# A thesis submitted in partial fulfilment of the requirements for the degree of Clinical Psychology Doctorate at the University of Birmingham

## VOLUME I

### RESEARCH PAPERS

Coping and adjustment following acquired brain injury

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#### Overview

Volume I of this thesis addresses the adjustment of individuals who have sustained acquired brain injuries. To date there has been a only a thin evidence base for the aetiological factors involved in people's emotional reactivity following what is a profound and potentially devastating life changing event. The first paper critically reviews the concept of 'coping' following an acquired brain injury. This draws on two main bodies of literature. First, Kurt Goldstein's 'organismic theory' and, in particular, the catastrophic reaction model is examined from its phenomenological and existential perspective on adjustment to acquired brain injury. Contemporary developments of the catastrophic reaction model have also been considered. Second, applications of Lazarus and Folkman's stress-appraisal and coping theory to adjustment following injury is reviewed for its more empirically based propositions. A comparison and contrast between the two theories is made. This paper is intended for submission to Clinical Psychology Review. The second paper, in Volume I, is a full length research report exploring the subjective nature and frequencies of threatappraisals, and related avoidance coping, reported by people with traumatic brain injury. This goes on to explore the relation of these threat-appraisals, and avoidance coping, to adjustment factors of anxiety, depression and quality of life. This paper is intended for submission to Neuropsychological Rehabilitation.

Volume II comprises five clinical practice reports representing work conducted in the clinical psychology specialities of adult, child, learning disabilities, older adults and acquired brain injury rehabilitation. The reports include a formulation study of a woman presenting with difficulties relating to domestic violence, a small scale service related research piece upon an intervention conducted by health visitors for infant related problems, a single case design study of a man with learning disabilities presenting with self-injurious behaviour difficulties, a cross-battery neuropsychological assessment with a man to test for the early stages of dementia, and a summary of an oral presentation that described a psychosocial therapy group for people with acquired brain injuries. The final section of Volume II includes a set of appendices relevant to the clinical practice reports.

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### Literature Review

Models of coping and theories of adjustment following acquired brain injury:

A conceptual and methodological review

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For submission to Clinical Psychology Review.

#### Abstract

This review examines models of coping as aetiological factors of adjustment following acquired brain injury. This is set in context of more parsimonious models that view adjustment to acquired brain injury in relation to neurological, neuropsychological and diagnostic profiles. Two theoretical frameworks are considered. First, Goldstein's (1939; 1942; 1951) models of 'catastrophic reaction' and 'self-actualisation', formulated within his phenomenological 'organismic' theory, considers emotional difficulties after brain injury as subsequent to organic damage. The catastrophic reaction model now informs much of the growing literature on psychotherapeutic approaches to emotional adjustment after acquired brain injury. A second independent literature of coping after acquired brain injury has drawn upon Lazarus and Folkman's (1984) empirical stress-appraisal and coping theory in conjunction with research upon reduced speed and efficiency of information processing and emotional concomitants (van Zomeren et al., 1984;1985). Consistent with Goldstein, contemporary theories have distinguished between organic and reactive emotional complaints. Furthermore, an emerging model of 'avoidance coping' has emerged that echoes aspects of the 'catastrophic reaction' model and appears to predict negative indices of adjustment. Each theory is critiqued in turn and a comparison and contrast of both are made. Methodological considerations are discussed that propose both standpoints may be mutually beneficial, though each has advantages over the other. Overall, although circumscribed aspects of coping hypotheses proposed following acquired brain injury have been supported, the evidence base is as yet incomplete.

#### Introduction

It has been argued that the psychosocial consequences to brain injury may be more of a handicap than the individual's residual cognitive and physical impairments (Lishman, 1973; McClelland, 1988; Slagle, 1990). Acquired brain injury presents challenges to the individual's emotional balance, relationships with families and friends, tolerances towards an uncertain future, and pre-injury self-concept (Antonak, Livneh & Antonak, 1993; Gordon & Hibbard, 1992; Smith & Godfrey, 1995). Acquired brain injury has been associated with increased anxiety (Askenasy & Rahmani, 1988; Bornstein, Miller & van Schoor, 1988; Dikmen & Reitan, 1977; Fordyce, Roueche & Prigatano, 1983), depression (Howell, Fullerton, Harvey & Klein, 1981; Turner & Wood, 1985), self-directed anger (Levin & Grossman, 1978; Tyerman & Humphrey, 1984) and hostility towards others (Bergland & Thomas, 1991; Bornstein, Miller & van Schoor, 1988). Despite the established association between these difficulties and acquired brain injury, Kendal and Terry (1996) underline the persisting shortfall in current understandings of individuals' coping characteristics that may serve to moderate such difficulties.

#### Parsimonious Models of Adjustment

The literature on acquired brain injury has reported inevitable attempts to understand the consequences of acquired brain injury using neurological profiles, or to a lesser extent, diagnostic methods. Neurological profiles are amenable to objective measurement and thus provide a potentially simple and linear predictive model of post injury adjustment. Research has typically investigated the locality of lesion or the severity of brain injury by measures of post-traumatic amnesia, depth and persistence of coma after injury, or measures of intellectual decline from neuropsychological profiles. However, Prigatano (1992) and Kendall and Terry (1996) point to the failure of research efforts to consistently establish a relationship between deficits indicated by neurological profiles and indices of emotional adjustment or psychosocial well being (Levin *et al.*, 1986; Levin & Grossman, 1978; Prigatano, 1987; Prigatano, 1986; Skell, Johnston, Schopp, Shaw & Petroski, 2000). Equally, explanations of adjustment after acquired brain injury that are

based on diagnostic categories, such as 'borderline personality disorder' (see for example, van Reekum, Bolago, Finlayson, Garner & Links, 1996; Hibbard, Bogdany, Silver, Gordon & Haddad, 2000), might similarly be prone to over-simplicity due to their lack of aetiological explanations.

Thus, attempts to fully explain psychosocial outcome in terms of the injury itself appear limited. Instead, outcome may be better understood by taking into account the individual's reaction to conditions brought on by acquired brain injury. The present review takes as its focus two such approaches to understanding post-injury adjustment; the writings of Kurt Goldstein (1939; 1942; 1952; 1971) and studies that have drawn upon the stress-appraisal and coping theory of Lazarus and Folkman (1984). Broadly, both models employ the central theme of 'coping' with events after acquired brain injury, and its influential factors. Coping may be construed as the individual's reaction to a stressful situation. This does not however suggest the consequence or success of a reaction, but may be hypothesised to moderate the relationship between acquired brain injury and emotional adjustment.

#### Scope of the Present Review

Literatures Reviewed. First, Goldstein's (1939; 1942; 1952) phenomenological theory of adjustment to acquired brain injury, and in particular the catastrophic reaction model, is considered. Despite a lack of empirical evidence, Goldstein's writings have been chosen for their descriptive and historical values, and for their influence on a recently growing literature on psychotherapy for people with acquired brain injuries. Second, attempts to apply the stress-appraisal and coping theory of Lazarus and Folkman (1984) to people with acquired brain injury will be reviewed. This theory has had a growing influence upon multi-factor theories of disability after acquired brain injury over the last decade. Given that the stress-appraisal and coping theory has been conceptualised within non-clinical populations (Lazarus, 1966), its development has been independent from Goldstein's theory, even when it has been applied to adjustment following acquired brain injury. The stress-appraisal and coping theory also differs to that of Goldstein in its associations with positivist methodologies that attempt to establish empirically supported models of reactions to stress. The advantages and

disadvantages proposed for each literature are described and critiqued in turn. Further, a comparison and contrast of the stress-appraisal and coping research and that of Goldstein's phenomenological theory is made. Although both have shared features, each also comments on matters about which the other appears silent. Nevertheless, it will be argued that in terms of both content and methodology, the two approaches are complementary, not in opposition.

<u>Terminology</u>. Acquired brain injury is a generic expression referring to injury to the brain caused by aetiologies of closed or penetrative head injuries (traumatic brain injury), stroke, infections or tumours. The use of the terms 'psychosocial adaptation' or 'psychosocial outcome' tends to be ubiquitous, yet is frequently employed in the absence of a clear definition. 'Psychosocial' will refer here to the close reciprocal relationship between the psychological and social effects of acquired brain injury. Psychological effects refer to the individual's reactions to events after an acquired brain injury. These reactions may be manifest in emotions, behaviour, thoughts, and how a situation may be perceived and understood. These responses are considered in relation to social effects; that is how the experience of acquired brain injury may alter, and be altered by people's relationships to each other. Social effects may apply to familial, social and economic contexts. Consistent with this definition, 'adjustment' represents the degree of emotional acceptance of one's impairment that is reflected in their degree of adapted self-concept, behaviour and social re-integration (Antonak, Livneh & Antonak, 1993). These concepts of 'psychosocial', 'adjustment' and coping are in broad alignment with the recent move by the World Health Organisation (WHO) from a biomedical to biopsychosocial model (ICIDH-2; WHO 1999 [www3.who.int/icf/icftemplate.cfm]; see also Bickenbach. Chatterji, Badely & Ustin, 1999). The biopsychosocial model attempts to incorporate a more comprehensive model of disablement than that afforded by biomedical conceptions of disability. Instead, individual differences are now conceptualised in context of the individual's physical or mental condition in relation to their environment.

Goldstein: The Organismic Theory and Catastrophic Reaction Model
Goldstein was a neurologist and psychiatrist. His theories of neurology and personality had begun from his early studies of neuro-anatomy under the tutelage of Wernicke and Edinger (Goldstein, 1959). Goldstein ultimately found the study of isolated brain-behaviour relationships inadequate for explaining post injury adjustment. His first major work, *The Organism* (Goldstein, 1939) reflected his attempts to formulate a 'holistic' theory of adjustment to impairment as an alternative to localisationist approaches that sought to explain behaviour in relation to regions of brain functioning. The theory was ubiquitous in its outlook; applicable to any biological process in the organism's attempt to maintain equilibrium after impairment as an evolutionary process. The theory's development was largely driven by Goldstein's observations of World War I veterans who had sustained acquired brain injuries.

Although Goldstein did not align himself entirely with the Gestalt School, it had contributed significantly to his theory's 'holistic' stance; particularly influenced by the writings of Max Wertheimer and through his collaboration with Adhemar Gelb (Goldstein, 1959). Goldstein's theory referred to the whole as 'the organism'. The contribution of Goldstein's work was greatly evident in the neuropsychological concepts of Luria (1973; 1980) who considered the beginnings of modern neuropsychology to have stemmed from Goldstein's writings (Luria, 1966). As psychogenic processes in reactions to brain injury gather interest, Goldstein's theory has been heralded by the literature on psychotherapy with people with brain injuries (Prigatano, 1986; 1991; 1992; 1999; Miller, 1999; Lewis, 1991; Langer, Laatsch & Lewis, 1999).

The Holistic Theory of Adjustment. Consistent with the central tenet of the Gestalt movement, Goldstein (1939) emphasised the personality's trend to act as a 'whole'; the whole being greater, and different from the sum of its parts. This stance was a reaction to the natural sciences' tendency to 'anatomise' scientific phenomena, a model also adopted by experimental psychology. Anatomistic approaches to psychology traditionally reduced the individual into an inventory of independently functioning parts, similar to those of a machine; hence mechanistic theories of psychology. However, Goldstein argued that this manner of

investigation is limited in its value given its inherent failure to consider the 'parts' in their natural context. For example, the isolation of reflexive behaviours in laboratory experimentation will be limited to their environmental context; given different environmental conditions, they may not remain constant.

Goldstein (1939) therefore considered the oft-made distinction between physiological and psychological states to be counterproductive for understanding emotion and behaviour. Instead, it is the reciprocal relationship of the parts, and the organisation of the organism that constitutes the personality. This can be exemplified by the inconsistencies found, for example, between frontal lobe damage or left and right hemisphere brain damage and their hypothesised relationship to emotional functioning (Kendall & Terry, 1996; Sackheim, Greenberg, Weiman, Gur, Hungerbuhler, & Geshwind, 1982; Bakchine, Lacomblez, Benoit, Parisot, Chain, & Lehermitte, 1989; Robinson & Szetala, 1981). Goldstein (1939) reasoned that, due to a failure in considering the environmental context of behaviour, such inconsistencies are inevitable. Instead, the individual's adjustment is conceptualised within the context of environmental demands after brain injury and are considered a potential threat to the individual who now has an altered relation to their world.

Theory of Abstract Attitude. Fundamental to this altered relationship is the impairment of what Goldstein (1939;1952) called the abstract attitude. Abstract attitude represents the ability to assume an alternative mental set to one's own, to reflect upon one's own behaviour, to verbalise that reflection, and to grasp the individual elements of a situation or problem yet recognise the essentials of the given Gestalt, or whole. The abstract attitude further pertains to the use of symbolism and the capacity to plan ahead. Goldstein considered impairment here to result in concrete thinking and represents a hallmark consequence of brain damage that compromises the individual's capacity to manage everyday demands. He therefore made the distinction between 'primary' and 'secondary' symptoms of brain injury (p.36; Goldstein, 1939). One group of symptoms, the compromised abstract attitude is a direct sequela of injury: the subsequent indirect sequela is the individual's attempt to meet an environmental or internal demand with their residual capacities, or to avoid or escape that struggle (Goldstein, 1942).

Existence and the Self. Goldstein (1951; 1971) made considerable reference to Sartre's (1948/1984) existential writings on emotions but ultimately retained an independent stance in his own theories of existence, principally inspired by Kant's transcendental theory of knowledge. A fundamental tenet of existential philosophy is the person's experience of their self in relation to their world and particularly man's (sic) relation to himself, i.e., how humans know about their existence. These relationships are particularly concerned with the awareness of one's beliefs, desires and sense of purpose. One's existence continually involves tensions, or polarities. These, for instance, may involve the tension created by the qualification of one's rational behaviour against the frequent threat of irrationality, or of the individual in relation to society. Such tensions mean that existence is characterised by an ever present and fundamental anxiety given the freedom of choice between two poles, a central theme for existential writers such as Sartre or Heidegger (cf. Macquarrie, 1977).

Goldstein (1939) considered the abrupt transition in life brought on by acquired brain injury, and specifically, the individual's newly compromised capacities, to threaten their existence: their potential for self-realisation. The significant negative changes in self-concept after acquired brain injury are, for instance, evident from Tyerman and Humphrey's (1984) analysis of subjective reports of people with head injury. Specifically, the individual's premorbid expectations, in accordance with their pre-morbid self-concept, are more difficult to meet after injury. Anxiety is therefore elevated due to subsequent perceptions that self-realisation has been made impossible because of the difficulties bought on by acquired brain injury. Goldstein (1939; 1952) cited the conceptualisations of anxiety proposed by the philosophies of Pascal, Kierkegaard and Heidegger. A distinction is made between anxiety and fear where fear represents an emotional reaction in response to a specific object or event. Anxiety on the other hand is a reaction to threats of not realising oneself or of not existing. It is therefore an anxiety of *nothingness* (p. 231; Goldstein, 1939); it has no reference to a specific object.

The Catastrophic Reaction. Before brain injury, a failure to fulfil a task will be merely disagreeable. After brain injury the individual may not be explicitly aware of a failure but it would nevertheless signify their impossibility of self-realisation, and therefore existence.

Specifically, this occurs when the individual cannot accomplish a task that before their injury was accomplished with ease. Thus, Goldstein (1952) proposes that it is not the failure itself that produces the catastrophic reaction, but the danger that it poses to the person's existence. For example, if the sitting of an examination is of great importance to an individual's sense of life purpose through, for instance, their professional careers, failure attributable to a brain injury would violate one's pre-morbid sense of existence and a catastrophic reaction would therefore be evoked. Goldstein (1952) describes the typical expression of this reaction:

A patient may look animated, calm, in a good mood, well-poised, collected and cooperative when he is confronted with tasks he can fulfil; the same person may appear dazed, become agitated, change color, start to fumble, become unfriendly, evasive, and even aggressive when he is not able to fulfil the task. (p.255-256).

Goldstein also describes the catastrophic reaction as characterised by extreme anxiety.

Coping and Self-Actualisation. The individual attempts to cope by avoiding and escaping situations that may induce a catastrophic reaction, which the individual finds unbearable. Due to a reduced tolerance for frustration, and compromised impulse control inherent in acquired brain injury, escape from a catastrophic situation may be achieved through alternative means by which to discharge emotion; for instance through food, sex or aggression. Active avoidance of potentially demanding or frustrating activities is learned from repeated exposure to catastrophic situations. Goldstein (1939) also describes how avoidance is possible by remaining 'aloof' and passive in demanding situations. Avoidance circumvents the prospect of failure and its adverse consequences upon the individual's self-concept. Goldstein described this process as a protective mechanism, adapted from the psychoanalytic principles of defence mechanisms. Accordingly, people with brain injuries were observed to employ the following protective mechanisms to avert reacting catastrophically; these were primarily driven by the concept of self-actualisation (Goldstein 1939; 1942; 1952).

• By utilising one's capacities in the best possible way, self-actualisation is considered by Goldstein to be the fundamental drive of behaviour and serves to escape the existential nothingness described earlier. Following acquired brain injury, the individual achieves this by limiting their environment to a more circumscribed range of activity in proportion to that which they can cope with, and by utilising abilities that have been preserved in a compensatory fashion for those that have been impaired. This therefore attains an optimal level of performance akin to former capacities. Further, individuals may keep themselves busy with this more circumscribed range of activity so that, to the concrete attitude, self-actualisation is continuous.

- People with acquired brain injury will avoid situations that would expose their disability and thus produce a catastrophic reaction. Goldstein (1942) noted a tendency to avoid company and seek tranquillity.
- People will find excuses for failures other than their cognitive limitations.
- Failures may be avoided by the use of trick movements and ingenious manoeuvres.
- Other senses will be used to take place of the affected ones.
- An extensive use of routines and orderliness are employed to prevent excessive demands being placed on a newly compromised memory and capacity for reasoning. Goldstein (1939; 1942; 1952) often exemplifies this by descriptions of his patients' tendency to keep their wardrobes in a model condition; everything had its definite place and was arranged so items could easily be found.

#### Critique of the Catastrophic Reaction Model

Goldstein's (1939) emphasis upon the context of behaviour in relation to the environment attempted to bridge the divide created between traditional organic and psychogenic explanations of behaviour. This endeavour employed the hitherto indistinct concepts of subsequent emotional reactions to neurological injury, the use of compensatory strategies and the underlying role of existential anxiety. Herein lay the main advantage of the theory by portraying a humane yet thorough approach to understanding the consequences of acquired brain injury. Christensen and Rosenberg (1991), in response to Klonoff and Lage (1991), Prigatano (1991) and Lewis's (1991) emphasis upon the catastrophic reaction within a psychotherapeutic framework, states that Goldstein's theory left the field open for others to develop and therefore implicitly suggested the initial theory's lack of completion. Yet, they acknowledge Goldstein's pioneering use of a thorough and systematic phenomenological

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analysis for an understanding of the psychological processes and personality changes after acquired brain injury.

Reviewing Goldstein's (1939; 1942; 1952; 1971) theory is, however, problematic, not least because of a lack of empirical evidence in support of the theory. Sacks (1995) explains that, given a lack of English translations, many of Goldstein's case examples have not come to light outside Germany. Less than half the volume, *Selected Papers* (Goldstein *et al.*, 1971), are in English. Therefore, data that reveal detailed analyses of behaviour, or reports of an individual's subjective experience may be absent from English translations.

Even taking this into account, the theory can be criticised for a lack of detail. Aside from the short volume, After Effects of Brain Injury in War (1942), Goldstein's writings do not explicitly focus upon therapeutic approaches to brain injury but rather formed a generic existential philosophy derived from 'pathological data' (Goldstein, 1939). Thus, aspects of post brain injury conditions that may, for example, threaten an individual's existence or the longer term consequences of coping efforts are not sufficiently detailed. For instance, the longitudinal role that the so-called protective mechanisms occupy in different stages of adaptation generally lack clarity: they may protect the individual from reacting catastrophically by avoiding failure in the short term, but their longer term effects upon well being are generally not detailed. Further, the model has not considered whether or not each protective mechanism creates more or less difficulties in the long term. Goldstein (1952) does however posit an association between the individual's employment of strategies based on routines and orderliness and the development of obsessive-compulsive type behaviours. Obsessive-compulsive disorder after acquired brain injury has since been recognised by studies of psychiatric diagnoses (e.g., Childers, Holland, Ryan & Rupright, 1998), although its aetiology has received less empirical emphasis. This deserves more attention, particularly since the endorsement of routines and orderliness to compensate for memory and problem solving ability is a common feature of rehabilitation techniques.

