemented one day a week for twelve weeks and provided arts and crafts and drama based activities during two, two-hour, weekly workshops. The project included four workshops provided by a psychologist to develop awareness of the effects of brain injury and promote the use of strategies to compensate for cognitive difficulties.

Conclusions

Evaluation of the project identified the following perceived benefits for some participants

- engagement and motivation
- a sense of social and emotional support
- increased independent functioning

While participants did not identify the psycho-educational workshops as directly relevant to these benefits they did report progress toward the agreed group goals.

The benefits reported in this evaluation broadly reflect those reported in the literature on the health hand social impact of arts based interventions.

Recommendations for the future

It was agreed that the future development of the project should ideally involve a monthly meeting of the group, which should include:

- Social support - an opportunity for participants to share experiences and discuss feelings
- Activities chosen by participants
- Social outings – arranged for after the meeting or at a later date

Introduction

' The arts clearly have the potential to make a major contribution to our health, wellbeing and life skills. It is important, however, to capture the evidence of the impact of the arts on health to ensure proper recognition of their effect and the availability of appropriate levels of investment to sustain positive influences' (Health Development Agency, 2000).

An increasing number of community projects and interventions use arts to help achieve health or social objectives. This is reflected in a number of recent reviews of the approaches, benefits and evaluation methods used in community based arts projects (e.g. Matarasso 1997, Hamilton 2003, Smith 2001, Angus 2002) and in the development of range of forums for researching and providing advice on this topic (e.g. The National Network for the Arts in Health (NNAH), The Centre for Arts and Humanities in Health and Medicine (CAHHM))

A review of good practice in community based art projects, commissioned by the Health Education Authority in 1998, discusses the link between the psycho-social benefits of arts projects and their indirect impact on general health and wellbeing. The author of the report suggests that the following factors enhance people's health by building 'social capital' (in terms of community involvement and social inclusion):
• Enhanced motivation
• Greater connectedness to others.
• People's own perceptions about having a more positive outlook on life.
• Reduced sense of fear, isolation and anxiety.
• Increased confidence, sociability, and self-esteem.

In a review of evaluation methods in community based art for health activity in the UK, Angus (2001) reports that many projects emphasise *'the use of art for personal development through the discovery of creativity and social connectedness leading to increased confidence, self-esteem and empowerment'* and that this in turn *'assists people to question their boundaries, explore issues, voice aspirations, identify needs and facilitates learning'.*

Arts based interventions have been implemented with reported benefits with people with acquired brain injury. For example, McKenna and Haste (1999) suggest that a short course of drama therapy aided psychological adjustment to disability following brain injury . Garner (1996) describes a 'Neuropsychological Art Therapy (NAT) model which suggests that art therapy can be useful for retraining and maintaining cognitive, psychological and motor skills in individuals with traumatic brain injury.

Background

The Bromley Arts Project ran between 2nd February 2004 to 10th May 2004. The group met once a week for a total of twelve weeks. The day comprised of two workshops, one in morning (11am to 1pm) and one in the afternoon 2pm-4pm. Each day comprised a workshop in arts and crafts, facilitated by Georgina Batty and a workshop in drama and creative writing, facilitated by Pamela Gilmore.

The group was open to adults who had an acquired brain injury known to social services and participants were recruited by the client (Care Manager) who invited 14 individuals to take part. Eight people joined the group at the outset, two did not attend beyond the first session and additional participant began attending in the fifth session. Four clients attended all twelve sessions, the remaining three attended at least 3 sessions.

The project took place at the United Reform Church in Bromley. Transport was provided to enable participants to access the project and support worker was also provided for one participant.

A psychologist was recruited to provide a psycho-educational approach to the group. The aims of this approach is to provide people with a brain injury information about brain injury and it's potential effects in order to develop awareness and to promote the use of compensatory strategies. It is recognised that individuals who have limited understanding of the nature, degree or impact of their difficulties may be reluctant to engage in rehabilitation or to learn compensatory behaviours to lessen their limitations. Developing insight and awareness following brain injury can therefore have important benefits for subsequent functioning.

Aims

At the outset of the group the project had a number of broad aims. These were:

- To provide a forum for people who had an acquired brain injury to meet and to engage in activities for enjoyment and fun.
- To provide a project which participants would choose to attend in order to develop motivation, particularly for those individuals who had not engaged fully or enthusiastically in other services.
- To develop brain injury awareness and to develop skills and strategies for compensating for cognitive functioning, particularly in relation to memory difficulties, which was identified as a common issue within the group.

The following were identified as potential indicators of success for evaluation:

- mood
- motivation (in terms of attendance)
- sense of autonomy
- confidence
- functional independence
- use of compensatory strategies

However, it was agreed that it was important for the participants to be fully engaged and empowered within the project and therefore it was agreed that identifying individual needs, and setting goals and targets, would be an ongoing part of the group process and that these aims and indicators may change as the group progressed.

Project delivery

Arts based activities: Crafts

Initially this was to involve pottery and paper based activities but over time it became apparent that a wider range of activities were necessary to engage all participants interests. Activities introduced included:

- Egg blowing
- Cake decorating
- Seed painting
- Plant Pot decorating
- Chandelier making
- Painting glass disks for mobile making
- Glass Painting on glasses and picture frames
- Bread making
- Stained glass window making
- Wire sculptures
- Mask making
- Basket weaving
- Jotters for ideas
- Drawing

Participants were encouraged to suggest additional activities

Arts based activities: Drama

These sessions involved a range of activities including creative writing, memory games, and discussion groups. As the group developed these sessions also included a more 'peer support' element as the group began to use this forum to discuss feelings and problems.

Psycho-educational workshops:

This involved four half day workshops provided by the psychologist.

- Session 1: Brain Injury awareness. Presentation of the brains functions and group work to identify areas of difficulty and current strategies.

- Session 2: Needs analysis and goal setting. Identifying individual strengths and areas of need and common themes for group goals and future workshops. The group goals elicited by this exercise were:

1. To develop communication skills (assertiveness, being heard, expressing self positively)
2. To increase self-confidence (belief in self)
3. To develop memory strategies
4. To improve motivation

The remaining two workshops were designed to address these areas

- Session 3: Memory strategies. Discussion of memory function and how memory can be affected by brain injury. Introduction of memory strategies.

- Session 4: Assertiveness skills. Discussion of assertiveness and non-assertive behaviours. Role play of assertiveness skills.