Goldstein also makes a brief reference to what Christensen and Rosenberg (1991) interpreted from his 1952 analysis as 'depressive signs' due to the individual's avoidance of the catastrophic reaction and resulting state of withdrawal. Ownsworth and Oei's (1998)

review of the aetiological and treatment studies of depression after traumatic brain injury provides indirect but convergent evidence for this aspect of the catastrophic reaction model, albeit from a more complex interpretation. They suggest the individual is most susceptible to depression when the following conditions are met: a pre-morbid history of psychiatric disturbance; anterior left brain damage; and, consistent with the catastrophic reaction model, poor insight into difficulties, attempts to resume pre-injury roles and the consequent experience of failure. Estimates of depression rates after traumatic brain injury have varied between 27% - 60% (cf. Smith & Godfrey, 1995). Goldstein (1939) states, however, that 'in time' (p. 49) the organism will return to an ordered state through the protective mechanisms. But little or no description is provided as to how this may be achieved without an onset of the depressive signs he later described (Goldstein, 1952).

Individual Differences. Within the catastrophic reaction model, no individual differences are described by Goldstein that may reveal those who are psychologically more resilient to failure, with less intense catastrophic reactions, and those who are not. This may be due to the apparent emphasis Goldstein places upon circumstances around the earlier stages of acquired brain injury where it seems to be assumed that most, if not all, people react with some distress when becoming aware of compromised capacities. He therefore describes the catastrophic reaction process, but not in terms of its variability.

The Social and Environmental Milieu. In one of the first expositions of compensatory strategies for brain injury rehabilitation, Goldstein (1942) emphasised the arrangement of environmental conditions to employ behaviours retained from before the injury to substitute those that were lost. Given his emphasis upon the environmental context of behaviour, Goldstein's writings perhaps lend the individual's social environment a surprisingly limited emphasis. Goldstein's (1942) chapter entitled 'Social Adjustment' is in fact a guide to the benefits of vocational re-training after brain injury. The role of others, such as the professional, in reorganising and facilitating the ease of the individual's environment is only mentioned in passing. The organismic theory essentially declares the basis of human behaviour to emanate from the central nervous system outwards (Sacks, 1995). For the individual attempting to come to terms with a brain injury however, there appears to be little

or no role for the impact of social, familial or socio-economic factors in facilitating their adjustment. This is perhaps incongruous with the emphasis that Goldstein (1939; 1952) placed upon existential anxiety after brain injury. However, his description of the existential anxiety of 'nothingingness' (p.231) generally lacked the comprehensiveness provided around the same time by Sartre (1943; 1957). Specifically, in its early form the theory lacked Sartre's thesis of the individual's self-understanding through the perceptions of those around them.

Nothingness is the absence of a reifying other to prove that one actually exists and which leads the individual to 'despair' (p. 241; Sartre, 1943/1957). It was not until 1957 that Goldstein described human existence as only being possible in relation to the self-realisation of the other. This was not, however, described in the context of adjustment to acquired brain injury. Elsewhere in existential theory, sex, sociality and language are considered basic human characteristics intrinsic to human existence, and the individual or their place within society cannot therefore be ignored (Macquarrie, 1977).

Existential Anxiety and Hope. In addition to the comparisons made with Sartre's (1943/1957) perspective on nothingness, Goldstein's (1939; 1952) employment of anxiety within an existential theory suggests a circumscribed conceptualisation of existence in comparison to other existential writers. As already mentioned, the role of anxiety is a fundamental feature of Sartre's and Heidegger's philosophies (Macquarrie, 1977). However, for other writers, anxiety represents merely one 'polarity' of existence, that is, the threat of negativity and nothingness. On the other hand, existence can also be described in terms of hope, hope that one's existence is also worthwhile (Macquarrie, 1977), perhaps even beyond an acquired brain injury. In this context, hope may apply to the initial unsuccessful attempts after acquired brain injury to maintain pre-injury life styles or, equally, hope may be achieved through the construction of a new self-concept with new, realistic and attainable goals. Either way, hope is proposed as a means to maintain emotional buoyancy and facilitate adjustment. The emphasis of hope as a means to self-actualise is, at best, implicit in Goldstein's theory and deserves greater emphasis. Whether writers make anxiety or hope central to the otherwise ambiguous existence of humans largely reflects whether or not they share with Sartre (1939) the view of human existence as self-contradictory and absurd. Despite their

'polarity', existential anxiety and hope are intertwined and essentially represent two ways of experiencing the same relation, much in the same manner as would perceptions of the glass being half empty, or half full. The limits of Goldstein's theoretical optimism appears to be exemplified by the individual's 'capacity to bear insufficiency, that is, suffering' (p.392; Goldstein, 1939). Thus the theory did not progress further by entertaining the notion of personal development after acquired brain injury.

Goldstein's Methodology. Goldstein's method was essentially that of a phenomenologist, open to both behavioural and mental acts with which to understand the nature of difficulties experienced by the people he observed. An understanding of the individual's behaviour was attained through systematic and phenomenological analyses. Phenomenology was fundamental to the Gestalt school of psychology and can be traced to the 19<sup>th</sup> century predecessors in the field, Husserl and Stumpf. Human subjective experiences or phenomena are its primary data of analysis. Phenomenology has traditionally opposed the natural sciences' stance of employing a priori decisions to determine and isolate the elements of being. This has been the embodiment of physics, and followed by the other natural sciences. Experimental psychology in its dominant positivist and post-positivist paradigms has, since its 19<sup>th</sup> century beginnings and along with the rise of statistical methods, traditionally aspired to this position. Quantifiable methods are thus employed by experimental psychology to measure and predict mental events or behaviour. Consistent with the 18<sup>th</sup> century philosopher Kant, Goldstein (1939) recognised the usefulness of empirical methods yet stated they cannot represent the totality of our knowledge on existence. Empirical methods must therefore be synthesised with the phenomenological approach for a holistic understanding of adjustment to the part injury constituted by neurological damage.

The later qualitative writings of Nochi (1997; 1998a; 1998b; 2000), Crisp (1993) and Krefting (1989; 1990) on people with acquired brain injuries also ultimately descend from this perspective. Here the data have mainly derived from entering the participants' own phenomenological field by making use of their subjective interpretations of life after injury. Conversely, Goldstein's writings appear to be largely based on his interpretation of the behaviours observed and therefore constitute a supposedly objective analysis. There are few

indications as to whether these match the patient's own interpretations, or the interpretations of other observers, and thus the validity of the descriptions are open to question. Furthermore, Goldstein's observations, although thorough, were nevertheless based upon a limited number of patients within his treatment centres and the generalisability of propositions made is therefore in question.

A further difficulty with objectivity of the type employed by Goldstein lies in the assumptions made based on his, the observer's, values and judgements. The interpretative/constructivist methods employed by Nochi (1997; 1998a, 1998b, 2000) and Crisp (1993) are founded on the fundamental tenet that the 'reality' to be explained is the person with brain injury's construction of their experience and what it is like for them. This may only be described and cannot be analysed in the manner of hypothetico-deductive methods. Goldstein's objective methods instead implicitly assume and reflect the 'expert' position that presupposes a reality awaiting discovery. A potential problem relating to 'objective' assumptions may be exemplified by those employed by Starkstein, Federoff, Price, Lieguarda and Robinson (1993). Their attempt to identify the neurological locality of the catastrophic reaction in people with dementia devised a scale purporting to measure the catastrophic reaction as a dependent variable. It contained the following items to be rated by the researcher: 'Patient expressed displaced anger (patient complained about the hospital, doctors, and fellow patients)', and 'Patient refused to do something (patient stopped doing a task or refused to answer some questions)'. These behaviours may be due to reasons other than the individual's failure in coping, or their existential anxiety. Nevertheless, the researcher's supposedly objective stance presupposes the underlying cause. 'Objectivity' of this type may be criticised from an interpretative/constructionist perspective as having been socially constructed by the researcher's theoretical in-group. And yet the individual with dementia may alternatively attribute these behaviours to, for example, poor hospital food or unhelpful staff and, further, may not be prepared to co-operate with a researcher's agenda.

From a social constructionist perspective (see for example, Berger & Luckmann, 1967;
Burr, 1995; Searle, 1996) the labels employed by Goldstein such as 'self-actualisation',
'catastrophic reaction' and 'primitive personality' may be prone to overgeneralisation, over-

use and are perhaps counterproductive to the individual's well being. Social constructionism has become an increasingly influential approach in psychological concepts (Willig, 2001). It proposes that what we know is not a direct reflection of our environment, but rather an interpretation mediated by linguistic, historical and cultural norms. Accordingly, Foucault (1971; 1972) discusses how, through scientific, medical, legal and educational institutions, such concepts become infused within the accepted discourse and thereby take on a concrete entity. Consistent with this premise, Nochi (1998a) reports the tendency for some individuals with traumatic brain injury to believe that others possess the power to label them, thus further contradicting the individual's self-definition and preventing them from feeling understood. This is regardless of whether the label is intended to be positive or negative. Though Gordon (1999) advocates a social constructionist approach for ethical professional relationships with people with acquired brain injury, social constructionist perspectives have yet to make any significant impact within this field.

Goldstein (1939) did not believe that his methods were compatible with the positivist methods of the naturalistic sciences. This polemic stance is consistent with the power and divisiveness of the Gestalt and phenomenological movements during the early 20<sup>th</sup> century. However, arguments between the phenomenological and post-positivist modes of enquiry are currently less frequent and an intersection between the two is considered complementary in some quarters (Thines, 1977; Gallagher & Depraz, 2002). Gelder (1996), writing on the scientific foundations of cognitive behaviour therapy, stresses the importance of observation for generating psychological models and more restricted hypotheses. Thus the piecemeal process that drives the hypothetico-deductive method (i.e., theories that have their foundations in other theories and evolve slowly over time) is not necessarily exclusively subscribed to by the 'scientific' community. It is worth noting that behaviourism too was opposed to the hypothetico-deductive method. But of course, behaviourism was not phenomenological and external behaviour, not human experience, was its focus. Nevertheless, it was recognised that Lashley's (1929) behavioural studies had arrived at the same anti-localisationist conclusions as Goldstein's holistic theory (Teuber, 1966). By breaking with the hypothetico-deductive tradition of the science associated with evidenceempirical theories. What is more, models such as the catastrophic reaction explain phenomena in a broad comprehensive fashion but cannot be easily falsified. Hypotheses, on the other hand, empirically test aspects of a model in 'bite sized' chunks more amenable to positivist methods. Both methods have their respective advantages and disadvantages. A critique of research findings or phenomenological observation therefore requires an appreciation of the limitations of the method employed.

#### Developments of the Catastrophic Reaction Model

Writing in 1986 Prigatano commented that, clinically, the natural course of the catastrophic reaction was only beginning to be investigated. He does however report (Prigatano, 1986) that the individual may experience relatively little emotional distress during the early stages of acquired brain injury, perhaps due to increased cognitive confusion. But during the first year the individual becomes more distressed due to misjudgements of cognitive abilities and failures in work and social situations. Additionally, the catastrophic reaction is described as a repeated event over the course of rehabilitation (Prigatano, 1999).

Both Prigatano (1991) and Klonoff and Lage's (1991) writings on psychotherapeutic approaches demonstrate their integration of the catastrophic reaction model within the psychoanalytic theories of Jung and Kohut respectively. Goldstein (1959) did not believe such a convergence between his method and that of psychoanalysis was possible. Even so, it appears that the catastrophic reaction has been of most theoretical use to later conceptualisations of adjustment, rather than Goldstein's wider philosophies.

Prigatano (1988; 1991; 1999) supplants Goldstein's (1939) perspectives on existentialism with Jung's (1933) concept of individuation. Briefly, individuation refers to the process of becoming a unique individual through the balancing and integration of the conscious and subconscious. This process divests 'the self' from the pervasive effects on the unconscious of cultural norms, such as professional titles, roles or habits of social behaviour (the 'persona archetype'). Thus, the recognition of hitherto neglected (unconscious) aspects of the personality produces the unique true 'self'. Therapy is directed towards helping the

individual achieve a new organisation and construction of existence by facilitating the development of neglected aspects of their personality. In context of adjustment to acquired brain injury, Prigatano therefore provides some basis for individual differences in the catastrophic reaction model. For example, Weinstein and Khan (1955; cf. Gainotti, 1993), Gronwall (1991), Kay (1992; cf. Ponsford, Sloan & Snow, 1995), and Prigatano (1991) identify particular adjustment difficulties for individuals who, pre-morbidly, were driven to achieve professional, educational or physical excellence. Thus the individual's perceived self-concept is likely to be more severely threatened by the changes brought on by acquired brain injury. Conversely, the individual with a less rigid pre-morbid self-concept may more easily integrate new sources of activity and satisfaction into their new sense of self. Perceived self-actualisation after injury may therefore be less problematic, catastrophic reactions may be less intense and the longer-term impact of failure upon the individual may be less pervasive. Although it is proposed here that his theory had sufficient scope to take into account the role of pre-morbid identity issues in post-injury adjustment, Goldstein did not consider differential rates of reacting catastrophically on this basis. Neither was the issue of an existential hope expressed as clearly. This, however, is the catalyst for Prigatano's therapeutic emphases on helping an individual find meaning to life after acquired brain injury. Adjustment is facilitated by pursuing new 1) satisfying work or activities, 2) mutually satisfying relationships, and 3) recreation, or exploration to experience the new self through fantasy (Work, Love and Play Therapy; Prigatano, 1991; 1995; 1999). These pursuits are encouraged in place of attempts to achieve ideals of intelligence, physical beauty or of competitiveness that are considered counterproductive to personal well being. Klonoff and Lage (1991) present a similar therapeutic focus upon realistic, attainable goals rather than an all or nothing pursuit of excellence.

Crisp (1993) provides qualitative data to support the association proposed between differences in self-concept and resultant satisfaction after traumatic brain injury. In a typological analysis two groups of participants were identified on this basis. A first group (n = 4), who valued highly the attributes of intelligence, physical attractiveness and achievement at work, school or sport, reported more threats to self-image and personal well-being after

injury. However, a second group (N = 6) sought satisfaction in productivity, such as voluntary work or leisure activities, and from mutually satisfying relationships with others. These participants reported a relatively greater sense of control and well being.

Klonoff and her associates (1991;1993) also supplant Goldstein's existential perspective with Kohut's (1973) standpoint on existence, termed as 'self-psychology'. Here the authors emphasise the shared features of the catastrophic reaction and narcissistic rage. Narcissistic rage is defined as the reaction of the self to its sense of helplessness and loss of integrity. Both narcissistic rage and the catastrophic reaction's deleterious effects upon self esteem stems from the perception of failure. In addition to anxiety, Kohut (1973) regarded the catastrophic reaction to be one of rage due to the awareness of reduced capacities, and the interruption of a pre-morbid quest for absolute perfection. What is more, narcissistic rage is characterised by a need for revenge and to redress the injury. This serves to bolster selfesteem through grandiose, external expressions of rage against others. It is associated with a lack of internal regulatory ability, described as 'self-soothing' (p.13), and structures that allow an integration of changes into a new self-concept. Pre-morbid narcissistic traits are considered responsible for greater adjustment difficulties after injury. Klonoff, Lage and Chiappello (1993) also present three phenomenological case studies that illustrate how the catastrophic reaction may become manifest, either in withdrawal, violent rage or the attempted concealment of one's disabilities. The authors propose that the experience of shame and anxiety attached to the acquired brain injury is fundamental to each case.

Prigatano (1986; 1991; 1995; 1999) and Klonoff et al's (1991; 1993) incorporation of alternative theories gainfully expand the meaning of acquired brain injury in relation to the individual's self-concept and provide a greater social emphasis than that of Goldstein's theory. Others have, however, further developed the social aspects of self-concept after brain injury. Nadell (1991), from an additional existential account, discusses the strong self-alienation made possible after brain injury due to the internalisation of negative appraisals held by others. Nochi's (1998a; 1998b) qualitative analyses further substantiates this notion by describing the 'loss of self' that the individual with acquired brain injury attempts to minimise or avoid. Loss of self was reported to emerge through the contradictions of the

individual's self-definition by others, and also by the limitations of self-knowledge brought on by injury, and the individual's pre-and post morbid comparisons of self. Additionally, the critique from a social constructionist perspective described earlier can also be applied to Prigatano and Klonoff *et al's* use of terms such as 'narcissistic personality' and 'personality disorder' that may also impact negatively upon the individual's self-concept through stigmatisation.

Aside from the accommodation of pre-morbid personality structures, there continues to be a lack of clarity concerning the individual differences that may moderate the catastrophic reaction and excessive generalisations regarding its occurrence persist. Accordingly, the factors that mediate and moderate the catastrophic reaction may not yet be fully investigated. If for example acquired brain injury (independent variable) is a predictor of the catastrophic reaction (dependent variable), this relationship may hypothetically be compromised by another variable (moderator) such as high levels of social support or an individual's particular belief structure.

The longer term effects of avoidance of the catastrophic reaction also continue to lack clarity. Prigatano (1999) states from clinical experience that, as initially proposed by Goldstein (1939; 1952), the experience of repeated failure precipitates depression but a greater level of insight into their difficulties does not accompany this, presumably due to cognitive deficit. This is argued contrary to Godfrey, Partridge, Knight and Bishira's (1993) contention that depression worsens as insight improves due to the environmental and social feedback of difficulties. Godfrey *et al.* describe limited insight after acquired brain injury partly as a normal process given that adults have a strong bias towards an enhanced perception of their self-concept (see for example Taylor & Brown, 1988). Insight difficulties are thus due to highly resistant pre-morbid performance expectations and, given the rapid onset of acquired brain injury, a limited opportunity to learn new performance expectations and coping strategies. Further, the often overtly unaffected physical appearance of individuals with acquired brain injury and their families' commensurate expectations may contribute to the individual's overestimation of performance. Given the lack of consensus between Prigatano and Godfrey *et al.*, this clearly is an issue that requires more investigation, not least

because of the confusion associated with definitions and uses of the term 'insight' (Malia, 1997). The relationship between insight and depression proposed by Godfrey *et al.* is also incongruous to that offered by Ownsworth and Oei (1998; described earlier) who suggest that depression is due, in part, to a lack of insight.

It is interesting that, from the more empirical foundations of cognitive-behavioural therapy, the documentation of Smith and Godfrey's (1995) rehabilitation programme also makes reference to Goldstein's (1952) catastrophic reaction model. Examples are provided where the reaction is precipitated by events as diverse as changes in living situations, receiving bad haircuts, failure to complete plumbing work, receiving lower than expected compensation payments, or being served poorly cooked meals. Smith and Godfrey comment further upon the rapid transition between a stable mood to severe imbalance within a few hours. Nonetheless, a return to stability may be evident within days. A catastrophic reaction to any of the above triggers may result in mood difficulties ranging from depression to the extremity of suicide<sup>1</sup>. Moreover, the authors note that the catastrophic reaction only appeared in a subset of their clients who have sustained traumatic brain injury, particularly those who had poor impulsive control associated with frontal lobe damage and more severe injuries. When an individual is in a catastrophic situation the authors recommend the provision of social support to help resolve the source of the reaction (rather than to simply avoid a further reaction) and to ensure the individual's physical safety.

Smith and Godfrey's (1995) description of the catastrophic reaction is at best brief, anecdotal and their proposed precipitating factors, moderators and incidence may prove contentious. It is nonetheless helpful in this way, and through the case studies presented by Klonoff and Lage (1991), to detail concrete features of the catastrophic reaction in terms of its associated conditions, temporal pattern, range of consequences and recommendations for its management. Further elucidation of this nature is required; and an empirical analysis of its identified features would be useful, not least to establish whether or not the catastrophic reaction is unique to acquired brain injury, or if it is evident in other chronically disabling conditions that may threaten the individual's self-concept. Longitudinal research designs

Suicide is also discussed in Klonoff and Lage's (1991) account of the catastrophic reaction.

would also be useful to clarify the temporal patterns, intensities and frequencies of the catastrophic reaction, and reveal its vulnerability factors. However, despite the reverence given to the catastrophic reaction model it has not been empirically tested for its precipitating factors, the range of reactive coping strategies employed, or their longer term outcomes. Still, a recent independent body of research applying the stress-appraisal and coping framework to the adjustment of people with brain injuries may provide some indirect convergent evidence for the coping processes proposed by the catastrophic reaction model.