Evaluation methods

The project was evaluated using a range of qualitative evaluation methods:

Participant evaluation was carried out by

- *focus group;*

it was felt that this approach would be more useful than questionnaire alone as some participants have difficulties expressing themselves in writing. Also it was felt that more in depth information could be obtained in a forum where participants could be encouraged to give feedback, prompted to expand on comments and could discuss their ideas with each other.

The discussion was mediated by psychologist with the care manager and facilitators who also gave feedback on their perceptions and observations of the group. (see Appendix C14.1 for Focus Group Topic Guide)

- *evaluation questionnaire;*

At the end of the session participants were asked to fill in a brief evaluation questionnaire designed by the facilitators (see Appendix C14.2 for Evaluation Questionnaire). These were also sent to participants who did not attend the focus group.

Facilitator evaluation was carried out by

- *evaluation survey;*

The two group facilitators were asked to complete a short questionnaire to obtain feedback on their observations of the group, including perceived strengths and weakness and recommendations for improvements and future developments (see Appendix C14.3 for Evaluation Survey)

- *end of project review meeting;*

attended by the Care Manager, two course facilitators and psychologist to review the project and to consolidate suggested areas for the future into an action plan.

Observations made by facilitators during the focus group discussion are also included in their evaluation.

Participant Evaluation

All participants were invited to take part in a focus group held on the last day of the pilot project. The four most regularly attending participants agree to take part. The focus group lasted one hour and was audiotaped with participants written consent. The focus group discussion aimed to obtain participants views of the following areas:

- expectations before starting the group and how these were met
- an evaluation of the psycho-educational approach
- perceived benefits of the group overall
- recommendations for the future of the group

The focus group discussion was transcribed and the data provided by participants analysed using thematic analysis to identify key themes which recurred throughout the discussion. Some of these themes are relevant only to the particular topic under discussion others occurred across topics. The results of this analysis will be summarised here in relation to topic and themes with an example of quotes.

Expectations

Participants stated that they did not have clear expectations of the group before attending. Perceptions ranged from not knowing, *'I didn't have a clue'*, to some understanding of engaging in activity *'I thought I was going to do things that was all'*. There was some expectation of social interaction in terms of meeting people *'more of a social group, which I like,'* or seeing existing friends *'...I knew who was going so I had to go and see her'*. One participant expressed anticipating psychological support but expected one to one intervention to address personal issues and reported that the group had been different to expected.

Psycho-educational approach

Participants generally did not relate the benefits of the group to the psycho-educational workshops and reported finding these confusing and difficult to understand. However, it was concluded that this could be a potentially useful approach and the following recommendations were made by participants:

- a focus on one issue presented in greater detail
- information broken down into stages
- information ' spread over more time'
- repetition of information to aid understanding
- less written material
- reinforcement of strategies
- more related to individuals experiences

Perceived Benefits

The overall perceived benefits of the project were grouped into three overall themes. These are listed below in the order of importance in terms of the number of times the theme recurred in the discussion.

Engagement

This theme related to motivation to engage in the group in some way. Some participants expressed this in terms of active engagement and enjoyment of the arts and drama activities. All participants described at least one activity they had enjoyed. *'I really enjoyed painting those pots'*, *'that singing session we had a few weeks back...it was great'*.

One participant, who was initially reluctant to engage in the prepared activities, bought in objects of interest from home to share with the group and increased participation by drawing these objects. This participant expressed engagement in terms of enjoying learning by watching others,

'mainly I enjoy watching people', '..although you don't want to do it you can still learn', ' when you go home it gives you ideas...those were things I never even knew how to do'

Participants considered their engagement in the group compared with other services for people with brain injury they had been involved in and identified a number of aspects of the group they considered favourably. These were:

- a more relaxed atmosphere
- participant focused, allowing participants to make decisions about what activities they engaged in and to influence the way in which the group developed
- a small group promoting confidence to speak out

These factors seems to develop a sense of empowerment in the group - *'it is freedom ... to get what you want '*

Emotional support

Many comments related to peer support in terms of sharing feelings with others in the group who had similar experiences and having a sense of being understood - *' I find it easier to talk to people who have been through the same sort of stuff as you..you can understand their way of reacting to it as well as yours...sort of comparing it'*

'basically it just one person talking to another person about the same thing and we can learn more about each other....'

Other comments related to the support received by the group facilitators in terms of having someone to talk to who understood their problems - *'it's very easy to talk to them* (the facilitators*)..about your troubles'*

Increased independent functioning

This related to comments made about overcoming anxiety, developing cognitive strategies and increasing confidence. One participant who experienced difficulty going out in public alone due to anxiety related how they had used the group to set themself a 'target' of going out at lunch time alone and had achieved this objective - *'to go out for my dinner and get back on my own'.* This participant also commented that the group allowed a *'freedom'* to be more independent - *'you allow me to go out, lunch time I go out....without the door locked'.*

One participants reported beginning to use an existing memory strategy (a diary) more often - *'I've used a diary..start putting in what days I am working what days I'm not'.* Another reported learning the name of another client he was familiar with before attending the group - *' learnt the name for X that is a miracle that is, I could never remember names..if your put in the right position and let people do it they can learn'*

Another participant expressed an increase in confidence -*'I am more outgoing now than I ever was, I know it's hard to believe....yeah with these two young ladies* (facilitators)*help'*

Future Developments

The participants had brainstormed ideas for future activities in an earlier session. These were discussed again in the focus group. It was agreed that the group would like to focus on arranging social activities

They recommended the group meets monthly to discuss and decide between them an activity for that month. A range of general social and cultural activities were suggested:

- museums
- art galleries
- cinema
- theatre trips
- newsletter

Individual participants also suggested personal interests that they would like pursue themselves or for the group to be involved in.

- photography
- engineering and metal work
- horse grooming
- driving lessons
- creative writing / poetry group
- arts and crafts
- gym
- swimming
- cookery course
- aromatherapy
- computing

It was also recognised that the emotional support and sharing experiences was an important part of the group and should be incorporated into future plans for the group. - *'I want someone to help me get through it and overcome it and it's basically get on with your life...'*

Evaluation questionnaire to participants

Six questionnaires were returned, two from participants who had not attended the focus group. Results of this evaluation suggest that all participants had enjoyed the course, rated the quality of teaching as good and that they had enough support form the tutors.

All comments on what aspect of the course they liked related to the social aspects of meeting people and making friends in a relaxed atmosphere. One participant commented that they wished they had been able to attend all sessions and recommended that a written schedule of each weeks activities had been provided.

Facilitators evaluation

The feedback received from the facilitators from the evaluation survey, end of project review and their observations during the focus group was collated and summarised below.