#### Empirical Models of Coping Following Brain Injury

### The Coping Hypothesis

Writing on attentional difficulties and speed of information processing, van Zomeren, Brouwer and Deelman (1984) made reference to Goldstein's (1939) proposition that 'neurotic symptoms' (p.96) after brain injury were subsequent to cognitive deficit. Here the underlying cognitive deficit appeared to be evident in the tendency of people with acquired brain injuries to process distracting stimuli more slowly than 'normals'. Prolonged neurological deficits are, however, rarely overtly apparent in less severe cases of brain injury and expectations are such that normal living and employment will be returned to without significant delay: patients are therefore often discharged from hospital within a few days (Ponsford et al., 1995). Nonetheless, research by Gronwall and Sampson (1974) and Wrightson and Gronwall (1981) found that, in some people with 'mild' traumatic brain injuries<sup>2</sup>, their so called postconcussional symptoms tended to persist longer than would be expected. Residual memory difficulties, concentration difficulties and difficulties in coping with work were found to characterise a group deemed not to have 'recovered'. Gronwall and Sampson (1974) suggested that a reduced speed of information processing was the underlying cause of difficulties in concentrating on tasks requiring a high information load. Indeed, an organic basis of reduced processing speed is now widely accepted given recent advances made in brain imaging techniques that can identify subtle yet persistent traces of neuronal damage

<sup>&</sup>lt;sup>2</sup> Where consciousness has been lost for less than 20 minutes or post-traumatic amnesia (PTA) is less than one hour.

(Pilz, 1983; Levin *et al.*, 1987; MacFlynn, Montgomery, Fenton & Rutherford, 1984; cf. Ponsford *et al.*, 1995). However, on this basis neuronal damage would be expected in all mild head injury cases, yet post-concussional symptoms appeared to persist in some people, but in not others.

Subsequent Reactions to Neuronal Damage: Empirical Investigations. van Zomeren and van den Burg (1985) investigated the presence of 17 residual deficits in the psychological functioning of 57 participants at two years post injury. Factor analytic techniques revealed two main clusters of complaints: one indicating a direct cognitive impairment, (i.e., forgetfulness, slowness, poor concentration and an inability to divide attention between two concurrent activities). This was positively related to the severity of injury (as measured by post-traumatic amnesia) and the extent to which previous work could be returned. The second cluster related to so called 'intolerances' (p. 27). These included a loss of initiative, irritability, fatigue, dizziness depressed mood, indifference, intolerances of noise and light, an increased need of sleep, headache, crying more, depressed mood and greater anxiety. These intolerances did not relate to the severity of injury. All were however related to anxiety.

van Zomeren and van den Burg (1985) therefore suggest, consistent with Goldstein's (1939; 1952) theory, that the 'intolerances' are not directly related to the injury, but represent the product of a reaction to the cognitive consequences of the injury. They propose further that the intolerances are due to the over-expenditure of effort from chronic attempts to compensate for cognitive deficits. This effort is a response to compensate for demands made by the social environment and the individual's own pre-morbid standards. This may, somewhat paradoxically, be true more often for those less severely injured, given that social and personal expectations exceed the individual's capacity more so when the disability is less apparent and goes undetected. Despite the usefulness of this formulation, the individual differences between, on the one hand, those who coped more efficiently with the cognitive deficits and, on the other, those who coped less well and thus reported more intolerances, were not investigated.

In a replication and elaboration of van Zomeren and van den Burg's (1985) findings, Hinckleday and Corrigan (1990) assessed 55 participants. Some differences were present between the factor structures of the complaints. Nevertheless, van Zomeren and van den Burg's two classes of complaints and intolerances, and their relationships to severity and anxiety respectively were supported. Consistencies were also found for the association between the second class of complaints and anxiety. Hinkleday and Corrigan's replication of van Zomeren *et al's* results differed in its additional use of a measure of coping strategies traditionally employed in stress-appraisal and coping research. Participants reported considerably more avoidance coping on the Indices of Coping Responses measure than that reported in the original standardisation of 424 non-clinical community adults (Moos, Cronkite, Billings & Finney, 1984). The authors suggest that their sample may therefore have employed ineffective coping strategies that contributed to the intolerances. Coping strategies were not however the primary emphasis of the study and received no further analyses.

#### The Stress-Appraisal and Coping Theory

van Zomeren, Brouwer and Deelman (1984) proposed that Lazarus and Folkman's (1984) stress-appraisal and coping concept may be an appropriate theoretical basis for further investigations of what they coined as the coping hypothesis. The theory was formulated (Lazarus, 1966) in an attempt to explain individual differences in adaptation to stress from a cognitive-phenomenological perspective, primarily with a non-clinical population. Three fundamental ingredients are employed with which to explain how the individual's idiosyncratic *appraisal* of *stressors* enacts a consequent *coping* strategy. To elaborate these concepts, it is necessary to delineate each in turn.

Stressors. Stressors are everyday demands upon an individual that constitute emotional encounters (Lazarus, 1991). Demands may either be external, i.e., a deadline imposed by one's employer to complete a task at work; or internal, i.e., the individual's own expectation for the job to be completed within a certain time frame. A conflict between internal and external demands may also be a stressor. Emotional distress occurs when the individual appraises the demand to be in excess of, or taxing to, their resources. This therefore places a central role on the individual's subjective appraisal of the threat. Two appraisal processes are proposed.

<u>Primary Appraisal</u>. Primary appraisal refers to the individual's subjective inference of the impact associated with a stressor. Specifically, the inference of what and how much is at stake is made. Primary appraisal can be of four types: harm/loss, threat, challenge, or benefit. The intertwined and simultaneous process of secondary appraisal influences the individual's primary appraisal.

<u>Secondary Appraisal</u>. Secondary appraisal refers to the subjective evaluation of one's coping options in meeting a threat. These are determined by two antecedents, environmental resources and personal resources, such as self-esteem, self-efficacy, locus of control or hopefulness.

Coping Strategies. A coping strategy is an effortful act employed in reaction to a demand. This need not be an overt behaviour but may also be a covert cognitive response, for instance, when one attempts to forget about a problem. Coping responses will only be implemented in situations that are appraised as stressful. Since the stress-appraisal and coping literature's evolution from Lazarus's (1966) original conception, the nature of coping strategies has become a somewhat amorphous concept and a lack of conceptual consensus may contribute to imprecise and inconsistent findings. Nonetheless, most formulations of the stress-appraisal and coping model derive from Lazarus and Folkman's (1984) formulation that identifies two basic coping dimensions: problem focused coping and emotion focused coping. Problem focused coping is action centred, tackling a problem with instrumental, interpersonal, attentive, vigilant or confrontative strategies. Emotion focused coping attempts to avoid, escape, palliate or emotionally regulate reactions to the stressor. Roth and Cohen (1986) make the broad distinction between these groups as approach and avoidance strategies. The latter group do not directly attempt to change the stressor, but minimises the emotional impact of the event and protects the individual from becoming overwhelmed (see also Schwarzer & Schwarzer, 1996; Krohne, 1993; Suls & Fletcher, 1985).

Kendall, Shum, Lack, Bull and Fee (2001) argue that this distinction may still be insufficient for populations with chronic disabilities given that their patterns of coping may be more complex than those without chronic difficulties and that findings on the types of coping employed when disabilities are chronic have been mixed (Wineman, Durand & Steiner, 1994;

Willer, Allen, Durnan & Ferry, 1990; Willer, Allen, Liss & Zicht, 1991). Kendal *et al.* propose that it is necessary therefore to clarify further active and passive coping strategies given that some researchers suggest that these will determine coping effectiveness (Finset & Andersson, 2000). Consequently, Lazarus and Folkman's (1984) dichotomy may be divided further into an active and passive problem focused dimension and an active and passive emotion focused dimension. For instance, problem focused coping can involve active attempts to solve problems or passive attempts to cognitively reframe one's perception of a difficulty. Depending on the context of the stressor, an active problem solving effort may be maladaptive (for instance, attempting to sit an examination before one is ready). Whereas a passive problem focused strategy may be adaptive (for example the cognitive acceptance that one is not ready and resolves therefore to adopt a strategy of patience). On the other hand, an active emotion focused strategy (for example the sharing of a problem with a friend or relative) may be useful in some instances, while a passive emotion focused strategy may be maladaptive (for instance, keeping feelings to oneself when there is a problem).

Lazarus and Folkman's (1984) methodology employed a cognitive-phenomenological method that informed an empirical self-report questionnaire method. Subsequent researchers have tended to borrow items from such pre-existing questionnaires, perhaps add more items and re-factor analyse the measure with new theoretical assumptions. Given the addition of the researcher's theoretical and empirical basis, the methodologies employed within the stress-appraisal and coping field have therefore tended to become more deductive rather than inductive (for a review of coping measures see Schwarzer & Schwarzer, 1996). The exact nature of coping and the strategies from which it is comprised are thus open to different interpretations.

Stress-Appraisal and Coping Studies of Adjustment to Acquired Brain Injury<sup>3</sup>

Three reviews of the literature on stress-appraisal and coping and people with acquired brain injuries appeared in the mid 1990's (Kendal & Terry, 1996; Godfrey, Knight & Partridge, 1996; Martelli, Zasler & MacMillan, 1998). Each proposed the potential utility of the stress-appraisal and coping framework to understand the intervening variables between neurological impairment and disability. The stress-appraisal and coping model has largely utilised empirical methods by which to investigate adjustment to post-injury conditions. These tend to rely heavily on the structured self-report of the individual. Investigations of coping strategies in people with brain injuries have primarily aimed to identify the patterns of coping responses employed by people with brain injuries. There have been few a priori hypotheses involving avoidance coping *per se*. There does however appear to be an emerging trend in the acquired brain injury literature that has broadly associated avoidant type coping (along the lines described by Roth and Cohen [1986], and Kendal *et al.* [1996]) with negative indices of emotional or psychosocial outcome.

Empirical Investigations of Coping Strategies. In the first published study on coping strategies in people with closed head injury, Moore, Stambrook and Peters (1989) employed cluster analysis techniques to investigate the relationship between coping strategies and emotional and social difficulties in 69 people with closed head injuries. They report that the use of a range of emotion focused coping strategies (those that did not attempt to change a situation) measured by the Revised Ways of Coping Scale (Folkman, Lazarus, & Dunkel-Schetter, 1986) were associated with greater emotional difficulties on the Profile of Mood States (McNair, Lorr & Droppleman, 1977), Katz Adjustment Scale for Relatives (Hogarty & Katz, 1971) and social disturbance on the Sickness Impact Profile (Berger, Bobbit & Pollard, 1976). A narrower range of problem solving strategies was associated with less emotional and psychosocial difficulty. A later re-factor analysed Revised Ways of Coping Scale administered to 175 individuals with mild, moderate and severe traumatic brain injuries

<sup>&</sup>lt;sup>3</sup> Although most studies are concerned with traumatic brain injuries (TBI), the term acquired brain injury will continue to be employed here given that some studies reviewed have heterogeneous aetiologies (e.g., Finset & Andersson, 2000; Malia, Powell & Torode, 1995). Here mainly TBI samples have also included some participants with cerebrovascular or anoxic injuries.

(Moore & Stambrook, 1994) revealed four categories of coping associated with higher levels of emotional distress. Three were broadly consistent with the avoidant (passive emotion focused) types of coping, and were labelled by the authors 'repression', 'denial' and 'escape'. Additionally, females with traumatic brain injury, who had what Moore, Stambrook and Gill (1994) identified as a distinct coping pattern consisting of avoidance and self-blame, were also more likely to have a poorer outcome.

Malia, Powell and Torode (1995) investigated the coping strategies and psychosocial outcome amongst 75 people with a heterogeneous cohort of acquired brain injuries. This was compared with a matched control group of 46 people who had undergone disfiguring injuries but without a neurological deficit. A lower use of emotion focused, avoidant and wishful thinking coping strategies on the Revised Ways of Coping Scale (Lazarus & Folkman, 1984) predicted better psychosocial adjustment on a previously unpublished scale purporting to measure psychosocial functioning. Coping patterns were found to be similar for both groups, despite the differences in cognitive functioning. In accordance with Kendal *et al* 's (2001) demarcation of active and passive coping dimensions, Malia *et al*. postulated the positive nature of active emotion focused coping strategies that involve the acceptance of a problem and therefore the processing of emotional reactions.

The similarities found by Malia *et al.* (1995) between coping strategies and adjustment of groups of people with brain injuries and those of non-neurological controls were echoed by the findings of Curran, Ponsford and Crowe (2001). 88 people with traumatic brain injuries were compared to 40 people who had sustained orthopaedic injuries. Higher levels of depression and anxiety were associated with the 'non-productive' (those that did not attempt to change a situation) coping styles of worry, wishful thinking and self-blame on the Coping Scale for Adults (Frydenberg & Lewis, 1993<sup>4</sup>).

Finset and Andersson (2000) advocated the consideration of active and passive coping strategies corresponding to the demarcation described by Kendal *et al.* (2001). The COPE

<sup>&</sup>lt;sup>4</sup> Frydenberg and Lewis (1993) follow conceptualisations of coping 'styles' (Cox, Gotts, Boot & Kerr, 1985; Seiffge, Krenke & Shulman, 1990) that reflect trait coping rather than the 'strategies' that constitute state coping. These are manifest in three differing styles 1) solving problem, 2) non-productive coping (associated with avoidance and an inability to cope and 3) reference to others.

assessment (Carver, Scheier & Weintraub, 1989) was employed to assess the coping strategies of 70 people with impairments due either to traumatic brain injury, cerebrovascular accidents or hypoxic injury. 71 non-clinical participants were employed as a control group. A positive relationship was found between avoidant coping and depression (Montgomery & Asberg Depression Rating Scale; Montgomery & Asberg, 1979) and a negative relationship was found between approach oriented coping and apathy. Apathy is described as reduced goal directed activity, lowered motivation, reduced awareness, lowered autonomic reactivity and is associated with sub-cortical and right hemisphere lesions (Andersson, Gundersen & Finset, 1999). Apathy shares with depression the symptoms of anhedonia and reduced initiative. Depression is differentiated by its affective and somatic symptoms (Finset & Andersson, 2000). Analyses also explored the relationships of lesion locations to the factors explored. Coping strategies were not related to lesion locations. A mixed analysis of covariance suggested that apathy and avoidant coping strategies acted as a covariate with left hemisphere lesion location in association with diagnostic indices of depression. Apathy and avoidance thus contributed to depression. After distinctions were made between apathy and depression, it was suggested that, consistent with the propositions of Ownsworth and Oei (1998; described earlier), left hemisphere lesions made participants vulnerable to depression. These findings therefore suggested a complex interplay between the location of lesion, presence of apathy and coping style in depression, and therefore suggest the need for considerations of neurological factors in depression but also for the potentially moderating effect of coping strategies upon depression.

Kendal, Shum, Lack, Bull and Fee (2001) attempted to synthesise the familiar quantitative methods of stress-appraisal and coping research with qualitative methods. This was considered necessary in order to elaborate the need for analyses of coping to take into account the context of the demands or threats faced after brain injury. For instance, Karlovits and McColl's (1999) qualitative investigation of coping strategies following traumatic brain injury point out the appropriateness of some avoidance strategies. Withdrawal from potentially aggressive encounters was, for example, identified for its perspicacity in certain situations. Accordingly, Kendal *et al's* semi-qualitative methodology examined coping

strategies in response to four video-based scenarios, deemed to be stressful by a preliminary focus group of people who had sustained traumatic brain injuries. Each scenario was based on the same character with traumatic brain injury whose driving licence was refused, was denied employment, was socially rejected, and one scenario portrayed a memory difficulty. 24 participants were subsequently asked to describe how they would cope with their situations. Coping responses were analysed, coded and classified by independent raters. Emotional functioning over the previous five months was self-rated on the Bradburn Affect Scale (Bradburn, 1969). It was noted that the number and type of coping strategies employed differed significantly across situations. Consistent with Malia *et al's* (1995) proposition, a rigid use (strategies employed more frequently and repeatedly across all four scenarios) of active emotion focused coping was associated with better emotional functioning. This also held true for active problem focused coping. As hypothesised, a rigid use of avoidant (passive emotion-focused) coping was associated with poorer emotional adjustment and low self-esteem.

Appraisal Processes. The relationship between coping strategies and appraisal within stress-appraisal and coping studies has so far received only limited empirical attention in the acquired brain injury literature. Kendal *et al's* (2001) study is unique in encompassing both the processes of primary appraisal and secondary appraisal processes. Active problem focused coping (approach) was related to high self-esteem (Rosenberg Self-Esteem Scale, 1965): a rigid use of passive emotion-focused (avoidance) coping was associated with low self-esteem. Appraisal, to some extent, is expected to determine which coping strategy is enacted (Lazarus, 1993). Emotion focused coping strategies are likely to be employed after situations are appraised as uncontrollable: approach (active problem focused) strategies are expected after appraisals of situational control are made. Accordingly, Moore and Stambrook (1995) proposed a conceptual model that hypothesises the role of a learned-helplessness cycle incorporating limiting and self-defeating beliefs and a lack of control in association with avoidant coping strategies. Curran, Ponsford and Crowe (2001) similarly found low self-esteem and low optimism to be significantly related to non-productive coping (that which

does not attempt to change a situation). Self-esteem contributed a further 14% of their variance in predicting depression, and a further 5% in predicting anxiety.

Moore and Stambrook (1992) report that higher reports of internal locus of control beliefs were associated with attempts at self-control and positive reappraisal of a situation.

Moreover, their participants with traumatic brain injury (N=53) were less likely to be depressed. From a psychotherapeutic perspective, Cicerone (1991) concurs with the available evidence by observing that a lack of perceived control or 'self-efficacy' appears to be associated with helplessness, demoralisation and exacerbated disability after acquired brain injury. Crisp (1993) and Kendall (1991; cf. Kendall and Terry, 1996) from qualitative analyses support the notion that a giving up of hope will result in the individual's lack of belief that they can do anything to alter a situation. However, without more direct empirical tests, the relationship of these appraisal processes to avoidant coping strategies requires greater clarification.

Social Support. Perceived social support has been identified as an important variable within the mainstream stress-appraisal and coping literature (i.e., Kessler, Price & Wortman, 1985). Given a variety of potential sources, it is therefore a multi-dimensional concept. Support may be received through informational, emotional and practical mediums and received from families, peers, professionals and employers. Social support has not so far received any great empirical emphasis in relation to the coping strategies of people with acquired brain injuries. This is despite it having been discussed by reviewers for its importance (Kendal & Terry, 1996; Godfrey, Knight & Partridge, 1996; Martelli, Zasler & MacMillan, 1998), and the identification of increased rates of isolation from networks outside one's family after injury (cf. Smith & Godfrey, 1995).

The mainstream stress-appraisal and coping literature has postulated two effects of social support on emotional well being. A main effect model explains a direct impact through the provision of a positive effect and stability to the individual's life. Additionally, a buffering model hypothesises the intervention of social support between significant life events and emotional adjustment. Individuals who perceive themselves as supported, compared to those who do not, should therefore experience better adjustment (Wolchik, Sandler & Braver,

1987). Kendal and Terry (1996) highlight research suggesting that low levels of perceived support lead to greater difficulties for people with brain injuries (Elsass & Kinsella, 1987; Holosko & Heuge, 1989; Kaplan, 1990) and that an early high level of support predicts better emotional adjustment three years post injury (Kaplan, 1991). Leach, Frank, Bouman and Farmer (1994) found that families' effective use of problem solving and behavioural coping strategies predicted lower rates of depression in 39 people with traumatic brain injuries. This is broadly consistent with Kaplan's (1990; cf. Kendall & Terry, 1996) findings that people with closed head injuries who rated their family low in cohesion and expressiveness had higher levels of emotional difficulties. Wagner, Williams and Long's (1991) study of 40 participants with closed head injury and 26 non-injured controls suggested a strong relationship between social network support and recovery of function from closed head injury.