General observations

- Participants appeared negative toward the group and reluctant to attend the group in it's early stages. Some participants suggested that their motivation to attend the group was due to limited alternative options and concern that they may not be offered future activities if they did not attend rather than an interest in arts and crafts in itself.

- Participants expressed resistance to the topics presented in the psycho-educational workshops as this felt like learning and also they were expecting more immediate results or 'cure'.

- Participants initial response to the project prompted the facilitators to approach the group differently and to focus it more as way a of participants sharing and communicating together.

Strengths

- Facilitators observed that group cohesion and sharing of feelings grew as the group progressed. This was identified as a significant strength of the group in that it provided a forum to grow as a group and to be heard - *'as a group they bonded and felt that they had a voice'.*

- Both the arts activities and the peer support elements of the group were seen as important and were observed to compliment each other- '... *I think it needs both because the crafts give it the element of having a social, fun thing but then that kind of is balanced by the other .... the crafts, that doing something practical gave you a kind of safe fun way of doing things but .....other stuff could come out like if you were having troubles in your own life it felt like a good place to talk about it.'*

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- An improvement in communication skills was observed - *'We sat and talked as a group a lot and they enjoyed being heard and they started to truly listen and encourage each other'*
- Participants ability to engage and sustain attention on an activity was observed to improve.

Weaknesses

- A range of different activities need to be prepared for each session to cater for a wide range of interests and to continue to engage a participants interest if the lost interest in a task or if a particular task proved unsuccessful with the group. This increased the preparation time needed for the sessions.
- As the group progressed participants increasingly discussed their feelings within the group and began to share problems and emotional issues. Facilitators felt that they needed more experience, training and support to deal with these issues and were concerned about the 'safety' of participants raising emotional issues and– *'potentially taking ourselves to a certain place and then walking out in the streets and feeling raw...it was a potential danger'* It was felt that some participants would benefit from having additional support to meet their emotional needs.

Recommendations

- More comprehensive assessment of client suitability, need and interests prior to the project.
- Psycho-educational workshops to be focused on one area and delivered in a slower, simpler way, maybe incorporating games.
- The location of the session to have tea and coffee making facilities - *' The break was an important time to form bonds and friendships over a nice cuppa'*
- The sessions to be held in the same room each week and the room to be of an adequate size.
- The sessions to be shorter in order to hold participants attention. Two hour sessions involved a great deal of preparation for facilitators and could be emotionally draining.
- Facilitators to have more training in brain injury, particularly in relation to it's emotional effects.
- Facilitators to receive training, supervision and support to deal with issues that arise in the group.
- Greater collaboration between therapists and psychologist to develop activities and to review the work and participants progress.
- Additional resources or referral sources for clients identified with emotional needs greater than could be responded to in the group setting.

Conclusions

The evaluation suggests that overall participants perceived a positive impact of the project in terms of increased engagement and motivation, a sense of social and emotional support and increased independent functioning in terms of overcoming anxiety, using strategies to overcome cognitive difficulties and increased confidence. Participants were encouraged to have input into the direction in which the group developed and make decisions about future plans, which promoted a sense of empowerment.

These benefits can be seen to concur with those reported in the literature on the health and social gains of arts based interventions. While participants did not identify the psycho-educational workshops as directly relevant to these benefits, the project in a general sense resulted in perceived benefits in line with the stated initial aims of the project and with the group goals agreed in the early stages of the project; assertiveness, confidence, memory strategies and motivation.

It was observed that the group developed in stages. It became evident early on that participants were not fully engaging in the arts and drama activities but appreciated the opportunity to share their experiences and receive support from each other. While this developed as one of the projects strengths and was recognized as meeting and important need for participants it was also an area for concern for facilitators who were cautious to remain within boundaries.

Recommendations for the future

It was agreed that the future development of the group should include a monthly meeting group which would involve a facilitator but would be client led.

This meeting group should include the following elements:

- Social support - an opportunity for participants to share experiences and discuss feelings
- Activities chosen by participants
- Social outings – arranged for after the meeting or at a later date

Appendix C14.1: Focus Group Topic Guide

(Introductory question to facilitate discussion).
Can you each tell me one activity you have done while you have been in this group?

1. When you were first told about this group and invited to come along, what were your expectations of the project? *What sort of activities did you think you would do in the group? What did you know about the project? What did you expect the group to be like?*

2. What was it that made you decide to get involved with the project? *What made you come along in the first place? Why were you interested in this group?*

3. Did the project match these expectations? If not why not? *Was it what you thought it would be? How was it different*

4. Of all the activities you have done with the group what activities did you find most enjoyable?

5. Did you find the pyscho- educational workshops (the presentations I gave on brain injury, goal setting, memory strategies) useful? If not what activities or presentations would have been more useful?

6. Have you used any of the activities or strategies you have learned during the project out side of the group? *e.g. any of the arts activities, memory strategies, assertiveness skills*

7. Overall, what do you think you have gained most from attending the group? *What have you got out of the group? What has motivated you to keep coming?*

8. What activities or sessions did you find least enjoyable or think you have gained the least from? *What didn't you like doing? What did you not find useful?*

9. If the group were to continue how do you think it could be improved? *What would make the group better? If you would prefer another type of group what sort of group would you like? What would you have changed about the group?*

10. Lastly, what do you think of the facilities in this building? *e.g. Toilets, catering facilities, access etc* Is there any other information regarding your experience with the arts project that you think would be useful for me to know?

Appendix C14.2: Evaluation Questionnaire (for participants)

Creative Arts Course: Monday 11am – 4pm

Please take a few moments to complete the following evaluation form.

1. Did you enjoy the course?   YES/NO

2. What did you like about the course?

3. What did you not like about the course?

4. How would you rate the quality of the teaching?

Please circle where appropriate)   1 excellent 2 good   3 adequate   4 poor

5. Did you feel you had enough support from the tutors?   YES/NO

6. If you were to do the course again what changes if any would you make?

Please feel free to add any other comments.

Thank You

Appendix C14.3: Evaluation Survey for facilitators

What were your expectations of the project at the outset?

Did the project match your expectations? If not what aspects were different?

To what extent did you feel that the pyscho-educational workshops were beneficial for participants and/ or yourself? (Please comment on what aspects you thinks were useful, what aspects you think were not useful and how this may have been improved)

Overall, what do you think were the projects strengths? What aspects worked well?

Overall what do you think were the projects weaknesses? What aspects did not work so well?

What do you think could have been done differently to improve the project?

What would be your recommendations if the project were continue?

Any other comments?

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APPENDIX C15: Consent procedure for evaluation

28th April 2004

Dear *Name*,

As you know the last meeting of the Bromley Arts project will be on the 10th May 2004. I would like to attend the session in the afternoon.

In that session I would like to have a discussion with you all about the project and to get your feedback on how useful or enjoyable the group has been. This will be part of the evaluation of the project.

So that I can remember the discussion it will be useful for me to tape record it. However, this information will be kept strictly confidential. The tape recording will not be listened to by anyone but myself and anything you say will not be quoted in a way in which you can be identified.

You will be asked before the discussion if you agree to take part and to give written consent to being tape-recorded. I have included a consent slip below. Please bring this with you to the meeting on the 10th May 2004.

If you have any questions about this feel free to contact me on 0207 378 0505.

I look forward to meeting with you again.

Yours Sincerely,

Clare Eldred

I have read the information above and agree to take part in the discussion group and give consent to this being tape recorded.

Signed:_____

Date: _____

APPENDIX C.16: Example proposal

Psycho-educational Arts Project: Service Proposal

Overview of Project

To provide an arts and crafts based activities group, with a psycho-educational approach, to adults with an acquired brain injury, living in Bromley and receiving support from the Adult Disabilities Team.

The project will take place each Monday and will include two sessions; at 11am –1pm and 2pm – 4pm. These sessions will be led by arts facilitators.

Aims of Project

- To promote motivation and engagement in activities through a programme of arts and crafts sessions

- To develop brain injury awareness and strategies to compensate for cognitive difficulties through a psycho-educational approach.

Participants

Approximately 8-12 adults with acquired brain injury or neurological disorders. Carers of participants to be invited to attend with participant's prior informed consent.

Psychological services requested

The following input to be provided by Clare Eldred, Health Psychologist in training:
- brain injury education to service users, carers and arts facilitators,
- goal setting and development of compensatory strategies for cognitive difficulties with participants,
- supervision of arts facilitators
- evaluation of the project including the functional, psychological and health gains of participants
- completion of evaluation report.

The following plan and timescales to be implemented (as agreed by email with London Brain injury Centre Operations Manager on 19th January 2004)

Implementation plan	Date of input	Time allocated (including travel)
Week 1: Brain injury awareness session with participants, carers and arts facilitators	26th January 2003	3 hours
Week 3: Group session to identify needs and set goals with participants and arts facilitators	9th February 2004	3 hours
Week 6: Midway review / supervision session	1st March 2004	5 hours
Week 12: Evaluation meeting	19th April 2004 (12th April Bank Hol)	6 hours
Evaluation report to be completed	Completion date to be agreed	5 hours
Accessible to arts facilitators for supervision by telephone / email	Ongoing	As required

Changes to this plan to be made in agreement with xxxxxx (Care Manager), Clare Eldred (Health Psychologist in training) and Rehab UK's, London Brain Injury Services, Operations Manager.

These services to be provided on behalf of Rehab UK and in accordance with Rehab UK's Standard Operating Procedures relating to Confidentiality, Ethics and Data Protection and with the British Psychological Society's Code of Conduct.

Payment

Fee of xxxxxx payable to Rehab UK for the above services.

APPENDIX C.17: Stress Management Intervention Plan

Session 1	**Contracting** – agreeing the purpose and aims of the intervention. Provide overview of content of sessions. **Assessment** – preliminary exploration of patterns, triggers and physical signs of stress and assessing motivation to address stress issues in terms of belief in ability to tackle issue and desire to do so. **Motivation building** – If motivation to tackle issues is low, use motivational interviewing techniques to get client to assess impact of stress on life goals and consider perceived obstacles to success. **Introduction to stress response** – review of 'fight or flight' theory focusing on early signs of arousal and discuss how this relates to client's own experience **Introduction of stress monitoring chart** – client to keep a log of his incidents of stress and responses to these **Look forward to next session**
Session 2	**Recap of previous session and review of record from** **Identification of early signs of stress** – review of importance of recognising signs of stress at early stages in order to implement stress management strategies effectively, explore client's awareness of early sings, discuss asking others (e.g. wife, children) for their observations **Client to describe 'stressful scenario'** – explore any changes in stress levels while client relates a real situation, feedback any observed signs of stress, discuss the use of videotape if client does not report being aware of signs observable during this exercise (stressful scenario to be written down and used in future sessions for introduction of stress management strategies). **Reminder to continue to use stress monitoring form** **Look forward to next session**
Session 3	**Recap of previous session and review of record from** **Discussion of clients monitoring of early signs of stress** and feedback from significant other **Identification of cue term** – client to be helped to identify a word or phrase that will be used by them to cue the stress management strategies. **Introduction of breathing technique** – deep abdominal breathing technique to be introduced to client and client to demonstrate they are able to use technique correctly **Practice of breathing technique using stressful scenario** – client to review their 'stressful scenario' and to apply technique as soon as they experience an increase in stress * **Introduction of mini-relaxation technique and practice** (if time) – mini relaxation technique to be introduced to client and client to demonstrate they are able to use technique correctly. Client to continue to review their 'stressful scenario' (or describe a new scenario of the original is losing it's affect) and to apply technique as soon as they experience an increase in stress* **Reminder to continue to use stress monitoring form and** **Look forward to next session**

Session 4	• **Recap of previous session and review of record from** • **Mini-relaxation technique and practice** (as above) • **Introduction of visualisation technique and practice** - visualisation technique (create visual image of relaxing place or situation) to be introduced to client and client to demonstrate they are able to use technique correctly. Client to continue to review their 'stressful scenario' (or describe a new scenario of the original is losing it's affect) and to apply technique as soon as they experience an increase in stress* • **Reminder to continue to use stress monitoring form** • **Look forward to next session**
Session 5	• **Recap of previous session and review of record from** • **Continued practice of techniques** – and discussion about which techniques have been most effective • **Challenging negative thoughts** – it has been noted that the client may be reluctant to discuss feelings of stress other than related to specific, non-personal situations e.g. watching TV. If this is identified as continued issue some time may be spent on exploring client's automatic thoughts about talking about stress and cognitive restructuring techniques introduced ** • **Discussion of clients ability to use techniques effectively** in session and to transfer them to real incidents of stress • **Identification of any strategies which require further practice in final session**
Session 6	• **Recap of previous session and review of record from** • **Review of strategies identified as requiring further practice** – continue to practice techniques which client may not have fully mastered • **Evaluation** – client to complete evaluation questionnaire (to be developed), copies of record forms taken for analysis • **Agreement for follow up support** – e.g. if client perceives a need for further support in the future to discus with Keyworker or to make an appointment for a follow up session

*Initially client to be prompted to stop when they report an increase in stress and to use cue word and practice apply technique and return to 'scenario' when relaxed. When able to use technique effectively client prompted to use cue work and stress management technique simultaneously with reviewing 'scenario'

** *This element of the stress management programme may be introduced earlier in the intervention if identified as a barrier to working on stress issues or it may not be included if not considered necessary.*

APPENDIX C.18: Stress Monitoring Form

Date / Time	What triggered the stress? (Record when, where and with who you were when you felt stressed and what you were doing) How intense was it? 1 _____10 Low High	Note down any body cues (rapid breathing etc) or any particular thoughts	How did you react?	On reflection how could you have better coped with the situation?