Due to a lack of evidence it is, at present, unclear how these processes may impact upon, and be mediated by the coping strategies of people with brain injuries. It may however be postulated that, in accordance with related stress-appraisal and coping investigations in the health and mental health fields (Cassidy, 1999; Schwarzer & Leppin, 1992), low levels of perceived support predict higher levels of avoidance coping. Given this reduced level of personal resources, options for action-oriented strategies may therefore be limited with little else to do but minimise the potential emotional impact of the event through avoidance.

### Stress-Appraisal and Coping Formulation of Adjustment: Critique

The stress-appraisal and coping theory has begun to clarify the effect of coping upon adjustment after acquired brain injury and the individual differences involved. In particular, avoidance coping appears to be predictive of negative indices of adjustment. These findings are generally consistent with the stress-appraisal and coping research in other clinical populations. Moos and Scheafer (1993), for instance, reviewed research upon people suffering from a diverse range of medical difficulties. They conclude that those who tend to rely on active or approach coping strategies generally tend to adapt better to health related stressors in the longer term. Conversely, reliance upon avoidance coping during illness has

consistently been identified as a risk factor of distress in adults and children. Malia *et al*. (1995) and Curran *et al's* (2001) employment of control groups with non-brain injured clinical populations would further support the similarities in coping despite the presence of cognitive difficulties. Kendall *et al*. (1996) stress however that the presence of a chronic disability may make a difference to people's coping strategies in comparison with shorter term stressors. This distinction would therefore require further investigation.

The stress-appraisal and coping model also allows for the influence of social support factors. However, the literature has yet to sufficiently analyse this in the context of the coping and resources of people with acquired brain injuries. The social support model is also not explicitly relational in its nature. Social support may perhaps be measured for its presence, strength and nature but its direct effects upon, for example, appraisal processes and what it actually means to people with brain injuries requires further elucidation. For instance, Godfrey *et al.* (1996) briefly suggest the negative effects of others' evaluations on people with acquired brain injury. Although yet to be tested in this population, a cognitive process shown to mediate depression is that by which people evaluate themselves through comparison to others (Festinger, 1954). Negative information is a threat to self-esteem, and an established relationship has been found between negative social comparison and psychological difficulties (see for example Allan & Gilbert, 1995; Swallow & Kuiper, 1988; Dagnan & Sandhu, 1999). This is most likely to occur when the individual is deprived of sources conducive to self-worth (Champion & Power, 1995) such as satisfying relationships.

Appraisal processes have received a greater prominence in the stress-appraisal and coping research, yet the available evidence is limited to only a few direct tests of the influence of primary and secondary appraisal upon coping. Although Lazarus and Folkman's (1984) distinction between primary and secondary appraisal is clear, the literature reviewed here has been less consistent. Kendal *et al's* (2001) methodology represents one of the few systematic investigations to incorporate the nature of threat experienced by people with acquired brain injuries, but is limited to just four scenarios. What is more, Kendal *et al's* research has broken with a research tradition that has relied almost exclusively upon self-report questionnaires of coping strategies. These methods have demonstrated the frequency that

people with acquired brain injuries use avoidant type strategies and how they might avoid, but not why or what they might avoid. Alternatively, observational techniques, enabled by, for example, single case designs, or the semi-qualitative method demonstrated by Kendal *et al.* may augment the stress-appraisal and coping literature's descriptive power and bolster the external validity of its proposals.

Large correlations and effect sizes have been found in correlations between coping strategies and outcome: Malia *et al.* (1995) report a Pearson's (*r*) correlation of 0.47 thus accounting for 22% of the variance between avoidance and psychosocial outcome. Curran *et al.* (2001) report that coping strategies accounted for 38% of depression scores and 54% of anxiety. It is however probably over-simplistic to exclusively associate avoidance strategies with negative consequences and active strategies with positive consequences. In light of mixed observations, Kendal and Terry (1996) note that the stress-appraisal and coping theory's 'goodness-of-fit' to account for its proposed relationships between factors has not been fully demonstrated. For example, the authors suggest that the use of active coping strategies may fail to ameliorate longer term difficulties related to brain injury and therefore lead to greater distress. However, a greater use of avoidance strategies in the shorter term may be a protective factor against distress in the earlier stages of injury as postulated in research upon denial after acquired brain injuries (Malia, Torode & Powell, 1993; Nockleby & Deaton, 1987).

Godfrey et al. (1996), Kendall and Terry (1996), and Martelli et al. (1998) all stress the need for prospective research designs though none have so far been demonstrated. Given the situational determinants and dynamic nature of coping strategies, the use of cross-sectional studies only represent snapshots of the relationship between stressors, appraisal, coping strategies and emotional or psychosocial outcome; their temporal patterns, in context of the chronic nature of acquired brain injury, remain largely unidentified. The methods so far employed are also mostly correlational and, though relationships are established, the direction of whether, for instance, avoidance coping precipitates emotional distress or not cannot be verified. Nevertheless, theories of anxiety in particular have consistently established the maintaining role of avoidance (Mowrer, 1939; Rachman, 1984).

Though the stress-appraisal and coping model has demonstrated some theoretical worth in the acquired brain injury literature, it has not been applied to direct tests of the clinical efficacy of interventions based on coping strategies and subsequent adaptation. For instance, though Smith and Godfrey's (1995) cognitive-behavioural approach is informed by Lazarus and Folkman's (1984) theory, it does not empirically test changes in coping strategies within their documented rehabilitation programme. This appears to reflect the stress-appraisal and coping research in other clinical populations, where there is a plethora of studies upon coping patterns, but not in the context of clinical interventions (de Ridder & Schreurs, 2001).

## Conclusions: Comparisons and Contrasts

### Methodology

With the exception of Smith and Godfrey's (1995) discussion of the catastrophic reaction, it is remarkable that so few references are made between the psychotherapeutic literature's use of the catastrophic reaction model, and applications of the stress-appraisal and coping theory to adjustment after acquired brain injury. Each body of literature appears to make similar proposals but also has something to say about which the other is silent. Their divergence may be due, in part, to paradigmatic differences in methodology. The psychotherapeutic literature presented, for example, by Prigatano (1986; 1991; 1999) and Klonoff and Lage, (1991) are largely based on phenomenological theories of emotional distress outside of academic psychology, and are tailored to describe the unique phenomena observed in brain injury adjustment. Conversely, the ubiquitous measures of coping strategies and appraisal employed by the stress-appraisal and coping research derive from academic psychology. Given their formulation from non-clinical populations, stress-appraisal and coping measures are generally not specific to people with acquired brain injury and are not augmented by detailed clinical observation. For example, the episodes of extreme anxiety at the epicentre of the catastrophic reaction have not been described in reviews of the stress-coping and appraisal theory that have been applied to people with acquired brain injury (Kendal & Terry, 1996; Godfrey et al., 1996; Martelli et al., 1998) despite its remarkable characteristics. The phenomenology of the psychotherapeutic literature therefore affords additional scope here to accommodate

descriptions from clinical cases. Despite their methodological differences, case studies of the kind presented by Klonoff and Lage may, in conjunction with the stress-appraisal and coping theory, usefully augment the reader's empathic understanding of the difficulties faced after acquired brain injury.

Despite its phenomenological stance, the psychotherapeutic literature has also largely retained an objectivity akin to that of Goldstein that risks the criticisms made earlier from a social constructivist perspective. Prigatano (1999) partially redresses this balance by advocating phenomenological inquiries from subjective accounts (e.g., LaBaw, 1969) though his writings have yet to assimilate the more systematic qualitative analysis of subjectivity provided, for example, by Crisp (1993) or Krefting (1989). Despite a largely quantitative stance, Kendal and Terry (1996) and Kendal et al. (2001) do draw upon qualitative studies and thus to some extent have begun to bridge the paradigmatic divide between systematic qualitative and quantitative investigations. Accordingly, qualitative research has the advantage of accessing the individual's subjective meanings of changes brought on by acquired brain injury, rather than forcing people's experiences through theories at risk of social construction and pre-determination by the scientific or psychotherapeutic communities (Stainton-Rogers & Rogers 1997). On the other hand, the advantage of quantitative research efforts lies in their attempts to establish reliable theoretical relationships between beliefs or behaviour, and emotional difficulties that may be outside the individual's awareness. Accordingly the stress-appraisal and coping research has begun to operationalise the complex relationship between the individual's subjective appraisal, attempts to cope with demands after acquired brain injury and related emotional outcomes. The catastrophic reaction model has by comparison lacked clarity and comprehensiveness on the nature and incidence of such relationships. The character of the individual's appraisal of threat was only briefly implied by Goldstein (1952) as a real or imagined evaluation, and he alluded to the active and passive avoidance of catastrophic situations akin to the definition of emotion focused coping made by Kendal et al. (2001). Yet despite these similarities to the processes operationalised by Lazarus and Folkman's (1984) theory, Goldstein's descriptions are generally less concrete.

less detailed, and have not been revisited by later writers who have employed the catastrophic reaction model.

Sacks (1995) comments that the neurology texts of his own studies neglected Goldstein's writings, due mainly to their lack of a philosophical basis. The stress-appraisal and coping literature may be at a similar disadvantage through their lack of emphasis upon the underlying existential and holistic philosophies of the kind presented by Goldstein (1939), Prigatano, (1991) and Klonof and Lage (1991). The threat made to one's existence and the accompanying implications for one's self-concept is only briefly reflected by Kendal et al's (1996; 2001) reference to Nadell's (1991) application of existential theory and Yoshida's (1993) discussion of self-concept after spinal cord injuries. It may be proposed therefore that, by giving the insider's meanings of changes to their self-concept a greater priority, the reader is enabled to place emotional reactions to acquired brain injury within a wider holistic context. Otherwise, without reference to a unifying philosophy, the characteristic processes of adjustment after acquired brain injury are in danger of becoming lost under a mass of statistical methods and multitude of isolated facts. Curran, Ponsford and Crowe (2001), for instance, describe anxiety as an emotional 'outcome' of non-productive coping. They therefore inadvertently lose the central role of anxiety in adjustment, as proposed by Goldstein (1939) and supported by the findings of van Zomeren and van den Burg (1985) and Hinckleday and Corrigan (1990).

### Coping and Avoidance

A principal feature shared by the two literatures is their consideration of emotional difficulties as subsequent to organic impairment. Organic impairment is the underlying factor that makes achievement of tasks more difficult after brain injury, but conceptualisations of the nature of this impairment have differed since Goldstein's (1939; 1952) formulation. Goldstein attributed the underlying organic impairment to a loss of abstract attitude. Conversely, van Zomeren, Brouwer and Deelman (1984) attributed difficulties to a reduced speed of information processing, hindered further by memory difficulties. Furthermore, van Zomeren et al. (1984; 1985) explain subsequent 'intolerances' as due to the individual's persistence in

attempting to cope with deficits. Goldstein, however, emphasised avoidance of becoming overwhelmed with anxiety and the associated impact that failure has on one's self-concept, but did not suggest a perseverance of effort or indicate how many failures would be tolerated before being replaced by an avoidant strategy. Likewise, van Zomeren et al. make no reference to the experience of failure; intolerances are simply attributed to chronic compensatory effort. The temporal patterns of both accounts are thus contradictory and require clarification of their shared coping characteristics and precipitating factors. Until this point both literatures nevertheless emphasise participation in activities commensurate with the individual's personal standards, and therefore represent their struggle to maintain pre-morbid life styles. Goldstein's (1939) emphasis on the propensity for avoidance coping in people with acquired brain injury was empirically supported by Hinckleday and Corrigan's (1990) replication of van Zomeren and van den Burg's findings, and by subsequent research employing coping strategy questionnaires; this has galvanised a model that may predict difficulties in adjusting to brain injury. Like Goldstein's model, Lazarus and Folkman (1984) acknowledge the role of avoidance coping as the individual's attempt to prevent from becoming overwhelmed. However, the consideration of failure as an antecedent to avoidance coping has received less emphasis than within the catastrophic reaction model and appears not to be implicated within stress-appraisal and coping models. Still more, the catastrophic reaction model and research on stress-appraisal and coping share indistinct descriptions of what people with acquired brain injury might find threatening, or have failed at, and have therefore preferred to avoid.

Both literatures have associated emotional difficulties with the fundamental presence of anxiety; Goldstein (1939; 1952) from an existential perspective, van Zomeren and van den Burg (1985) from an empirically driven model. van Zomeren et al. (1984; 1985) and Hinckleday and Corrigan (1990) do not go on to analyse factors that might predict variance of the intolerances identified and therefore share with Goldstein a lack of consideration of the individual differences that might predict who has higher rates of intolerances and avoidance. To some extent this has since been redressed by Prigatano (1999), Klonoff and Lage (1991) and Smith and Godfrey's (1995) discussions of the catastrophic reaction, although as argued,

much confirmatory analyses are required. For example, the pre-morbid strive for excellence as postulated by Klonoff and Lage has not been directly tested for its detrimental effects in relation to coping strategies. Similarly, this may also be a factor that would predict the persistence of an individual's efforts to compensate for post-injury deficits, as briefly suggested by van Zomeren *et al.* Likewise, the stress-appraisal and coping literature has yet to fully substantiate who exactly may be vulnerable to cope by avoidance or why, though, as discussed, appraisal of one's personal resources and social support are postulated. A comprehensive investigation may also consider life-span developmental factors in relation to adjustment. Associations have been made for instance between the resurgent interest in styles of attachment (Bowlby, 1969; 1973; 1980) and adjustment to episodes of psychosis (Drayton, Birchwood & Trower, 1998), post-traumatic stress disorder and psychopathology (Pielage, Gerlsma & Shaap, 2000). Similar hypotheses may be investigated for variability within adjustment following acquired brain injury, coping and the catastrophic reaction.

Goldstein (1939) conceptualised avoidance of further catastrophic reactions as a protective mechanism, achieved through the shrinking of one's milieu to that which may be coped with after acquired brain injury. Yet he also later implied a negative, longer term consequence (Goldstein, 1952) whereby the resultant withdrawal may lead to depression. It is here particularly where the stress-appraisal and coping literature has advanced understandings of avoidance coping by accounting for individual differences in distress based on the strategy of coping employed. It has therefore identified factors, other than the pre-morbid difficulties proposed by the psychotherapeutic literature, which predict emotional adjustment after injury. Further advances in understanding individual differences have also been suggested by Finset and Andersson (2000) and Ownsworth and Oei's (1998) identification of left hemisphere lesions in predicting depression. This factor appears, however, to operate in interaction with avoidant coping styles and is not therefore a necessary condition of depression after acquired brain injury.

It appears that both literatures have yet to consider the stages of change models associated with loss or stressful events (i.e., Kubler-Ross, 1981; Horowitz, Filed & Classen, 1993; see also Meredith & Rassa's [1999] discussion in the context of traumatic brain injury). These

models typically incorporate initial patterns of avoidance strategies (particularly denial), a depressive stage and periods of facing up to and working through a loss or difficulty. Accordingly, Lezak's (1987) findings suggest that, after peaking at around 7-12 months post injury, the incidence of depression (and severe anxiety) declines significantly. A lack of further discussion here may be due in part to a lack of prospective studies and a general lack of clarity as to why a particular phenomenon, such as elevated depression or anxiety, might be no more than an expected stage by which the individual passes through, and not pathological. Malia, Torode and Powell (1993), for instance, report unpublished findings to suggest that coping by denial is a protective factor in the early stages after traumatic injury.

It is argued that both bodies of literature also require expansion upon the social aspects of acquired brain injury, particularly the social impact of disability upon the individual. Prigatano (1988; 1999) and Klonoff *et al.* (1991; 1993) progress social aspects of the catastrophic reaction from that of Goldstein's (1939; 1942; 1952) writings. It has been argued, however, that this has largely remained within an intrapsychic rather than interpersonal framework. The effects of social support on the catastrophic reaction model, as therapeutically recommended by Smith and Godfrey (1995), are not emphasised by Goldstein or the psychotherapeutic literature. Likewise, the stress-appraisal and coping theory, though sufficient in its scope, has yet to fully investigate the effects of social-support on the coping strategies of people with acquired brain injuries.

### Therapeutic Derivations of Models and Theories Reviewed.

It has been argued that the writings of Prigatano (1988;1991; 1999) and Klonof and Lage (1991;1993) have developed a therapeutic nucleus based on the catastrophic reaction's existential quandary. Prigatano, in particular, appears to have adopted Jung's (1933) model of individuation to incorporate the notion of existential hope, a polarity overlooked by Goldstein's (1939) theory but which is proposed to provide conceptual balance to that of anxiety. Applications of the stress-appraisal and coping literature to people with brain injuries by contrast have made fewer therapeutic proposals. Although issues of optimism, hopefulness and control are suggested (Curran *et al.*, 2001; Kendal *et al.*, 1996; Moore & Stambrook, 1995), this is done from a prescriptive intuitive basis, rather than being grounded

in a coherent philosophical account. de Ridder and Schreurs (1996) argue that coping, as formulated by the stress-appraisal and coping theory, does not necessarily improve emotional well-being, but rather prevents an already bad situation from becoming worse. Indeed, fewer conclusions are drawn by research on uses of problem-focused or approach orientated coping. An exception is Kendal *et al's* (2001) proposition and execution of a more contextually sensitive methodology that does suggest a relationship between approach coping and better emotional well being. Thus, the therapeutic need for research to encompass the experience of threat after brain injury is suggested. The longer term effects of approach coping to chronic stressors are however still unknown.

Finally, Klonoff and her associates (1991; 1993) present scenarios that describe a loss of hope due to threats made to an individual's existence after traumatic brain injury. These themes may also usefully relate to the loss of control, passivity and lack of hope associated with the reformulated learned helplessness model of depression (Abramson, Seligman & Teasdale, 1978). Learned-helplessness also bears similarities to the processes of anxiety that lead to depression after experiencing failure, as described by the catastrophic reaction model (Goldstein, 1952). Moore and Stambrook (1995) present the only, albeit brief, discussion of learned helplessness in the acquired brain injury literature by stressing the self-limiting beliefs of hopelessness and helplessness, and subsequent passivity that may be brought on by events after acquired brain injury. This deserves further emphasis given the potential of the stress-appraisal and coping model, and that of learned helplessness, to inform therapeutic understanding, particularly within the cognitive-behavioural framework proposed by Smith and Godfrey (1995).

The importance of hope in coping and adjusting to events following acquired brain injury may be exemplified by the maxim provided by Neitzsche: 'He who has a why to live for can bear with almost any how,' (cf. Frankle, 1963). In a similar vein, F.R. Linge (1980; 1990), a Canadian psychologist who had managed to resume his work after himself sustaining a severe traumatic brain injury provides the following rationalisation:

"When I meet a person with brain damage, I do not look first at the medical history or the testing that has been done. I look first for the presence in them or their family of a quality that could be called guts, the fighting spirit, or faith. With it we have a foundation on which we can build. Without it, full return to productive, giving, growing personhood is slower or impossible.

Sadly, I meet people whose brain damage is minimal, yet who lack this spirit and who cease to grow. Perhaps this is because the faith they had was extinguished at the beginning, or perhaps because their families' motivation to help was also snuffed out," (Linge 1990; also cited in Kapur, 1997; p.331).

Thus from a unique insider's perspective, Linge reflects the lack of relationship between an acquired brain injury and rates of subsequent adjustment, but also the need to avoid the passivity or avoidance that has been associated with findings from the stress-appraisal and coping research and the catastrophic reaction model. Ultimately, Linge attributes personal growth after injury to the secondary appraisal type processes of individual self-efficacy, the presence of hope akin to that of Prigatano's (1999) writings, and to the support of others that has so far been underemphasised in the literatures reviewed here. Research, particularly quantitative studies on the outcome of acquired brain injury, may benefit from the identification of coping factors that may represent, and predict, the notion of 'personal growth' after acquired brain injury. This might provide a useful adjunct and antidote to their otherwise principal focus upon an amelioration of difficulties.