APPENDIX C.19: Stress management training evaluation

Firstly, we would like to know what you feel you have learned from the course. For each statement below, tick the box that best describes the extent to which you agree or disagree with the statement.

As a result of attending the Rehab UK stress management training course...

I understand more about what factors cause and maintain anger, anxiety and stress reactions.

☐ Strongly disagree   ☐ Disagree   ☐ Neither agree nor disagree   ☐ Agree   ☐ Strongly agree

Give two reasons why people can be more prone to anger, anxiety and stress following an acquired brain injury.

[   ]

I am more aware of the impact that anger, anxiety and stress can have on my life.

☐ Strongly disagree   ☐ Disagree   ☐ Neither agree nor disagree   ☐ Agree   ☐ Strongly agree

Give an example of how anger, anxiety or stress have affected your life.

[   ]

I feel more motivated to tackle my anger, anxiety or stress issues.

☐ Strongly disagree   ☐ Disagree   ☐ Neither agree nor disagree   ☐ Agree   ☐ Strongly agree

I can identify more easily when I am starting to become angry, anxious or stressed.

☐ Strongly disagree   ☐ Disagree   ☐ Neither agree nor disagree   ☐ Agree   ☐ Strongly agree

What are the signs that you are becoming angry, anxious or stressed?

[   ]

I am more aware of the situations, thinking errors and other factors that tend to make me angry, anxious or stressed.

☐ Strongly disagree   ☐ Disagree   ☐ Neither agree nor disagree   ☐ Agree   ☐ Strongly agree

What situations tend to make you angry, anxious or stressed?

[blank box]

What are the thinking erros that tend to make you angry, anxious or stressed?

[blank box]

I am aware of a range of anger, anxiety and stress management techniques, understand the rationale behind them, the situations in which they are appropriate and their limitations.	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
	☐	☐	☐	☐	☐

I apply a range of anger, anxiety or stress management techniques effectively in a variety of settings.	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
	☐	☐	☐	☐	☐

What anger, anxiety or stress management strategies do you regularly use?

[blank box]

I am now less likely to view situations as being anger-provoking, anxiety-inducing or stressful.	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
	☐	☐	☐	☐	☐

I am now better able to control my feelings of anger, anxiety or stress.	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
	☐	☐	☐	☐	☐

I am now better able to resolve the underlying causes of my anger, anxiety and stress.	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
	☐	☐	☐	☐	☐

Next, we would like to know what you feel about how the course was designed and delivered. For each statement below, tick the box that best describes the extent to which you agree or disagree with the statement.

The course had a good balance between formal teaching, discussion and practical exercises.	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
	☐	☐	☐	☐	☐

The content and pace of the course were pitched at just the right level for me, being neither to easy nor too difficult.

☐	☐	☐	☐	☐
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

I could easily see how what was being taught in the sessions related to my own situation.

☐	☐	☐	☐	☐
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

I found the handouts and other course materials very useful.

☐	☐	☐	☐	☐
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

APPENDIX C.20: Pain Management Intervention: Needs Assessment Report

Literature review

Chronic pain is a common sequelae of acquired brain injury. Research suggests that between 52-58% of individuals recovering from traumatic brain injury report chronic pain, ranging from headache to neck/shoulder, back, upper limb, and lower limb pain[1]. A small number of patients (less than 10%) will develop severe pain following a stroke[2]. Central post-stroke syndrome is characterized by sensory disturbances and neuropathic pain with onset of pain often occurring more than 1 month after the stroke.

Chronic headache is the most frequent occurrence following traumatic head injury. The incidence of posttraumatic headache lasting longer than 6 months is estimated to be as high as 44% and cases lasting around 4 years estimated to be about 20%[3]. It is noted that posttraumatic headache is reported more frequently in those who have experienced a mild brain injury than those who have experienced a moderate or severe injury[1].

The impact of chronic pain subsequent to brain injury has also been documented. A relationship is reported between post-traumatic headache and reduced level of functioning and poorer quality of life[4]. Somatic pain and headache has also been noted as a 'distracter' which can reduce work efficiency and employment potential[5]

The benefit of cognitive behavioural approaches in pain management has been documented. In a systematic review and meta-analysis of randomised controlled trials of cognitive behaviour therapy (CBT) for chronic pain (excluding headache)[6] it was concluded that cognitive behavioural methods were effective. Meta-analytic literature reviews of CBT approaches in recurrent headache have also indicated clinically significant benefits with up to 35-50% reduction in migraine and tension-type headache activity.[7]

A programme which used attention diversion and thought management to decrease the perceived intensity of pain and minimize the negative thoughts which can increase pain severity in chronic headache patients [8] has been identified as effective for individuals with post traumatic headache[9]. The benefit of relaxation as an adjuvant therapy to pharmacological treatment in post stroke pain has also been indicated[10].

There are some issues which need to be considered when developing a pain management programme for people with acquired brain injury. Neuro-psychological impairment has been reported in non-brain injury patients with chronic pain, particularly on measures assessing attentional capacity, processing speed, and psychomotor speed[11]. Pain may therefore further exacerbate cognitive dysfunctioning in individuals post brain injury. Cognitive impairments may hinder individuals' efforts to learn or to apply psychological strategies appropriately and motivational deficits may make it difficult to persist with the treatment.

Introduction to pilot pain management intervention

A pain management intervention was established based on an identified need for some clients on the vocational rehabilitation programme to develop strategies to manage pain experienced subsequent to their brain injury. A six-week programme was developed based on A Treatment Manual for Attention Management in Chronic Pain[12] (see Appendix X.1 for training curriculum). This programme was offered to clients attending Element B of the programme who had already attended the group stress management Element A programme and therefore had a basic understanding of relaxation and cognitive restructuring techniques.

Three people were recruited to the intervention. The programme ran for 6 sessions between 21st Jan 2005 and 11th March 2005. Attendance of the training was inconsistent. One client attended all 6 session, one client attended the first four sessions (an additional follow up session was provided to this client following the end of the programme) and due to other commitments one client attended only 2 sessions.

Evaluation methods and results

1. Pain coping skills questionnaire:

This assesses the use of coping strategies and the extent to which these are effective in controlling and/or reducing pain. The items describe different coping responses which can be clustered into six different subscales (diverting attention, reinterpreting the pain sensation, catastrophising, ignoring sensations, praying or hoping, coping self-statements and increased behavioural activities). These items are rated on a 6 point scale with 0 = 'never do' and 6 = 'always do'. This questionnaire was chosen as an evaluation method as the subscales fit well with the aims and content of the intervention and also give an indication of any increase in control and self-efficacy.

All clients completed this questionnaire at the outset of the training. Two clients completed this again at the end of the 6 week programme. The client who attended only twice was not asked to complete the post-intervention measure. The results of the evaluation for those who completed both measures are shown below.

Case 1: H
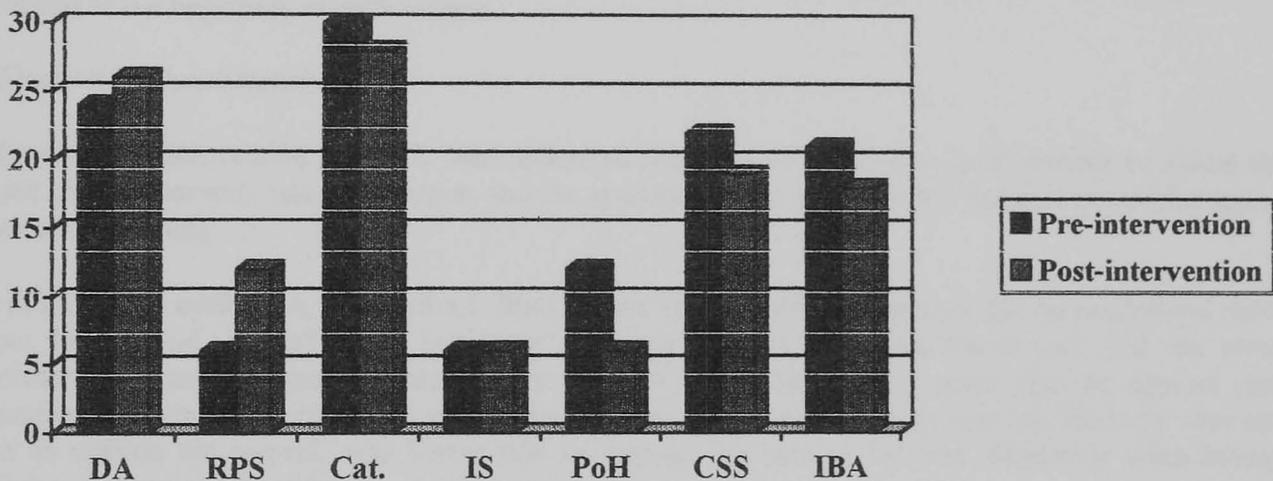
Key: DA = Diverting attention
RPS = Reinterpreting the pain sensation
Cat. = Catastrophising
IS = Ignore sensations

PoH = Praying or hoping
CSS = Coping self-statements
IBA = Increased behavioural activities

This represents an inconsistent profile with some positive signs (e.g. increase in use of attention diverting and reinterpreting pain sensations strategies and a small decrease in catastrophic responses) but also indicates some reduction in the use of coping self-statements and behavioural activities.

Case 2: L
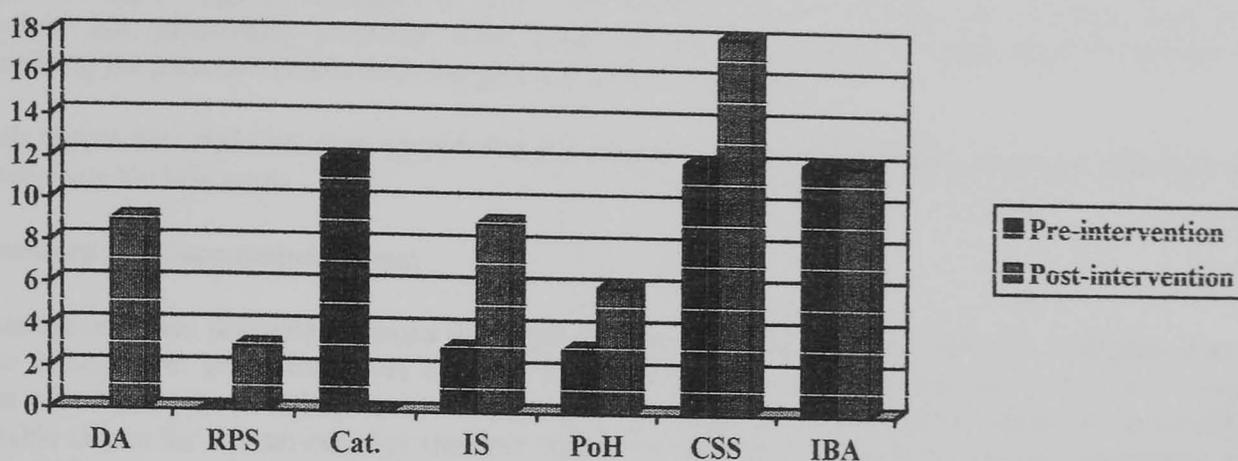
This indicates positive changes following the training. At the outset of the programme no diverting of attention or reinterpreting pain sensation strategies where being used. Following the training these had begun to be implemented by L. At the outset of training L reported some catastrophic thoughts about his pain but at the end of the programme no longer reported any catastrophic thoughts. An increase in the ability to ignore sensations, and to use coping self-statements, is also indicated.

2. *Pain management diary:*

Clients were asked to keep a pain dairy to monitor the nature and severity of the pain the use of strategies. However, the clients did not complete the pain diaries on a regular basis. It was reported that this was not appropriate as their pain and discomfort tended to be a constant experience and it was therefore discontinued. However, client's pain experience and application of any strategies was reviewed at the beginning of each session.

3. *Evaluation Questionnaire:*

Following the intervention H and L were asked to complete an evaluation questionnaire to assess the extent of new learning, use of strategies and the appropriateness of the design and delivery of the course to meet their needs.

As in the above evaluation, the feedback from H was inconsistent. He reported that he understood more about how mood, thoughts and behaviour influence the way he experienced pain and felt more motivated to use strategies to manage his pain. However he did not agree that he applied pain management techniques effectively and neither agreed or disagreed that he was less likely to view the pain as outside his control, was better able to manage his pain or to think differently when having negative thoughts about the pain.