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# Main Paper

Self-reported threat-appraisal and avoidance following traumatic brain injury: An exploration of their nature and relationship to anxiety, depression and quality of life

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#### Abstract

The present study explored the nature and incidence of threat-appraisals related to avoidance coping following traumatic brain injury (TBI). A preliminary qualitative study was employed to identify the subjective nature of threats that may lead to avoidance. This informed the development of a structured interview that assessed four main categories of threat-appraisals and related avoidance for the main study; 'Personal Safety', 'Dealing with People', 'Doing Things' and a second, 'Particular Activities', section. 50 people with TBI were assessed for the second main phase of the study. Substantial rates of threat-appraisal and avoidance were found, with a reasonable predictive relationship between them. It was, however, evident that threat-appraisals were also often endorsed without avoidance; possible reasons for this are discussed. Threat-appraisals and avoidance related significantly to the adjustment factors of anxiety, depression and quality of life. Additional regression analyses revealed particularly strong relationships to adjustment by the threat-appraisals associated with 'Personal Safety' and, above all, avoidance of social situations ('Dealing with People'). Marginal support was found for a weaker hypothesised relationship between avoidance and adjustment in the early stages of injury (0.83 -2.16 years) than in later stages following injury (16-32 years). A post hoc exploratory path analysis suggested that avoidance appeared to mediate the relationship between threat-appraisals and adjustment factors. Clinical implications and suggestions for future research are discussed.

#### Introduction

By any standards, traumatic brain injury (TBI) presents a major life event and challenge to the individual as he or she attempts to adjust to the abrupt onset of compromised capacities and altered relationships with their social, familial and material environment. Specific difficulties may be manifest in a reduced speed and efficiency of information processing (van Zomeren, Brouwer & Deelman, 1984), learning and memory difficulties (Brooks, Campsie, Symington, Beattie & McKinlay, 1987; Brown & Nell, 1992; Oddy, Humphrey & Uttley, 1978; Ponsford, Olver & Curran, 1995), distractibility (Posner, 1987), and difficulties in organisation and problem solving (Ponsford, Sloan & Snow, 1995). Much has been learned about these organically related cognitive sequelae of TBI, and their recovery over time. But contemporary understandings of the aetiology of emotional and behavioural difficulties associated with TBI remain comparatively neglected (Hanks, Temkin, Machamer & Dikmen, 1999).

The initial severity of injury is likely to be a major factor in any subsequent psychosocial outcome after TBI. Yet, attempts to establish a relationship between the neurological profiles resulting from TBI with subsequent emotional or psychosocial adjustment have yielded inconsistent findings (Kendall & Terry, 1995; Prigatano, 1992; Garske & Thomas, 1992; Jorge, Robinson, Arndt, Forrester & Starkstein, 1993; Dikmen, Ross, Machamer & Temkin, 1995). It is therefore important for research to identify additional factors relating to individual differences in adjustment after TBI.

Psychological models of coping after brain injury place an emphasis upon the individual's emotional reaction to their changed circumstances. Such reactions have been construed as indirect and subsequent to organic damage by Goldstein's (1939; 1942; 1952; 1971) holistic theory of adjustment, based on phenomenological observation, and van Zomeren, Brouwer and Deelman (1984) and van Zomeren and van den Burg's (1985) empirically driven investigations. Goldstein's catastrophic reaction model puts forward the idea that people with TBI will become overwhelmed by environmental demands due to the organic compromise of capacities brought on by injury, particularly impairment of the abstract attitude (see Brennan, 2002; this volume). The catastrophic reaction specifically occurs when the individual cannot accomplish a task that before their injury was accomplished with ease. The catastrophic

reaction is an expression of extreme anxiety owing to the threat that failure places upon one's core self-concept, constructed from pre-injury experience. They may therefore avoid further situations that precipitate this reaction in order to protect against future overwhelm, and the deleterious impact of failure upon one's self-esteem. Goldstein (1952) briefly alludes to the possibility that the state of withdrawal brought on by avoidance of the catastrophic reaction may precipitate depression.

In contrast to Goldstein (1939; 1942; 1952), van Zomeren, Brouwer and Deelman's (1984) 'coping hypothesis' proposes that the primary effect of organic impairment after brain injury is a reduction of processing speed, further hindered by memory difficulties. By employing factor analytic techniques, van Zomeren and van den Burg (1985) identify two classes of complaint after brain injury: those that were directly related to organic impairment, such as forgetfulness and concentration difficulties, and those that resulted from a reaction to these difficulties, described by the authors as 'intolerances' (p.27). These included a loss of initiative, irritability, fatigue, depressed mood, indifference, crying more, an increased need for sleep, headache, and intolerances of noise and light. The intolerances were hypothesised to result from an individual's over-expenditure of chronic effort in coping with demands after brain injury. Similar to Goldstein's theory, van Zomeren and van den Burg found that the subsequent emotional reactions were not predicted by the severity of injury but all related to a fundamental presence of anxiety. Still more, consistent with the catastrophic reaction model, van Zomeren, Brouwer and Deelman (1984) propose that the individual's effort is driven by their yearning to maintain pre-morbid lifestyle levels.

However, van Zomeren et al. (1984; 1985) do not discuss further the implications of failure, and avoidance of situations appraised as threatening, as did Goldstein (1939; 1942; 1952). On the other hand, Goldstein's model does not imply a persistence of effort that relates to emotional difficulties. Nevertheless, taken together it may be surmised from these models that anxiety is invoked by the consequential reduction of self-esteem and confidence after experiencing failure when attempting to resume activities post injury. As yet more hindrances are experienced, the ensuing anxiety will further affect performance and

confidence, and continue to exacerbate anxiety in a self-perpetuating cycle. Eventually, effort may discontinue and therefore lead to the withdrawal described by Goldstein (1952). Moore and Stambrook (1995) also suggest that it may lead to hopelessness and passivity associated with the learned helplessness cycle in models of depression. Broadly, learned helplessness may become manifest when one perceives that their actions (e.g., working hard) does not lead to the expected outcome (Abramson, Seligman & Teasdale, 1978).

Hinckleday and Corrigan (1990) successfully replicated the findings of van Zomeren and van den Burg (1985), and incorporated an additional measure from research on the stressappraisal and coping theory. The authors partially bridged the divide between the coping models of Goldstein (1939; 1942; 1952) and van Zomeren and colleagues (1984; 1985) by demonstrating that avoidance coping was found in their sample to have exceeded the figures reported by Moos, Cronkite, Billing and Finney's (1984) non-clinical standardisation of the coping measure employed. Goldstein's (1939) contention that there is a propensity of avoidance coping in populations of people with TBI was thus echoed. Hinckleday and Corrigan commented further that the avoidance coping responses reported by their sample are maladaptive, although no further analysis of their relationship to adjustment was reported.

Overall, the models of Goldstein (1939; 1942, 1952) and van Zomeren and colleagues (1984; 1985) provide an account of the presence of reactive emotional coping processes that are independent from organic deficit. However, these are single accounts, applicable to all, and they fail to provide analyses of individual differences that may help identify the vulnerability factors leading to emotional difficulties after TBI. For example, Hinckleday and Corrigan's (1990) figures on avoidance coping, and their suggestion that it is counterproductive to well-being would further imply that not everyone in their sample reported a reliance upon avoidance strategies and were therefore less vulnerable to adjustment difficulties.

A potential avenue with which to investigate individual differences has been through applications of the stress-appraisal and coping theory (Lazarus & Folkman, 1984) to adjustment after TBI (Kendal & Terry, 1996; Godfrey, Knight & Partridge, 1996; Martelli, Zasler & MacMillan, 1998). It has been argued (Brennan, 2002; this volume) that the stressappraisal and coping research on adjustment to acquired brain injury (ABI1) has established a relationship between frequency of reported avoidance coping strategies and negative indices of outcome typically represented by measures of emotion, such as anxiety or depression (Moore, Stambrook & Peters, 1989; Moore & Stambrook, 1994; Malia, Powell & Torode, 1995; Curran, Ponsford & Crowe, 2001; Finset & Andersson, 2000; Kendal, Shum, Lack, Bull & Fee, 2001). Malia et al. (1995) and Curran, Ponsford and Crowe (2001) also report findings that suggest the similarities of coping strategies between groups of participants with acquired brain injuries, and their relationship to adjustment, with control groups of participants who have other chronic health conditions, but without a cognitive impairment. Moos and Scheafer's (1993) review of the pertinent literature on adjustment to health related stressors concludes that a reliance on active strategies and less reliance on avoidance is generally an advantage for individual adjustment. The implication here is that the nature of coping is not significantly different for those with TBI than for other chronic difficulties.

This relationship between avoidance coping and adjustment factors is consistent with alternative avenues of research in the TBI literature. From single case studies employing behaviour modification techniques in TBI rehabilitation, Alderman (1991), Youngson and Alderman (1994), and Mozzoni and Hartnedy (2000) report interventions that targeted avoidance and escape behaviour to facilitate improved community integration. Avoidance is also an inherent factor in the syndrome of post-traumatic stress-disorder (PTSD). Bryant (2001) disputes the claims of Sbordone and Liter (1995) that the syndrome of post-traumatic stress disorder cannot co-exist with traumatic brain injury. These claims are due to the conceptualisation of PTSD that states an impaired consciousness does not allow for an explicit memory of the event and hence an avoidance of environmental reminders and memory flashbacks. Bryant argues that PTSD can however become manifest through implicit memory, fear conditioning and the individual's attempt to construct a memory of the event. He further proposes that additional stressors after the injury can contribute to the development of PTSD and thus compound an individual's anxiety. This proposal challenges the traditional concept of PTSD, in its strictest sense, that regards its aetiology in relation to a specific

Where necessary, mixed aetiological samples of TBI, stroke and hypoxia are labeled 'acquired brain injury' (ABI).

stressor. Bryant's proposed criteria does not, however, imply that PTSD is a necessary and sufficient condition for avoidance coping after TBI. Nevertheless, the implications are that post-traumatic stress may be alleviated after a restriction of avoidance strategies, and would therefore allow for more adaptive problem solving strategies to be employed (Valentiner, Foa, Riggs & Gershuny, 1996; Warda & Bryant, 1998; cf. Bryant, 2001).

Despite the sizeable body of literature that associates avoidance coping strategies with poorer outcome there are, however, several caveats that remain to be addressed. The stressappraisal and coping research discussed above has mainly assessed the frequency of coping strategies enacted when under stress, but not the demands that people with TBI might appraise as stressful. For example, the avoidance coping strategies associated with adjustment difficulties are indicated by the endorsement of statements such as; 'kept my feelings to myself', 'thought about fantastic or unreal things that made me feel better'; 'avoided being with people in general'; and 'slept more than usual' (Revised Ways of Coping Scale: Lazarus and Folkman, 1984). These may inform us about which type of avoidance strategy has been employed, how often an avoidance strategy is employed but not what has been avoided, or indeed why.

Lazarus and Folkman's (1984) stress-appraisal and coping theory does however postulate why people might adopt a certain coping strategy in the context of their appraisal of whether a situation is relevant or important (primary appraisal) and if so, the appraisal of one's personal resources (secondary appraisal) that determines whether and what coping strategy is mobilised (see Brennan, 2002; this volume). Accordingly Moore and Stambrook (1995) present a framework loosely conceptualised along these lines for adjustment to TBI that accommodates the processes of primary appraisal, secondary appraisal, coping and emotional outcome (see Brennan, 2002; this volume). However, Moore and Stambrook's framework is conceptualised from the results of a series of studies, and the link between primary appraisal. coping and adjustment was not directly tested. The infrequency of investigations of the relationship between appraisal and coping also appears to hold true for the literature on coping outside the field of traumatic brain injury (de Ridder & Schreurs, 2001). Furthermore, the self-report measures typically employed in stress-appraisal and coping research are

generally centred on the questions asked by the researcher, and not centred upon the concerns of the individual being asked. Thus, most measures that have been employed in stressappraisal and coping research are not specific to people with TBI.

The generally negative connotations associated with avoidance strategies of coping may however be over-generalised and therefore misleading. For example, Lazarus and Folkman's (1984) framework emphasises the adaptive benefits of employing a range of coping strategies, of which avoidance may be used in the short term for the regulation of affect. Consistent with this more dynamic conceptualisation, Kendal, Lack, Bull, Shum and Fee (2001; also described below) suggest that a 'rigid' (repeated frequent uses of strategies) use of avoidance coping is less of an advantage than 'flexible' (a use of mixed, less frequent, strategies) avoidance after traumatic brain injury. Additionally, Malia, Torode and Powell (1993) report unpublished findings to suggest that denial may be a protective factor in the first two years post-TBI. Models of the processes involved in adaptation to trauma also generally postulate a role for protective factors in the early stages of adjustment. These typically involve an initial phase of denial or avoidance, and are followed by a period of integration of the changes brought on by the trauma, but with a concomitant depression (see for instance Horowitz, Field & Classen, 1992; Kubler-Ross, 1980; Meredith & Rassa, 1999).

The nature of outcome employed by the stress-appraisal and coping research on ABI adjustment have mainly been represented by loose conceptualisations of 'psychosocial' in the absence of any further definition (e.g., Malia et al., 1995; Kendal & Terry, 1996; see Brennan, 2002, this volume) or by measures of anxiety and depression (Curran et al., 2001). Rates of anxiety and depression have been found at high levels and for prolonged periods following TBI (Olver, Ponsford & Curran, 1996; Morton & Wheman, 1995; cf. Curran et al., 2001). Although the relationship between anxiety and TBI has been conceptualised in Goldstein's (1939; 1952) and van Zomeren and colleague's (1984;1985) writings (see above) as a fundamental element of the reaction to intellectual impairment, it has since generally been explored for its relation to TBI as an index of emotional (or 'psychosocial', cf. Kendal and Terry, 1996) outcome but in the absence of models that explain its process (e.g., Curran et al., 2001). However, it may be conceptually argued that avoidance is intrinsically intertwined

and mutually maintained by a cycle of anxiety (e.g., Mowrer 1939; Rachman, 1984), and is therefore already an element of the proposed outcome. That is to say, some of the same processes may be present in measures of both avoidance coping and anxiety. Similarly, Curran et al. report findings of a relationship between anxiety and non-productive coping that is partly characterised by 'worry' (p.1270). Still more, the withdrawal associated with depression may also converge with measures of avoidance coping, rather than be a statistically related but different phenomena (Finset & Andersson, 2000).

Although anxiety and depression are significant factors with which to gauge an individual's current emotional adjustment, it may also be useful for outcome to be measured by a distinct index rather than elements of distress that may be difficult to disentangle from the use of avoidant coping. Individuals' perceptions of their quality of life may therefore merit some investigation. Quality of life has not so far been employed in stress-appraisal and coping models with people with TBI although it has been used in a variety of other TBI outcome studies (e.g., Hibbard, Gordon, Flanagan, Haddad & Labinsky, 2000; Steadman-Pare, Colantonio, Ratcliffe, Chase & Verniche, 2001; Collins, Lanham & Sigford, 2000). A single definition of 'quality of life' has yet to be agreed, but the extent of current consensus is that it is, at least, multi-dimensional in nature (Buck, Jacoby, Massey & Ford, 2000). Factors of quality of life include health status, socio-economic factors and social activity or support (Kearney, Plax & Lentz, 1985; Larson, 1978). Quality of life is considered to be an increasingly important healthcare measure for its evaluation of quality, in addition to traditional quantity measures of survival (Gill & Feinstein, 1994; Testa & Nackley, 1994; Furher, 1994; King, 1996; Fallowfield, 1990; Buck et al., 2000). The World Health Organisation's Quality of Life Group (WHOQOL Group, 1998) provide a recent definition as the individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectation, standards and concerns (cf. Buck et al., 2000). Gill and Feinstein propose that the implication of the individual's values and preferences distinguishes quality of life from all other healthcare outcomes.

A general conclusion to be drawn from these points is that researchers have hardly begun to explore the implications of the stress and coping paradigm for people with traumatic brain

injury. Despite the considerable amount of research on establishing what types of coping are of benefit, or not, in the health psychology literature, there have been disappointingly few studies considering its implications for intervention (de Ridder & Schreurs, 2001). This appears to hold true for people with TBI. This is surprising given the paradigm's potential to inform clinical assessment and intervention and, in particular, its broad compatibility with the cognitive-behavioural therapies (de Ridder & Schreurs, 2001) that have intermittently been endorsed for people with brain injuries (Ponsford, Slone & Snow, 1995; Smith & Godfrey, 1995; Moore & Stambrook, 1995; Maliniak-Whitehouse, 1994; Montgomery, 1995; Butler & Satz, 1999; Cicerone, 1991). However, the lack of clinical application may be due, in part, to the literature's overly circumscribed focus upon the types and frequency of coping strategies used, rather than considering why these strategies are employed, and the use of measures that are not specific to people with TBI. This has so far largely been at the expense of additional identified moderating factors and person centred methodologies that may provide a better understanding about why, for instance, an avoidance coping strategy might be enacted.

Alternatives to the use of traditional methodologies may therefore be required. Accordingly, Kendal, Lack, Bull, Shum and Fee (2001) note the stress-appraisal and coping model's lack of 'goodness of fit' in explaining outcome after TBI. This they consider to be owing to a failure to produce a contextually sensitive analysis of coping. An inventive methodology for the elicitation of coping strategies was therefore developed to address this failure. This attempted to synthesise qualitative and quantitative methods in order to gauge the nature of coping and the demands specifically faced by people with TBI. Data was obtained from responses to video based scenarios that were deemed stressful from a preliminary qualitative focus group study of 5 people with TBI; this process was not however detailed. The scenarios included a memory difficulty, social rejection, denial of employment and refusal of a driving licence. Though the authors reported that participants in the main study (N=24) had rated the work scenario as the most stressful, an analysis of variance did not suggest significant differences in perceived levels of stress between scenarios; each scenario attained a 'moderate' mean rating of stressfulness from the sample. Threats associated with primary appraisal processes were therefore presented for which participants were asked how

they would cope with the situations. A rigid use (more frequent and repeated use across scenarios) of avoidance coping methods (labelled as passive emotion focused) was associated with lower self-esteem (consistent with secondary appraisal) and emotional adjustment. A frequent use of approach strategies were however associated with higher self-esteem, and social adjustment. Avoidance coping was reported significantly more often in the social and employment scenarios than for those relating to the driving and memory scenarios. Frequencies of reported approach coping strategies that intended to alter a problem situation did not differ across the scenarios.

This more sophisticated profile of coping found by Kendal et al's (2001) study underscores the advantage of evaluating the coping of people with TBI in relation to the demands of the particular situation. However, only four situations were addressed. Thus, although Kendal et al., demonstrate the need to consider the context of coping, the range of difficult situations appraised as threatening by people with TBI continue to remain largely underrepresented in the research literature. In sum, although propounded models of coping after TBI (e.g., Goldstein 1939; 1952; van Zomeren et al., 1984, Kendal & Terry, 1996; Godfrey, Knight & Partridge, 1996; Martelli, Zasler & MacMillan, 1998) generally emphasise emotional reactivity within the context of demands made after injury, related research has so far failed to describe the phenomenology of such demands, particularly from the subjective appraisals of problems encountered by people with TBI in the context of their coping. Appraisals of threat following TBI have however been reported in the qualitative literature. These have typically included themes of threat associated with discrimination and stigmatisation (Crisp, 1993; Krefting, 1989; Nochi, 1998). As no quantitative studies have so far examined such themes, it would therefore seem that the subjective threat-appraisals of what people with TBI find difficult and therefore avoid, and how these may relate to emotional factors of adjustment or quality of life, would merit further investigation.

Primary appraisals made during stressful situations, as formulated by Lazarus and Folkman (1987) can be of four types: harm/loss, threat and challenge. However, threatappraisal specifically refers to anticipated harm, loss or damage and may therefore lead to avoidance. Threat may be appraised, for instance, from the possibility of an assault and

physical injury, or to the frustration caused by a memory lapse and the resulting impact upon one's confidence.

## **Study Aims**

To address some of the conceptual and methodological shortcomings of previous research, the main aims of the present study attempted to address the following two areas. First, previous research has identified that avoidance is a relatively frequent coping strategy after TBI. It has also identified an association between this strategy and negative indices of outcome, though Malia et al. (1993) and Kendal et al. (2001) suggest that there may be a more complex relationship between the two. Second, previous research findings have had little to say about the kinds of situations that may be avoided after TBI; what it is about these situations that people find threatening; and why some individuals will respond to the threat by avoidance but others will not. Perhaps because of these disparities, applications of the stress-appraisal and coping theory has not, as yet, had a significant impact upon intervention work in TBI rehabilitation. For instance if we know more about what people find threatening, we may have a clearer idea of how to develop an intervention that may help to overcome related emotional difficulties.