In sessions H showed good understanding of the material delivered and was able to apply the strategies effectively within the training setting however, he did not demonstrate any transfer of strategy outside of the sessions. This was discussed with him in the training on a number of occasions. This is consistent with the motivation and engagement issues observed throughout H's overall vocational programme.

On the other hand L reported positive benefits from attending the programme. He strongly agreed that he understood more about the way mood, thoughts and behaviour influenced the way he experienced pain. He agreed that he was less likely to view his pain as outside of his control, was more motivated to use pain management strategies and was aware of a range of techniques, which he was able to apply effectively. He also reported that he was more likely to think differently when he had negative thoughts about his pain.

In verbal feedback L reported that he had found the training 'encouraging' and that he had benefited from learning a range of strategies so that if one strategy was not effective he was more likely to try another. He particularly benefited from some of the visual pain transformation techniques e.g. visualising the pain as a colour and changing the colour of the pain.

Both clients reported that they agreed that the content, style and relevance and course materials were appropriate to their needs.

Summary and recommendations:

Attendance issues prevented a more thorough evaluation of this training. However, it appears that the pain management programme was effective for at least one client, indicating that it can be of benefit. This pilot highlighted the importance of assessing motivation and availability to attend when identifying suitable clients for this service. For the next Module of training it is recommended that assessment takes place before the beginning of the training to:

- establish that clients will be able to attend at the time agreed
- assess clients' expectations and motivation to attend
- assess the cause, nature and severity of pain to identify whether the issues reported by the client are relevant to the training
- identify the coping strategies currently used by clients in order to adapt the training programme to address the specific needs of the group

These recommendations will be acted upon when I train the Assistant Psychologist (RP) to implement this intervention.

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Appendix X.1: Pain Management Curriculum

Week 1	Introduction to pain management	• Agreeing purpose and aims of module & overview of content • Self-assessment • Introduction to pain management (the nature of pain, psychological factors in pain experience, pain behaviour) • Introduction to pain diary • Pain behaviour cycle • Review of session and set homework task
Week 2	Relaxation and attention management techniques	• Discussion of client's current pain management strategies • Review of relaxation techniques and practice brief relaxation exercise • Introduction to attention management and practice exercises • Review session and set homework exercise (internal v external attention)
Week 3	Imagery and pain transformation techniques	• Introduction to imagery as a distracter and guided practice • Identifying personal imagery • Introduction to pain transformation ('playing with the pain', changing a pain image) • Review of session and set homework task
Week 4	Challenging negative thoughts	• Identifying negative thoughts about pain • The link between pain thoughts and emotions (an example) • Identifying 'the vicious cycle' • The signal breath and challenging catastrophic thoughts • Planning coping statements • Review of session and set homework task
Week 5	Problem solving	• Revisiting the behaviour cycle – the impact of pain • The overactivity – rest cycle • Introducing goal setting and pacing • Identifying individual goals and a personal plan • Review of session and set homework task
Week 6	Review and evaluation	• Monitoring personal goals and plans from previous session • Review of pain management module • Self-assessment and evaluation • Agreeing additional support and follow up

APPENDIX C21: Directing the implementation of interventions: Supervision Plan

Date	Aims of supervision
1st April 2005 3.30pm (30 mins)	• CE to present principles of pain management intervention; psychological factors in pain, gate theory and overview of the strategies to be delivered to RP. • RP to look at some of the course materials used in pilot intervention and to discuss any additional training and supervision needs.
4th April 2005 9.30am (30 mins)	• CE to present assessment materials and to discuss content and delivery of assessment session.
11th April 2005 9.15am (30 mins)	• Review completed assessments and identified needs of clients. • Present session plan and materials for first two sessions of intervention. Review tutor notes for session with RP.
22nd April 2005 2.30pm (30 mins)	• Review previous two sessions and discuss any issues. • Present session plan and material for third session of intervention. Review tutor notes for session with RP.
6th May 2005 2.00pm (30 mins)	• Review previous session and discuss any issues. • Present session plan and material for fourth session of intervention. Review tutor notes for session with RP.
16th May 2005 9.15am (30 mins)	• Review previous session and discuss any issues. • Present session plan and material for fifth session of intervention. Review tutor notes for session with RP.
23rd May 2005 9.15am (30 mins)	• Present material for final session of intervention. Review tutor notes for session with RP. • Review evaluation materials and clarify how this will be carried. • Discuss methods for assessing need for further intervention with clients.
25th May 2005 9.15am (1 hour)	• Review the pain management intervention. RP to give feedback on the session content, plans and delivery. CE and RP to agree recommendations for amending curriculum and sessions plans. • Review evaluation assessments and questionnaires and plan analysis of these evaluation materials.
1st June 2005 2.45pm	• CE and RP to present an evaluation of the pain management intervention to Senior Psychologist in psychology team meeting. To agree dissemination of evaluation information to relevant others internally and to interested external agencies

APPENDIX C22: Pain Management Intervention Evaluation

Introduction to pilot pain management intervention

Following a pilot of a pain management intervention delivered to three clients in January to March 2005 it was concluded that the pain management programme could be effective for certain clients.

The pain management intervention was amended and updated based on the evaluation of the pilot and delivered to a further 3 clients by RP, Assistant Psychologist between April to June 2005.

The McGill Pain Questionnaire and a brief interview with each client were used to assess the nature and severity of the pain before the intervention was implemented. The pain management issues reported by the clients were varied within the group. One client (JT) reported regular headache. Another client (SH) reported chronic pain in his leg, back and neck as well as post-traumatic headache occurring mostly during the night. The third client (CC) reported occasional headache and also stated that situations in which she incurred any moderate acute pain would result in a loss of anger control. A third client

The Pain Coping Strategies Questionnaire was also completed by each clients prior to the intervention to indicate the way in which they cope with their pain and the strategies they currently used.

Evaluation methods

Clients were asked to complete the Pain Coping Strategies Questionnaire at the end of the 6 week programme in order to assess any change in coping methods and strategies. Two of the three clients who attended the training completed this assessment (one client did not attend the final session due to taking time away from the programme for personal reasons).

Following the intervention these two clients were also asked to complete an evaluation questionnaire to assess the extent of new learning, use of strategies and the appropriateness of the design and delivery of the course to meet their needs.