Thus, in sum, the present study aimed to address these neglected issues by investigating a) the threat-appraisals that may lead to avoidance following TBI, b) the frequency of avoidance in relation to threat-appraisals, and c) the relation of threat-appraisals and avoidance to emotional adjustment. The following specific research questions were therefore generated:

- 1. What are the relative frequencies, shared by a representative sample of participants, with which specific threat-appraisals are made?
- 2. How predictive of avoidance are these appraisals of threat? That is, to what extent do people limit their participation because of these appraisals?
- 3. What kinds of situations are avoided owing to a loss of confidence (threat-appraisals) after TBI?
- 4. What is it about these situations that people appraise as potential threats?

- 5. What might mitigate the effect of these appraisals on avoidance? Specifically, are those who employ approach coping strategies less likely to avoid, despite their appraisal of threat?
- 6. What is the relationship between appraisal of threat, avoidance, emotional adjustment and quality of life? On the basis of previous research it is hypothesised that, overall, higher frequencies of threat-appraisals and avoidance will predict negative indices of anxiety, depression and quality of life. This relationship may however be weaker for those in the earlier stages of adjustment to the injury (e.g., Malia et al., 1993).

A variety of methods were employed to address these questions. Questions 1-4 were addressed by two stages. Kendall and Terry (1996) recommend the use of focus groups and qualitative interviews to elicit the specific appraisals and coping efforts of people with TBI. Accordingly, in the first stage, a qualitative methodology using focus groups and individual interviews employed a preliminary thematic analysis (see Dey, 1993) of the threat-appraisals reported by people with generic acquired brain injuries, including people with TBI and stroke. This phase also included professionals and family members of people with acquired brain injuries. This was combined with a review of available personal accounts of ABI in the literature, and a feedback session between the author and two clinical rehabilitation psychologists on the qualitative data obtained. The thematic analysis was used to create categories of situations that may be avoided because of a lack of confidence. It also generated an inventory of what people found threatening within these situations. On the basis of this data, a structured interview was devised. Structured interviews with people with brain injuries have been demonstrated as a viable research methodology by previous research (Fleming, Strong & Ashton, 1996; Ownsworth, McFarland & Young, 2000; Levine, van Horn & Curtis, 1993; van Horn, Levine & Curtis, 1992). Furthermore, aspects of emotionality following TBI have received increasing attention in the past fifteen years, particularly through investigations of the subjective experience of people with TBI (Teasdale et al., 1997), and as stated by van Zomeren and van den Burg (1985) the 'head injured patient can be viewed as a relative expert in the field of head injury' (p.21). The present interview asked whether the person had made a specific threat-appraisal, and whether they had avoided specific activities

because of the appraisal. In the main study, this interview was administered to an aetiologically homogeneous sample of 50 participants who had sustained a TBI. This served as a means to validate the outcome of the first qualitative stage. Data on the frequency with which specific threat-appraisals (TAs) were endorsed and specific activities avoided in this sample gave an indication of the extent to which they were shared by a significant number of those with TBI. This data is also of interest in providing a general indication of how serious a problem that a lack of confidence and avoidance are in this population.

Question 3 was addressed by asking whether or not the individual had avoided situations because of the specific TAs. This data was used to address the question of how predictive of avoidance these appraisals are. Question 5 was addressed by employing a coping measure from the stress-appraisal and coping literature that measured active approach coping strategies. The frequency of reports for this strategy was then tested in a correlation to establish whether or not more avoidance was related to less approach strategies, and vice versa. The coping measure was also to be used to provide an indication of the convergent validity between it and the structured interview's measure of avoidance. Question 6 was investigated with correlation statistics for the strength of relationships between, on the one hand, TAs and avoidance, and, on the other, indexes of emotional adjustment as measured by anxiety and depression, and outcome as represented by quality of life. Furthermore, regression analyses were employed to test the relative strengths of relationships between the sub-domains of TAs and avoidance in the structured interview to anxiety, depression and quality of life.

## Method

# Design

The main study employed a cross sectional survey design using descriptive, correlation and regression analyses with which to investigate the research aims. Prior to this, a brief preliminary qualitative investigation was conducted for the development of the quantitative measure.

## **Participants**

50 people (41 male and 9 female) with TBI who had specifically sustained a closed head injury were recruited to participate in the main study. Nobody in the sample had sustained a penetrating traumatic brain injury. All participants were recruited either from health service rehabilitation programmes or community day services for people with ABI<sup>2</sup>. People who had a minimum time period of 9 months since their injury were asked to volunteer. 3 people declined to take part in the study. A 9 month threshold time since injury was set in an attempt to ensure that the majority of cognitive recovery had taken place after closed head injury (Kolb & Wishaw, 1997). The minimum time since injury in the present sample was 10 months; maximum was 32 years ( $\underline{M} = 8.67$ ,  $\underline{SD} = 8.04$ ). 30 individuals sustained injuries as a result of road traffic accidents, 11 had falls, 6 had been assaulted, 2 had industrial accidents and 1 had a sporting accident. The ages of participants ranged from 18 - 67 years (M = 39.7, SD = 11.8). Ages at time of injury ranged from 15 - 58 years (M = 31.5, SD = 11.3). Length of education ranged from 10 - 16 years ( $\underline{M}$  = 12.24,  $\underline{SD}$  = 2.22). Socio-economic status at the time of injury was assessed according to the National Statistics Rating Scale (www.statistics.gov.uk/methods quality, 2002). This classifies socio-economic status according to employment criteria. Table 1 displays the categories and the frequency counts of the present sample. The analytic classes shown in Table 1 are those that have been designated by the National Statistics criteria to correspond with employment status.

Table 1. Socio-economic status of sample at time of injury.

Operational category	Analytic classes	Frequency of participants
Employers in large organisations	1.1	0
Higher professional occupations	1.2	3
Lower professionals and higher technical operations	2	4
Intermediate occupations	3	4
Employers in small organisations	4	4
Lower supervisory occupations	5	6
Semi routine occupations	6	13
Routine occupations	7	3
Never worked and long term unemployed	8	3
Full time students	L15	10

<sup>&</sup>lt;sup>2</sup> Ethical approval granted for study. Confirmation letters shown in Appendix B. Correspondence letters sent to organisations shown in Appendix C.

Indicators of injury severity, such as the Glasgow Coma Scale (GCS; Teasdale & Jennett, 1974) or Post Traumatic Amnesia (PTA) were largely absent from available health records as most participants were recruited from post-acute care settings. 15 GCS scores were obtained ranging from 3-13 ( $\underline{M} = 5.4$ ,  $\underline{SD} = 2.53$ ). 'Mild' head injuries have scores 12 or more on hospital admission, moderate injury ranges from scores of 9-11, and severe injury is rated from scores of 8 or less. All except one participant had GCS scores indicating a severe injury. 7 PTA scores were obtained ranging from 1 month to 6 months (M = 3.14, SD = 2.11). Given the study's reliance on language based assessment, people who had expressive or receptive language difficulties were not approached for recruitment: if there was any doubt, the initial screening section of the Sheffield Test for Acquired Language Disorders (Syder, Body, Parker & Boddy, 1993) was administered. No participants were excluded on this basis.

The demographic character of this sample compares to the general TBI population in the following ways. In accordance with previous reports, road accidents were the main cause of injury (Kraus & McArthur, 1996; Rimel, Jane & Bond, 1992). Likewise, falls appear to be the next major cause of injury (Rimel et al., 1992). Assaults are also a major cause of closed head injury, although figures for these appear to vary between countries (Rimel et al., 1992). Females are somewhat underrepresented in the present sample at a ratio of 5.5:1, compared to the available figures from population-based US studies that vary between 2.0:1 and 2.8:1 (Kraus & McArthur, 1996). The age group at highest risk of head injury is considered to be between 15 and 24 years. Thus, the mean age at injury of the present sample is six years older than the upper limits of the highest risk group. The sample's mean age at participation in the present study is a little more consistent with the stress-appraisal and coping research with people with ABI that has ranged between 27.4 (Malia et al., 1995) to 38.6 years (Finset & Andersson, 2000). These studies do not however report ages at time of injury. Length of education in the present sample appears somewhat longer than US based population estimates (Rimel et al., 1992) of 50% between 8-12 years (62% between 10-12 years in present sample) and 25% with 12 years or more (38% for current sample). None of the present sample reported a length of education below 10 years, as reported in Rimel et al's US based figures. The socio-economic scale used in the present study is not strictly comparable to previous

figures. However, Rimel et al., report figures to suggest that students and lower socioeconomic groups are at higher risk of TBI which may be reflected by the figures shown in Table 1.

## Measures

Appraisal of Threat and Avoidance Interview (ATAI; Appendix F). The structured interview was devised on the basis of the preliminary qualitative study. First hand accounts of people with ABI in the literature were accommodated (e.g., Buck, 1983; Freedman, 1987; Linge, 1980; 1990; Newborne, 1997; Quinn, 1998) in the study, as was a feedback session with two clinical rehabilitation psychologists who suggested additional items germane to the developed qualitative themes. Focus groups and individual interviews have been recommended for identifying the problems experienced by people with TBI (Kendal & Terry, 1996) and have been endorsed elsewhere for their benefits in the initial stages of questionnaire and survey design (O'Brien, 1993a; 1993b). The qualitative phase involved four focus groups: two groups of people with ABI (n=2 and n=3 [all male]), one group of professionals working with people with ABI in a rehabilitation service ( $\underline{n} = 10$ ), and one group of family members of people with ABI (n = 9). The groups consisting of professionals and family members were considered necessary to provide additional perspectives to those of people who, themselves, have sustained an ABI. To explain, in some cases a professional or family member may be able to pass comment whereas some individuals with ABI may not be so ready to generate examples of situations where they have a loss of confidence and avoid. For instance, without a more structured or private forum, the protection of one's self-esteem or the group format may prevent disclosure by some individuals. Individual supplementary interviews were carried out to augment the low numbers of participants with ABI in the focus groups (2 females and one male: See Appendix E for details of rationale, procedure, development of themes and an example of a focus group's transcript).

The qualitative study aimed to identify the types of situations that people with ABI might appraise as difficult since their injury and may therefore go on to avoid, and also what it was about those situations that might be appraised as threatening. The qualitative data was coded by reference to these two main aims. In relation to identifying what it was about the situations that was appraised as threatening, the data was further coded in accordance with a number of emergent themes. These themes were 1) dealing with people after injury; 2) issues of personal safety after injury; 3) particular activities where confidence may be lacking; 4) issues about doing things after injury; and 5) awkward situations experienced after injury. The categories of themes then directly informed the sub-domains of the structured interview. These aimed to assess a comprehensive range of possible sources of threat that people with TBI may go on to avoid. The developed sub-domains were labelled as 'Personal Safety' (8 items), 'Dealing with People' (20 items), 'Awkward Situations' (5 items) and 'Doing Things' (7 items). The second part of the interview was an inventory of 'Particular Activities' (26 items) that people may report having less confidence doing since their injury. The individual items that were informed by the qualitative data were selected for their face validity and for their apparent significance to the clinical experience in ABI rehabilitation of the two clinical rehabilitation psychologists, and that of the author. The items included in the ATAI have been cross-referenced in Appendix F to their source, whether that was a focus group, an individual interview, a personal account in the literature, or suggested by the feedback from the rehabilitation psychologists.

The interview was designed to minimise difficulties reportedly associated with interviewing people with intellectual difficulties. To address issues of reliability the main data analysis employed closed questions that used an either/or response format (Sigelman, Budd, Spanhel & Schoenrock, 1991; Lowe & De Paiva, 1988; cf. Ruddick, 1999). Furthermore, an open ended question was included within each sub domain so that issues raised by the participant, that were not already asked within the interview, could be noted (Atkinson, 1988; Flynn, 1988; cf. Ruddick, 1999). These responses are documented in Appendix Gvi. The interview also began with an open ended question to encourage engagement in the interview process (responses also in Appendix Gvi) and to help facilitate a deeper consideration of any losses of confidence and avoidance by participants.

The ATAI employed two lines of questioning. The first set of 41 items had two parts asking if a TA was identified as a concern (part a) and an accompanying question that asked if

the individual has avoided the situation (part b; i.e., going out, being with people, doing things) because of the TA. For example, part 'a' of item 36 states: "I sometimes get upset or frustrated if things go wrong when I'm doing something,". Part 'b' of this item asks: "Have you avoided doing jobs or hobbies because of this,"? The second question was therefore filtered; if the item was not identified as a concern then the associated avoidance question was not asked.

The ATAI consists of 41 items across the first four sub-domains in the first data section. In addition to the verbal presentation of the interview items, each of the first four sub-domains were presented to participants written on cards. These attempted to aid participants' memory for the items. Each item asked the participant to consider if it was true for them over the last month. If they answered 'yes', then a further filtered question asked if they had avoided a situation because of the TA. The second part of the interview, 'Particular Activities', employed a second line of filtered questioning for each item. This sought to assess the particular activities that people with brain injuries had less confidence in attempting, and therefore did less of since their injury; for example, shopping. The questions were as follows:

- a) Did you do this before the injury?
- b) Would you feel less confident about it now compared to how you felt before the injury?
- c) Do you do it less often now?
- d) Is your lack of confidence one of the reasons why you do it less often? If the respondent answered 'no' for questions a, b or c then the line of filtered questions was discontinued and the next item was asked. Responses to question d were subsequently employed for analysis of this part of the interview and re-labelled 'Reduced Confidence and Activities'.

Each item within all the sub-domains were scored on a dichotomous 'yes' 'no' basis to report a TA, or avoidance because of a TA, and scored '1' or '0' accordingly. Items were summed across the first four sub-domains to provide two scores; one for Overall TAs and one for Overall Avoidance. Sub-domains 1 – 4 were also similarly scored individually so that each provided a TA and Avoidance score. The second part of the interview, 'Particular

Activities', was scored separately and received one score based on question d and labelled 'Reduced Confidence and Activities' (see above).

The interview was piloted with four people who had had a stroke (three males; one female). Comments made by these participants and any difficulties experienced by the researcher were subsequently modified for the final version of the interview. This included an opportunity for clients to say if a TA used to be a concern for them, but was something they had managed to overcome. It was found that the wordings of 10 items had caused some misunderstanding for these participants and were therefore subsequently re-worded.

Quality of Life Index (QOLI; Ferrans and Powers, 1985; 1992; Appendix F). Ferrans and Powers (1992) define quality of life as a multidimensional construct of a 'person's well being that stems from satisfaction or dissatisfaction with areas of life that are important to him or her' (p.29). Versions of the QOLI are available for a range of health conditions including stroke. The 'stroke version' was initially developed for both people with stroke and people with head injury and (although not published) is therefore deemed appropriate for head injury (Ferrans, 2001, personal communication). It has been applied in one study with people with stroke (King, 1996) that reported an internal reliability of  $\underline{\alpha}$  = .91. It has not previously been used in a study for people with traumatic brain injuries since the original unreported standardisation. The QOLI is a two-part measure that rates 36 items for satisfaction (part 1) and for importance (part two). Four domains considered to constitute quality of life are assessed: 1) health and functioning 2) psychological and spiritual 3) social and economic and 4) family. Responses are scored on a Likert scale that range from 1 (very dissatisfied/very unimportant) to 6 (very satisfied/very important). Overall quality of life scores are calculated by weighting each satisfaction response with its paired importance response. Because of this weighting, scores reflect values as well as satisfaction in order to more accurately reflect quality of life. This weighting is accomplished by making the midpoint on the scale 0 after subtracting 3.5 from each satisfaction score. Each recoded satisfaction item score was multiplied by its paired importance score (possible range = -15 to 15). To calculate overall scores, weighted items were summed and, to account for missing data due to inapplicable questions, divided by the number of items answered. In order to eliminate negative values a

constant of 15 is added (formal instructions are detailed by the authors at www.uic.edu/orgs/qli/, 2002). The QOLI is administered by reading out questions in an interview style and marking verbal responses on the corresponding Likert scale (King, 1996; Buck et al., 2000).

Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983; Appendix F). The Hospital Anxiety and Depression Scale (HADS) comprises two subscales purporting to measure 7 self report items relating to anxiety and 7 items relating to depression. All items are measured on a 4 point scale (0-3), each unit corresponding to a response indicating a greater intensity or frequency of difficulty. On each scale individual scores of 0-7 are considered normal, 8-10 borderline, and a score of 11-21 indicates a clinical case. The HADS was originally developed to measure anxiety and depression without confounding by items that were also sensitive to physical difficulties in medical settings. No standardised scores have been reported with people with TBI. It has however been employed in three studies of people with closed head injury (King, 1996; 1999; Williams, Williams & Ghadiali, 1998). Sufficient test-retest reliability was originally reported by Zigmond and Snaith. For the depression sub-domain false positives and negatives were below 1%, and for the anxiety subdomain false positives were below 5% and false negatives were below 1%.

Coping Schedule (Tyler & Cushway, 1995; Appendix F). Coping strategies, akin to those formulated in the stress-appraisal and coping literature were assessed using the Coping Schedule. This is an adaptation of the Indices of Coping Responses from the Health and Daily Living Form (Moos, Cronkite, Billings & Finney, 1984). This was originally a 29 item inventory that has been employed in various adaptations and lengths (e.g., Billings & Moos, 1980). It was also the measure used in Hinckleday and Corrigan's (1990) investigation of coping strategies in people with TBI. The Coping Schedule, in its present form, was adapted by Tyler and Cushway (1995) as a 25 item measure used in an investigation of stress in nursing staff. Participants are asked to consider a time in their life when they have had a personal problem or have been under stress, and to indicate the frequency with which they used the methods of coping included in the measure. It is left open for participants to decide which problem is considered and which is not recorded. Responses are recorded on a four

point Likert scale ranging from 0 (not at all) to 3 (fairly often). The methods of coping assessed by the measure included 3 categories (see Appendix F for a breakdown). A category of 'Active Cognitive Coping', consisting of eight items, refers to the individual's attempts to analyse a problem (e.g., "Considered several alternatives for handling the problem,"). The category of 'Active Behavioural Coping' consists of eight items and indicates efforts to solve a problem (e.g., "Made a plan of action and followed it,"). 'Avoidance coping' comprises 8 items that reflect attempts to avoid thinking about the problem, getting involved in distracting activities and letting off steam (e.g., "Refused to believe it had happened,"). Tyler and Cushway did not report any standardisation figures for this measure. Likewise, Hinckleday and Corrigan reported no standardisation figures for participants with TBI on the Indices of Coping Responses.

### Procedure

Participants with closed head injury were recruited through services for people with acquired brain injuries. Potential volunteers were initially approached by staff known to them within their service. Brief details of the study were explained and a summary of the study's rationale and aims were provided on an information sheet (Appendix D). Additionally, this informed them of their ethical rights to withdraw from the study at any time and of their rights to confidentiality.

Participants were seen for assessment over a period lasting approximately between 45 minutes to 1hr 30minutes. Longer administrations were either allowed breaks or were conducted over two sessions during a week. On all occasions, participants were either interviewed in a private room within their service, or in a private room at their home. Consistent with administrations of the ATAI and QOLI, assessments based on the HADS and Coping Schedule questionnaires were conducted verbally in the same interview format, as were demographic questions. Participants completed all measures on all but four occasions. The second part of the interview, 'Particular Activities', was, due to time constraints, missing on two occasions. For the same reason, the HADS was not completed on two other occasions. These were entered into the analysis as missing data.

#### Results

## ATA1: Descriptive Findings

First, internal reliabilities using Cronbach's Alpha (α) were calculated for the Overall TA scale across sub-domains 1-4. This consisted of 41 items and yielded a high internal consistency ( $\alpha = .92$ ). The internal reliability of the Overall Avoidance scale, consisting of 41 items from domains 1-4, was similarly high ( $\underline{\alpha} = .94$ ). An internal reliability of  $\underline{\alpha} = 0.7$  and above is considered good (Kline, 2000). Table 2 shows the internal reliabilities calculated for the interview sub-domains consisting of TA items, and Avoidance items.

<u>Table 2</u>. Internal reliabilities ( $\alpha$ ) for overall scales and sub-domains for the ATAI (N= 50 & 48).