Results of evaluation

*Pain Coping Strategies Questionnaire (PCSQ)*

Client's ratings on the subscales of the PCSQ are shown below. Ratings given prior to the intervention are shown in green and ratings given at the end of the intervention are shown in blue.
Case 1: SH
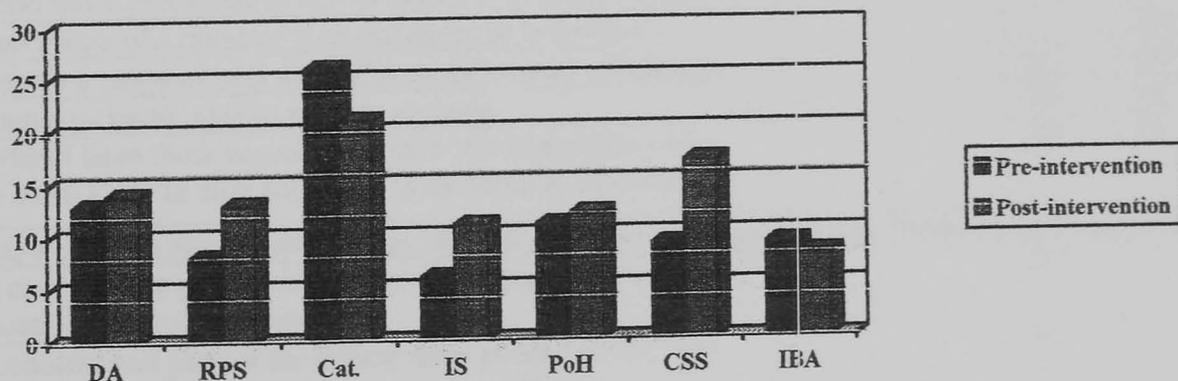
This profile indicates some change in response in terms of an increase in reinterpreting and ignoring the pain sensation. SH also indicates some decrease in his tendency to catastrophise in response to pain and an increase in his use of coping self-statements.

Case 2: CC
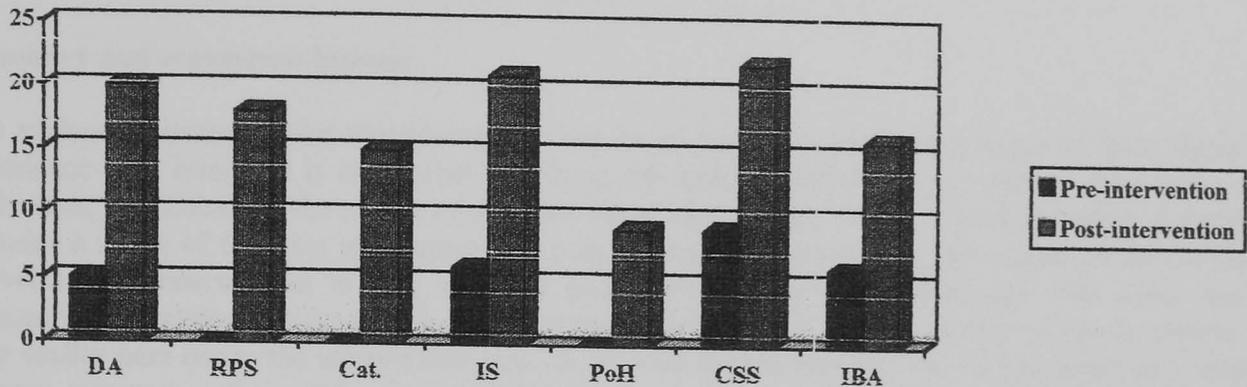
This indicates an increase in a range of positive responses to the client's pain in terms of diverting attention, reinterpreting the pain sensation, ignoring the pain sensation and increased behavioural activities. It is noted that CC did indicate an increase in catastrophising in response to her pain. It may be that this represents an increase in awareness of her catastrophic responses to pain rather than a change in her response as it is noted that she also reported an increased use of coping self-statements.

Evaluation Questionnaire:

See below for summary of client's response on the evaluation questionnaire.

As a result of attending the Rehab UK pain management training course…	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1. I understand more about how mood, thoughts and behaviour influence the way I experience pain.				SH	CC
2. I am less likely to view my pain as outside of my control.			SH	CC	
3. I feel more motivated to use strategies to manage my pain.				SH	CC
4. I am aware of a range of pain management techniques.				SH	CC
5. I apply a range of pain management techniques effectively.			SH	CC	
6. I am now better able to manage my pain.			SH	CC	
7. When I have think negative thoughts about my pain I am now more likely to stop and try to think about it differently?			SH	CC	
Next, we would like to know what you feel about how the course was designed and delivered.					
The course had a good balance between formal teaching, group discussion and practical exercises			SH		CC
The content and pace of the course were pitched at the right level for me, being neither to easy nor too difficult.			SH		CC
I could easily see how what was being taught in the sessions related to my own situation.			SH	CC	
I found the handouts and other course materials useful.				SH	CC

In summary SH reported understanding about the nature of pain and a range of pain management strategies and being more motivated to use strategies to manage his pain. However, he did not report applying these strategies effectively or being better able to mange his pain following the intervention.

CC evaluated the benefits of the training positively and indicated an increase in understanding pain and pain management techniques and agreed that she was motivated and able to use these strategies effectively pain and felt more in control of her pain.

Summary and recommendations:

The evaluation indicates that the intervention can be of benefit to adults with acquired brain injury who experience pain issues. It is noted that delivering the intervention in a group setting can present some difficulties, particularly if the nature of the pain issues reported are varied. The intervention implemented includes a range of different approaches and pain management strategies. The experience of the trainers delivering the intervention is that within a group programme each client may find some, but not necessarily all, methods relevant. It is therefore recommended that unless a number of clients present with very similar pain issues the intervention may be of more benefit delivered on an individual basis whereby a more targeted and possibly shorter intervention can be provided. This may also promote greater motivation and engagement of clients within the intervention.

APPENDIX D.1: Quality Assessment Tool

Ref No:_____   Initial of reviewer: _____

a) Have patients been randomly allocated to treatment groups?	0 2
b) Is a 'proper' control used?	0 2

c)   Have base line comparisons between control and intervention groups(s) been carried out in terms of: Age?
               Gender?
               Ethnicity?
               Length of time as carer?
	0 ½
	 0 ½
	 0 ½
	 0 ½

d) Is the sample size adequate? (100 + participants in each group or sample size established by power analysis)	0 2
e) Have checks been taken to establish that there are no other confounding interventions? (e.g. self-treatment in control group / use of medication in intervention groups)	0 2
f) Is loss to follow up < 25%?	0 2
g) Is data collection carried out 'blind'?	0 2
h) Are the outcome measures used relevant to the research question?	0 2
i) Has validity and reliability of measurement tools been established?	0 2
j) Is the statistical analysis appropriate for the data?	0 2
Notes:	Total =