ATAI Section	Scale & Sub-domain	Internal Reliability ( <u>α</u> )	N
Part 1	Overall TA	0.92	50
	Overall Avoidance	0.94	50
	Personal Safety TA Sub-domain	0.73	50
	Personal Safety Avoidance Sub-domain	0.79	50
	Dealing with People TA Sub-domain	0.86	50
	Dealing with People Avoidance Sub-domain	0.92	50
	Awkward Situations TA Sub-domain	0.3	50
	Awkward Situations Avoidance Sub-domain	0.35	50
	Doing Things TA Sub-domain	0.87	50
	Doing Things Avoidance Sub-domain	0.92	50
Part 2	Particular Activities: Filtered Question a	0.56	48
	Particular Activities: Filtered Question b	0.82	48
	Particular Activities: Filtered Question c	0.81	48
	Particular Activities: Filtered Question d	0.84	48

It can be seen that most sub-domains had substantial internal reliabilities. However, for the third sub-domain, 'Awkward Situations', the internal reliabilities were insufficient at  $\alpha = 0.3$ and  $\alpha = 0.35$  for TAs and Avoidance respectively. This may have been due, in part, to the few items (5) in each scale. It may also be the case that the situations included in the 'Awkward Situations' were too disparate to constitute a single category. Though the descriptive statistics relating to the items for the 'Awkward Situations' TAs and Avoidance

scores will be reported, they were not included in further analyses. In the second section the 'Particular Activities' filtered question 'a' also showed a low reliability but this, unlike question 'd', was not required for later analysis.

<u>Study Aims: Question 1</u>. What are the relative frequencies, shared by a representative sample of participants, with which specific threat-appraisals are made? Descriptive statistics were employed to assess the relative frequencies of TAs reported and their associated Avoidance as assessed by the filtered line of questioning in sub-domains 1-4. Expressed as percentages, table 2 displays 1) the percentage of the whole sample (N=50) who identified with each TA item; 2) the percentage of the whole sample who reported Avoidance for each item; 3) the percentage of the sample reporting a TA item that reported Avoidance (i.e., of those who endorsed a particular TA, the percentage of those who also went on to report Avoidance due to the TA). The items are ranked in order of the proportion of the sample that reported Avoidance due to each TA item (column 3).

Table 3. Sub-domains, individual items, corresponding percentages of reported TAs, percentages of related Avoidance, and percentages of Avoidance when TAs reported (N=50).

TA Sub-domain and item	Percentage of whole sample reporting TA	Percentage of whole sample reporting avoidance	Percentage of those reporting TA who report avoidance
1. Personal Safety			
3. Sometimes I feel home is the only place where I'm safe.	42	22	52.4
5. With regards to electrical appliances, or sharp knives or	40	20	50
tools, I sometimes worry that I'm not safe to use them.  4. Sometimes I worry that, if I'm attacked, I won't be able to stick up for myself.	38	18	47.4
Sometimes I worry I might fall and injure myself while I'm out.	44	20	45.5
Sometimes I worry I might get attacked and injured while I'm out.	38	16	42.1
8. I sometimes worry that I might get another brain injury.	42	16	38.1
6. When crossing the road, I sometimes worry about getting knocked over.	46	14	30.4
7. When I am out, I sometimes worry that I might walk into someone, or that they might bump into me.	40	12	30
2. Dealing with People			
9. I sometimes worry that people will patronise me, or talk down to me.	52	32	61.5
25. Sometimes when I'm with people, I feel like I don't fit in.	58	34	58.6
16. I sometimes worry that people think there's something wrong with me.	42	12	57.1
12. I sometimes worry that people will get annoyed if I make mistakes, or take too long to do things.	52	18	53.8
10. I sometimes worry about getting tearful or upset in front of others.	26	14	53.8
29. I sometimes feel I would be uncomfortable meeting people I haven't seen since the injury.	40	20	50
13. I sometimes think that people will laugh at me.	38	18	47.4
24. I sometimes feel that I'm not very good company.	62	28	45.2
17. I sometimes feel less sexually attractive since the brain injury.	48	20	41.7
28. I sometimes worry that people think I'm stupid.	44	18	40.9
14. I sometimes worry about losing my temper with other people.	44	9	40.9
11. I sometimes get fed up of people asking me about my brain injury.	30	12	40
19. I sometimes think that people prefer talking to others I'm with, rather than me.	38	14	36.8
21. I sometimes feel that other people look down upon me.	54	18	33.3
23. I sometimes feel that other people are watching me.	56	18	32.1
26. I sometimes think that people are comparing me to how	60	18	30
I was before the brain injury.  18. I sometimes think that people don't tell me things because they think I can't understand.	62	18	29
20. I sometimes feel that people treat me differently because of the injury.	74	20	27
15. Sometimes I don't like people seeing me using aids such as diaries, walking sticks or wheelchairs etc.	26	3	<b>2</b> 3.I
22. I sometimes feel my injury makes people feel sorry for me.	36	6	16.7

Table 3. (cont.)

Table 5. (cont.)			
TA Sub-domain and item	Percentage of whole sample reporting TA	Percentage of whole sample reporting avoidance	Percentage of those reporting TA who report avoidance
27. I sometimes think that people fuss over me because of my brain injury.	42	8	19
3. Awkward Situations			
33. I sometimes feel uncomfortable watching T.V. in case a programme contains something that reminds me of the injury.	24	22	91.7
32. Sometimes I don't like having to use aids such as diaries, walking sticks and wheelchairs etc.	28	20	71.4
30. I sometimes feel that I would be embarrassed going back to the place where I worked/studied.	30	20	66.7
31. I sometimes worry about going back to hospital since I had the brain injury.	22	8	36.4
34. It sometimes feels uncomfortable around people with a disability.	22	6	27.3
4. Doing Things			
39. If things go wrong when I'm doing something, I sometimes feel useless and stupid.	53.1	24.5	46.2
38. It sometimes bothers me that I can't do things like I used to.	77.6	34.7	44.4
35. I sometimes feel I make more mistakes now than I used to before the injury.	78	17	43.6
37. Sometimes when things go wrong, it reminds me of the brain injury and all the problems it's caused me.	66	28	42.4
36. I sometimes get upset or frustrated if I do things wrong.	74	28	37.8
40. I sometimes get frustrated because it takes me too long to do things.	58.8	25	36.4
41. Doing some things sometimes reminds me of how different I have become since the injury.	69.4	20.4	29.4

Table 3 shows that each item from sub-domains 1-4 generated responses indicating that between 22% (31. "I sometimes worry about going back to hospital since I had the brain injury,": 34. "It sometimes feels uncomfortable around people with a brain injury,".) and 78% (35. "I sometimes feel I make more mistakes now than I used to before the injury,".) of the whole sample identified with a TA item ( $\underline{M} = 46.75$ ,  $\underline{SD} = 15.52$ ). Between 3% of the whole sample (15. "Sometimes I don't like people seeing me using aids such as diaries, walking sticks or wheelchairs etc,".) and 34.7% (38. "It sometimes bothers me that I can't do things like I used to,".) reported Avoidance items ( $\underline{M} = 17.75$ ,  $\underline{SD} = 7.32$ ).

Study Aim: Question 2. How predictive of avoidance are these appraisals of threat? That is, to what extent do people limit their participation because of these appraisals? Table 3, column 3, shows that the percentage of Avoidance reported by participants who reported a TA item ranged from 19% (27. "I sometimes think that people fuss over me because of my brain injury,".) to 91.7% (33. "I sometimes feel uncomfortable watching T.V. in case a programme contains something that reminds me of the injury,".) ( $\underline{M} = 46.6\%$ ,  $\underline{SD} =$ 14.54). The sub-domain of 'Personal Safety' yielded a mean Avoidance rate of 41.9% after TAs were endorsed (SD = 8.5); 'Dealing with People' yielded a mean of 39.9% (SD = 13.1); 'Awkward Situations' produced a mean Avoidance rate of 58.7% (SD = 26.4); 'Doing Things' mean Avoidance rate was 40% (SD = 5.9). In response to Study Aim: Question 2, the figures described here suggest that, although participants may have identified with a TA, this did not necessarily lead to their self-reported Avoidance. This would suggest that TAs were not an entirely sufficient condition for Avoidance to be reported. Nevertheless, the mean percentages appeared to be reasonably high and the TA's therefore appeared reasonably predictive of avoidance. As a further test of this interpretation, the Overall TAs and Overall Avoidance scores yielded a significant correlation ( $\underline{r} = 0.68$ ,  $\underline{p} < 0.01$ ). The sub-domain of 'Personal Safety' TAs and Avoidance items also yielded a significant correlation ( $\underline{r} = 0.7$ ,  $\underline{p} < 0.7$ 0.01), as did 'Dealing with People' ( $\underline{r} = 0.58$ ,  $\underline{p} < 0.01$ ), and 'Doing Things' ( $\underline{r} = 0.5$ ,  $\underline{p} < 0.01$ ) 0.01). These correlation results are displayed in Table 8 below.

Study Aim: Question 3. What kinds of situations are avoided owing to a loss of confidence (threat-appraisals) after TBI?

To explore the frequencies of general situations (as represented by ATAI sub-domains 1-4) appraised as threatening and avoided, Figure 1 and Table 4 display the mean percentages for each sub-domain, calculated from each of their items. These relate to 1) the mean percentage of TA sub-domain reported; 2) the mean percentage of the sample that reported Avoidance for each sub-domain; and 3) as already reported above, the mean percentage of participants who reported TA item and therefore reported Avoidance.

Figure 1. Bar chart depicting relative mean percentages of sample (N = 50) that endorsed TAs and reported Avoidance.

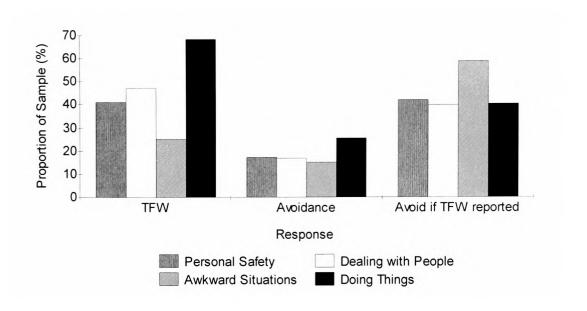


Table 4. Mean (st. dev.) responses for items in sub-domains 1 - 4 (N=50).

Sub-domain	_	f whole sample ting TA		whole sample Avoidance	Percentage of t Avoidance wh	
	<u>M</u>	SD	<u>M</u>	SD	<u>M</u>	<u>SD</u>
1. Personal Safety	41.2	2.3	17.3	3.3	41.9	8.5
2. Dealing with People	46.9	12.7	18.7	7.7	39.9	13.1
3. Awkward Situations	25.2	3.6	15.2	7.6	58.7	26.4
4. Doing things	68.1	9.5	24.4	5.7	40	5.9

Figure 1 and Table 4 show that the sub-domain, 'Doing Things', shared the highest rate of endorsement of the TA items and the highest rate of consequent Avoidance within the whole sample. 'Awkward Situations' had the lowest percentage of reported TAs and also the lowest percentage of reported Avoidance from the whole sample, but the highest percentage of Avoidance if a TA had been reported.

To test further for the presence of any statistically meaningful differences between the subdomains, a one-factor within-participant analysis of variance (ANOVA) was performed using each participant's (N=50) percentage of TA and Avoidance responses calculated from the maximum possible scores for each sub-domain. The percentage of Avoidance when TAs were endorsed was also calculated from each participant's scores. The corresponding ANOVA and follow-up t-test tables are shown in Appendix Gi. The corresponding means and standard

deviations are displayed in Table 5. Due to the different method of calculation, these differ somewhat from those shown in Table 4.

Table 5. Means (st.dev.) for	TA and Avoidance rates (%)	for sub-domains 1, 2 & 4 (N=50).
		,

Sub-domain	•	whole sample	Percentage of whole sample reporting Avoidance		_	Percentage of those reporting Avoidance who reported TA	
	<u>M</u>	SD	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	
1. Personal Safety	41.3	29.4	17.3	24.5	27.3	35.4	
2. Dealing with People	46.9	25	18.7	24	33	41.9	
4. Doing things	68.9	34.6	24.4	36.6	31	35.4	

For the TA sub-domains, the one-factor ANOVA revealed a significant main effect ( $\underline{F}_{(1,49)}$  = 48.47, p < 0.001). Unplanned multiple comparisons, using the Bonferroni method of pairedsample t-tests revealed that the sub-domain, 'Doing Things', had significantly higher rates of reported TA's than did 'Personal Safety' ( $\underline{t} = -6.96$ ,  $\underline{p} < 0.001$ ) and 'Dealing with People' ( $\underline{t} =$ -5.92, p < 0.001). 'Personal Safety' and 'Dealing with People' yielded no significant differences ( $\underline{t} = -1.53$ ,  $\underline{p} > 0.05$ ). Thus, issues relating to the sub-domain, 'Doing Things', generated a markedly higher endorsement rate of TA's than 'Dealing with People' and 'Personal Safety'.

The ANOVA procedure was repeated for the ATAI Avoidance sub-domains. This also yielded a significant main effect ( $\underline{F}_{(1,49)} = 7.13$ ,  $\underline{p} < 0.05$ ). Again, the Bonferroni method of paired-sample t-tests revealed that the sub-domain, 'Doing Things' Avoidance, had significantly higher rates of reported Avoidance than did 'Personal Safety' Avoidance (t = -2.67, p < 0.05) and 'Dealing with People' Avoidance (t = -2.56, p < 0.05). 'Personal Safety' Avoidance and 'Dealing with People' Avoidance yielded no significant differences ( $\underline{t} = -0.47$ , p > 0.05).

The one-factor ANOVA procedure was repeated for the participant's percentages of Avoidance from their reported TAs. This did not yield a significant main effect  $(\underline{F}_{(1,49)} =$ 1.33, p > 0.05). No differences between the sub-domains in rates of Avoidance, as a percentage of the endorsed TAs, were therefore suggested.

It was evident from Figure 1 and Table 3 that although the sub-domain, 'Awkward Situations', had the lowest rates of TAs and Avoidance, it also had the highest mean percentage of reported Avoidance after a related TA had been identified with (58.7%). For example, the particular item "I sometimes feel uncomfortable watching T.V. in case a programme contains something that reminds me of the injury," (Item 33) had a 91% avoidance rate if the TA was endorsed. It was suggested therefore that, if an 'Awkward Situation' item was a concern, participants were then more likely to report Avoidance of the issue. However, because of the low internal reliabilities of the separate TA and Avoidance scales for this sub-domain, no direct statistical comparison to sub-domains 1, 2 & 3 were made.

Further exploratory analyses examined the strength of correlations between the demographic variables of age, age at the time of injury, time since injury, years in education, Overall TA and Avoidance rates, and rates obtained for the ATAI sub-domains. No significant relationships were found (p > 0.01; Appendix Gii).

Study Aim: Question 3 (cont.) Specific Situations of Reduced Participation

The second part of the ATAI interview, 'Particular Activities', represented the more specific situations that may be avoided. This was because a lack of confidence since injury was given as one of the reasons. This part of the interview employed a different line of questioning from sub-domains 1-4 (see 'Measures' section). Table 6 shows each of the 26 activities and the percentage of 'yes' responses for each of the following filtered questions:

- a) Did you do this before the injury?
- b) Would you feel less confident about it now compared to how you felt before the injury?
- c) Do you do it less often now?
- d) Is your lack of confidence one of the reasons why you do it less often?

Items have been ranked in order of the highest rates of reported non-participation due to a lack of confidence (Question d, column 5).

<u>Table 6</u>. 'Particular Activities' and percentage of 'yes' responses expressed by participants for filtered questions a, b, c & d.

Particular Activity item	a (%yes)	b (% yes)	c (% yes)	d (% yes)
11. Paid work.	83.7	38.8	38.8	38.8
23. Being in crowds.	95.9	38.8	38.8	38.8
9. Filling in forms.	85.7	24.5	24.5	24.5
20. Going out to a pub or club.	87.8	22.4	22.4	22.4
24. Doing DIY jobs.	73.5	22.4	22.4	22.4
6. Dealing with money.	98	20.4	20.4	20.4
3. Travelling alone.	98	18.4	18.4	18.4
8. Paying household bills.	77.6	16.3	16.3	18.4
10. Arranging appointments for yourself.	93.9	16.3	16.3	16.3
7. Having friends around your house.	91.8	12.2	12.2	14.3
13. Studying, training, doing courses.	69.4	14.3	14.6	14.3
18. Visiting friends and relations at their house.	98	14.3	14.3	14.3
4. Being at home alone.	95.9	10.2	10.2	12.2
16. Pursuing your hobbies.	91.8	12.2	12.2	12.2
19. Going to the theatre or cinema.	79.6	12.2	12.2	12.2
22. Playing sport.	81.6	12.2	12.2	12.2
26. Driving.	71.4	12.2	12.2	12.2
12. Doing unpaid or voluntary work.	36.7	10.2	10.2	10.2
15. Reading	87.8	10.2	10.2	10.2
17. Using the telephone.	100	10.2	10.2	10.2
5. Preparing snacks and meals.	93.9	6.1	6.1	8.2
21. Eating out.	93.9	8.2	8.2	8.2
1. Using buses trains and taxis.	81.6	4.1	4.1	6.1
2. Shopping.	87.8	4.1	4.1	6.1
14. Looking after children.	73.5	6.1	6.1	6.1
25. Doing housework.	89.8	0	0	0

It can be seen from Table 6 that the highest rates of reduced participation due to confidence difficulties were reported (question 'd') for 'doing paid work' (item 11) and 'being in crowds' (item 23). 'Doing housework' was not reported to be a difficulty by any participants. It is also apparent that, with the exception of items 8,7,4,5,1 and 2, there were no differences in response rates between the filtered questions b, c and d. These response rates thus suggested that, if participants reported taking less part in a particular activity, these were then often

attributed, at least in part, to confidence issues. Research aim, Question 4 will be discussed from the results presented thus far in the 'Discussion' section below.

Correlation, Regression and Path Analyses. Before the research aim questions of 5 and 6 are addressed, Table 7 presents the means, standard deviations and ranges (and frequency of 'cases' on the HADS scales) for the additional measures used in the analysis: quality of life (QOLI), anxiety (HADS), depression (HADS).

<u>Table 7</u>. Means, standard deviations, ranges and internal reliability (Cronbach's  $\underline{\alpha}$ ) for additional measures used in analyses (N = 48 & 50).

Measure	N	<u>M</u>	<u>S.D.</u>	<u>Minimum</u>	Maximum	Cases	α
Quality of Life Index	50	25.65	4.83	11.97	29.25	n.a.	0.93
Depression (HADS)	48	5.8	3.91	0	19	13* (6)**	0.7
Anxiety (HADS)	48	8.7	5.01	0	21	25* (16)**	0.82
Coping Schedule	50	n.a.	n.a.	n.a.	n.a.	n.a.	0.72
Active Cognitive	50	16.38	5.5	3	27	n.a.	0.64
Active Behavioural	50	14.31	5	2	39	n.a.	0.5
Avoidance Coping	50	10.46	4.39	2	22	n.a.	0.5

<sup>\*</sup> Scores within the HADS borderline range at 9 and above (as previously used for report by Williams et al, 1998).

Table 7 shows a high internal reliability found for the QOLI. This is comparable to that found by King's (1996) sample of people with stroke ( $\alpha = .91$ ). The present sample's mean is marginally higher than that of King's sample although the range is comparable (in King's sample: M = 22.9, SD = 3.8, Range 12.6 - 29.3). Sufficient internal reliabilities were also found for the HADS measures of anxiety and depression. For the HADS, the case range has been reported for scores of 11 and above, as set by Zigmond and Snaith (1983) and also that reported by Williams et al., (1998) who employed the HADS in a TBI sample, and considered cases to be indicated by scores of 9 and above. Either way, more people were found to be in the 'case' range on the HADS for anxiety than for depression. From 18 participants, Williams et al's (1998) study found caseness for depression in 33.3% of their sample and

<sup>\*\*</sup>Scores above the HADS borderline range (11 and above, as set by Zigmond and Snaith, 1983).

caseness for anxiety in 50%. Using Williams et al's scoring criteria, the present sample's caseness is slightly lower at 27% for depression and 52% for anxiety. Although the internal reliability score for the overall Coping Schedule is satisfactory ( $\alpha = 0.72$ ) the reliability for its sub-domains, particularly for active behavioural and avoidance coping, are low, although just within the  $\underline{\alpha} = 0.5$  level argued by Nunnally (1967) as sufficient for research. Low internal consistencies are not unusual for coping questionnaires of this type given that just one coping response reflected by an item may consistently serve to reduce an individual's stress; other coping responses may not therefore be enacted and internal homogeneity of related categories is accordingly compromised (Billings & Moos, 1981). The patterns of coping strategies found here are similar to those reported by Hinckleday and Corrigan (1990) from the original Health and Daily Living Form's coping measure. That is, Avoidance Coping strategies are enacted less than are Active Cognitive and Active Behavioural. Finset and Andersson (2000), who further state that corresponding patterns are found in the general population, also report this similarity. Also, consistent with Hinckleday and Corrigan's comparison with a 'normative' sample, the present means for coping strategies on the Coping Schedule are considerably higher than for those reported by Tyler and Cushway (1998) from a sample of 79 mental health nurses. Their obtained mean for Avoidance Coping, after a square root transformation, was 0.73 (present transformed M = 3.23); for Active Behavioural Coping, M = 1.46 (present transformed  $\underline{M}$  = 3.78); and for Active Cognitive Coping,  $\underline{M}$  = 1.9 (present transformed  $\underline{M} = 4.04$ ).

Values for the correlations (Pearson's r) of all measures, including the ATAI overall scores and sub-domains, are displayed in Table 8 and described thereafter. Part 2 of the interview, 'Particular Activities', has been analysed with each participant's sum of 'yes' responses to question 'd' and this is labelled 'Reduced Confidence and Activities'. Due to the high number of correlations the significance level was set at p < 0.01.

<u>Table 8</u>. Correlations of TA, avoidance, sub-domains of TA and Avoidance, Coping Schedule domains, anxiety, depression and quality of life.

	Overall TA	Overall Overall TA Avoid	RCA	PS TA	Avoid PS	DWP TA	Avoid DWP	DT TA	Avoid DT	ACC	ABC	AC	Anx	Dep
Overall Avoidance 0.68** Reduced Confidence and Activity 0.60** Personal Safety TA 0.77** Avoidance - Personal Safety TA 0.63**	0.68** y 0.60** 0.77** 0.63**	0.75** 0.59** 0.79**	0.70**	***************************************	** - -									
Dealing with reopte 1A Avoidance-Dealing with People Doing Things TA Avoidance – Doing Things	0.53 ·· 0.61 ** 0.83 ** 0.59 **	0.95 ** 0.54 ** 0.89 **	0.45** 0.45** 0.71**	0.47** 0.63** 0.54**	0.61** 0.46** 0.70**	0.58** 0.65** 0.50**	0.48**	0.50**						
Active Cognitive Coping Active Behavioural Coping	-0.08 -0.35	-0.31* -0.22	-0.24 -0.19	0.02 -0.33	-0.33* -0.17	-0.12 -0.19	-0.28 -0.20	-0.15 -0.05	-0.29* -0.23	-0.49**				
Avoidance Coping Anxiety (HADS)	0.39**	0.37*	0.14	0.26	0.18	0.40**	0.41**	0.22 0.34*	0.26	0.37**		0.38**		
Depression (HADS) Quality of Life (QOLI)	0.47**	0.47** 0.44** 0.55** -0.58**	0.42**	0.41**	0.43**	0.44**	0.43**	0.39**	0.30**	-0.43** 0.22	-0.24 0.25	0.1	0.56**	**09'-

Key. Overall TA = Overall threat-appraisal; Overall Avoid = Overall Avoidance; RCA= Reduced Confidence and Activity Participation;

PS TA = Personal Safety Threat-appraisal; Avoid PS = Avoidance due to Personal Safety Threat-appraisal;

**DWP TA** = Dealing with People Threat-appraisal; Avoid DWP = Avoidance due to Dealing with People Threat-appraisal; Avoid DT = Avoidance due to Doing Things Threatappraisal; ACC = Active Cognitive Coping; ABC = Active Behavioural Coping; AC = Avoidance Coping Anx = Anxiety; Dep = Depression.

<sup>\*</sup> p< 0.05 (2-tailed) \*\* p< 0.01 (2-tailed)

Convergent Validity Between Measures of Avoidance. It can been seen from Table 8 that Avoidance Coping, as measured by the Coping Schedule, did not correlate with the overall Avoidance scores as measured by the ATAI ( $\underline{r} = 0.37$ ,  $\underline{p} > 0.01$ ), although it did significantly correlate with the 'Dealing With People' Avoidance sub-domain. Thus, convergent validity of avoidance, as measured by the ATAI and by The Coping Schedule was only partially supported. 'Avoidance Coping' on the coping schedule also correlated substantially with Overall TAs, 'Dealing With People' TAs and 'Awkward Situations' TA scores.

Research Aim: Question 5. What might mitigate the effect of these appraisals on avoidance? Specifically, are those who employ approach coping strategies less likely to avoid, despite their appraisal of threat?

In response to the question of whether those who employed approach strategies were less likely to avoid, Table 8 shows that, contrary to hypothesis, no significant negative correlations were evident between Avoidance on the ATAI, and its sub-domains, and the active coping strategies as measured by the Coping Schedule. There was no evidence to suggest therefore that the active coping strategies, as measured by the Coping Schedule, had the opposite relationship to that of Avoidance coping as measured by the ATAI; that is, reports of fewer Avoidance strategies did not appear to be accompanied by reports of more Active Coping strategies and vice versa. Interestingly, for the Coping Schedule scales, the corresponding relationship between Active Behavioural Coping and Avoidance Coping strategies was positively correlated, rather than negatively correlated, so higher frequencies of reported Avoidance Coping also related to higher frequencies of Active Behavioural Coping. Furthermore, whilst Avoidance Coping on the Coping Schedule yielded a substantial correlation with anxiety only, Active Cognitive Coping yielded a substantial negative correlation with depression; higher reports of active cognitive coping strategies were therefore related to lower depression scores. None of the coping strategies on the Coping Schedule correlated with the QOLI. Overall, these figures suggest few predictive relationships between coping measured on the Coping Schedule and the other measures used in this study.

Research Aim: Question 6. What is the relationship between appraisal of threat, avoidance, emotional adjustment and quality of life? On the basis of previous research it is hypothesised that, overall, higher frequencies of threat-appraisals and avoidance will predict negative indices of anxiety, depression and quality of life.

This aim hypothesised a relationship between threat-appraisals (TAs) and Avoidance to anxiety, depression and quality of life. It can be seen that, from Table 8, as hypothesised, both the Overall TA and Overall Avoidance scores were substantially and significantly correlated with the QOLl, anxiety (HADS) and depression (HADS) scores. This hypothesis was explored further through the ATAI sub-domains.

Quality of Life. Higher rates of reported TAs and Avoidance in all sub-domains were associated with lower QOLI scores. This held true for the 'Reduced Confidence and Activities' scores, although the relationship was weaker with quality of life. The TA subdomain that correlated most strongly with the QOLI was 'Personal Safety'. All TA and Avoidance sub-domains negatively correlated with quality of life (QOLI) with the exception of 'Doing Things' Avoidance.

Depression. All Avoidance sub-domains in addition to 'Reduced Confidence and Activities' correlated with depression (HADS), although 'Dealing with People' Avoidance bore the strongest relationship. Likewise, all TA sub-domains correlated with depression. Again, 'Dealing with People' bore the strongest relationship.

Anxiety. All TA sub-domains, with the exception of 'Doing Things' TAs, correlated substantially with anxiety (HADS). 'Personal Safety' TAs bore the strongest relationship. Likewise, all the Avoidance sub-domains in addition to 'Reduced Confidence and Activities' correlated substantially with anxiety, but the strongest relationship was with the 'Dealing with People' Avoidance sub-domain.

To explore further the relationships of the ATAI scales to each outcome measure, a series of regression analyses were performed for the TA and Avoidance sub-domains.

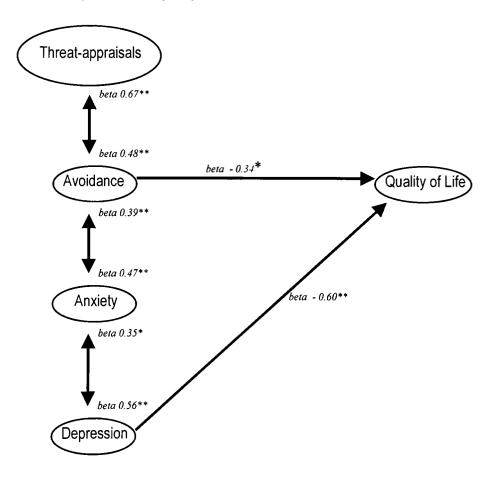
Multiple Regression Analyses of Threat-Appraisal and Adjustment. Standard multiple regression analyses (regression tables presented in Appendix Giii) were performed to analyse the relationships between the dependent variables of adjustment (quality of life, anxiety and depression scores) and the independent variables of threat-appraisal sub-domains ('Personal Safety', 'Dealing with People' and 'Doing Things' scores). Although, as can been seen from Table 8, the ATAI sub-domains are significantly correlated, these range from r = 0.46 to 0.70 and are therefore below the 0.8 threshold used as an indication of difficulties due to multicollinearity (Clarke-Carter, 1997). The combined TA sub-domains accounted for 30% of the QOLI variance (Overall Adj.  $\underline{R}^2$  = 0.30,  $\underline{F}_{(3,46)}$  = 8.13,  $\underline{p}$  < 0.001). 'Personal Safety' TA was the only sub-domain variable to reach statistical significance (beta = -3.95 = p < 0.05). None of the TA sub-domains reached statistical significance in predicting depression (p > 0.05) although their combined contribution accounted for 19% of the variance in depression scores (Overall Adj.  $\underline{R}^2 = 0.19$ ,  $\underline{F}_{(3,44)} = 4.58$ ,  $\underline{p} < 0.05$ ). The combined TA sub-domains accounted for 27% of the Anxiety variance (Overall Adj  $\underline{R}^2 = 0.27$ ,  $\underline{F}_{(3,44)} = 6.72$ ,  $\underline{p} < 0.05$ ) and 'Personal Safety' was again the only variable to reach significance ( $\underline{\text{beta}} = 0.49$ ,  $\underline{\text{p}} < 0.05$ ). Thus the TA sub-domain that appeared to have the highest predictive values for the QOLI and anxiety scores was 'Personal Safety'.

Multiple Regression Analyses of Avoidance and Adjustment. The standard multiple regression analyses were repeated to analyse the relationships between the dependent variables of adjustment (quality of life, anxiety and depression scores) and the independent variables of Avoidance sub-domains ('Personal Safety', 'Dealing with People' and 'Doing Things' scores) and also the second part of the ATAI: 'Reduced Confidence and Activities' scores. These combined Avoidance scores accounted for 32% of the QOLI (Overall Adj R<sup>2</sup> = 0.32,  $\underline{F}_{(4,44)}$  = 6.06,  $\underline{p}$  < 0.001). 'Dealing with People' Avoidance was the only variable to reach significance (beta = -.575, p < 0.05). The combined Avoidance sub-domains accounted for 36% of the anxiety variance (Adj  $\underline{R}^2 = 0.36$ ,  $\underline{F}_{(4,42)} = 7.45$ ,  $\underline{p} < 0.001$ ) and 'Dealing with People' Avoidance was the only variable to reach significance (beta = .455, p < 0.05). The Avoidance scores accounted for 21% of the depression variance (Adj  $\underline{R}^2 = 0.21$ ,  $\underline{F}_{(4.42)} = 4.07$ , p < 0.05) and again 'Dealing with People' Avoidance was the only variable to reach

significance ( $\underline{beta} = .417$ ,  $\underline{p} < 0.05$ ). Thus, the Avoidance sub-domain that appeared to have the highest predictive values for the QOLI, anxiety and depression scores was 'Dealing with People' Avoidance.

Post-Hoc Exploratory Path Analysis. An exploratory path analysis, using a hierarchical regression procedure along the lines recommended by Bramwell (1996) and Tabachnik and Fidell (1989), was conducted to investigate the relative predictive pathways between anxiety, TAs, Avoidance, depression and quality of life. Appendix Giv displays the adjusted  $\underline{R}^2$  and beta values for each significant predictor and the stepwise regression procedure. The predictive relationships have been depicted in Figure 2.

Figure 2. Suggested pathway diagram for relationships between Overall TA, Overall Avoidance, anxiety, depression and quality of life.



<sup>\*</sup> Beta values where p<0.05

<sup>\*\*</sup>Beta values where p < 0.01

The path diagram in Figure 2 shows that two predictors appeared to have had a direct significant negative relationship with quality of life, depression (beta = -0.60; p = 0.001) and ATAI Overall Avoidance ( $\underline{\text{beta}} = -0.34$ , p < 0.01). Together, these accounted for 42.5% of the variability in quality of life scores ( $R^2 = 0.425$ ). As quality of life was assigned as an index of outcome, this variable was not re-entered into the analysis. In the second step, depression was taken as the dependent variable. Overall TA's, Overall Avoidance and anxiety were the independent variables. Anxiety was the only variable entered into the equation and found to significantly relate to depression scores ( $\underline{\text{beta}} = 0.35$ ; p < 0.001). In the third step, Avoidance was taken as the dependent variable. Depression, anxiety and TAs were the independent variables. TAs (beta = 0.48; p < 0.001) and anxiety (beta = 0.39; p < 0.001) were entered into the equation and related significantly to the Avoidance scores. In the fourth step, Anxiety was taken as the dependent variable. Depression, TAs and avoidance were the independent variables. Avoidance related significantly to anxiety scores (beta = 0.47; p < 0.001), as did depression ( $\underline{\text{beta}} = 0.35$ ,  $\underline{\text{p}} < 0.01$ ). Finally, in the fifth step TAs were taken as the dependent variable. Anxiety, depression and Avoidance were the independent variables. Only Avoidance was entered into the equation and related significantly to TAs scores (beta = 0.67, p < 0.001).

These results are considered in terms of a post-hoc exploratory analysis. However,

Avoidance appears to mediate the relationship between TAs and quality of life as measured
by the QOLI. This relationship of TAs to Avoidance is reciprocal as Avoidance also predicts
TA. Avoidance directly predicted quality of life. The relationship between TAs and
adjustment factors was indirect.

Avoidance was also found to mediate the relationship of anxiety to quality of life. Anxiety and avoidance had a reciprocal relationship as avoidance also predicted anxiety. Anxiety did not directly predict quality of life but was mediated by depression and Avoidance.

The relationship between anxiety and depression was also reciprocal, although depression predicted anxiety to a lesser extent. Depression was the most strongly associated predictor of quality of life. Avoidance and TAs had no direct predictive relationships with depression.

For the second part of the ATAI, the 'Reduced Confidence and Activities' scores were not included in this analysis. Therefore, a second path analysis procedure was attempted with this in place of Avoidance in the previous model described above. It was not however predictive of quality of life, although depression did again predict quality of life.

Study Aim: Question 6 (cont.). On the basis of previous research it is hypothesised that, overall, higher frequencies of threat-appraisals and avoidance will predict negative indices of anxiety, depression and quality of life. This relationship may however be weaker for those in the earlier stages of adjustment to the injury (e.g., Malia et al., 1993).

Further correlation analyses were employed to explore the relationships between avoidance and outcome whilst controlling for participants' time since injury between a group of participants late after injury and a group of participants early after injury. Thus from 50 participants, those with the 10 earliest time periods since injury ( $\underline{M} = 1.79$  years,  $\underline{SD} = 0.46$ years, Range = 0.83 - 2.16 years) and the ten longest periods since injury ( $\underline{M} = 22.26$  years, SD = 4.8 years, Range = 16 - 32 years) were analysed independently.

Table 9 shows the means, standard deviations and  $\underline{N}$  of the early and late groups for each of the variables. One set of scores for depression and anxiety were missing for the late group. Independent group t-tests were performed between the early and late groups for each of the variables (shown in Appendix Gv). None reached significance (p > 0.05).

Table 9. N, means and standard deviations between early and late groups of time since injury for Avoidance, anxiety, depression and quality of life.

Dependent variable	Group	N	Mean	<u>SD</u>
Avoidance (ATAI)	Early	10	6.6	8.54
	Late	10	5.6	7.14
Anxiety (HADS)	Early	10	7.5	4.53
• • •	Late	9	6.44	3.54
Depression (HADS)	Early	10	5.1	2.64
, ,	Late	9	6.1	5.58
Quality of Life (QOLI)	Early	10	20.22	3.91
~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~	Late	10	21.22	5.56

The specific issue here was whether Avoidance was more predictive of outcome for those with a longer time since injury, as it has been suggested that avoidant type coping strategies may be of some benefit in the earlier stages of recovery (Malia et al, 1993). Correlation (Pearson's r) tests (shown in Appendix Gv) were conducted between Avoidance and anxiety, depression and quality of life. Avoidance related significantly to quality of life for the high group (r = -.766, p < 0.01) but not for the low group (r = -.412, p > 0.01). A test of this difference (calculations in Appendix Gv) suggested that the difference between the two correlations was not significant ( $\underline{Z}_{obt} = 1.07$ , p > 0.05). No other significant correlations were found between Avoidance and anxiety and depression for either group (p > 0.01). It was suggested therefore that, although there was little difference between the mean QOLI and Avoidance scores for the early and late groups, there was nevertheless a substantial relationship between reported avoidance and QOLI scores for the late group of participants who had 16 years or more since their injury. This relationship was not significant for the early group, between 0.83 - 2.16 years since injury. The hypothesis that avoidance would not reflect a negative index of adjustment in the earlier stages after injury, compared to the later stages, was therefore partially supported by a significant negative correlation with quality of life in the late group and not in the early group. However, evidence that this relationship is stronger for the late group was weakened by a lack of a statistically significant difference between it and the early group's correlation. Further, Avoidance did not relate to better indices of adjustment in the early group as previous conceptualisations of avoidant type coping strategies have suggested. The relationship found here for quality of life and Avoidance were not reflected in the relationships between Avoidance and anxiety, or Avoidance and depression.

### Discussion

The present study has explored the nature and incidence of threat-appraisals and rates of associated avoidance made by people with TBI. The relationship of these threat-appraisals and avoidance has been explored with anxiety, depression and quality of life. Results and implications will be discussed in relation to the study aim questions.

Question 1. What are the relative frequencies, shared by a representative sample of participants, with which specific threat-appraisals are made? Across all threat-appraisal items (1-41), these were endorsed by just less than half of the sample at 47.6%. The minimum proportion of items endorsed by any individual from the threat-appraisal scale was 22% and the maximum was 78% out of the possible 41 items. When threat-appraisals were reported, there was a broad range in the number of participants who also avoided the items (17% to 92%). The item "I sometimes feel uncomfortable watching T.V. in case a programme contains something that reminds me of the injury," (no. 33) generated the highest proportion of related avoidance (92%). The item "I sometimes feel my injury make people feel sorry for me," (no. 22) generated the least avoidance (17%). From these findings, it is therefore suggested that the items generated by the preliminary qualitative phase of the research produced substantial endorsements from the participants with TBI in the second, main, research phase.

Question 2. How predictive of avoidance are these appraisals of threat? That is, to what extent do people limit their participation because of these appraisals? The mean percentage of the population who reported avoidance, as a proportion of the antecedent threat-appraisals endorsed, was 42.6%. As expected there were strong correlations between the overall and sub-domains of threat-appraisals and avoidance. However, it is clear that a threat-appraisal does not automatically lead to avoidance. Possible reasons for this are considered below.

First, however, it may be that some aspects of the injury itself may lead to avoidance. For example, although the specific reminders of the circumstances that may have caused peoples' traumatic brain injuries were not comprehensively assessed by the ATAI, the threat-appraisal and particularly high rate of proportionate avoidance associated with item 33 ("I sometimes feel uncomfortable watching T.V. in case a programme contains something that reminds me

of the injury,": 91% avoidance) may converge with features of post-traumatic stress-disorder diagnoses. Thus, the possibility that some of the avoidance reported may be due to PTSD type difficulties, as discussed by Bryant (2001), cannot be disregarded. Furthermore, when considering the effect that the cause of injury may have, it may also be hypothesised that different reasons for injury may be related to different outcomes. Wenden, Crawford, Wade, King & Moss (1998), for example, report findings of prolonged post-concussional symptoms when head injury has been due to an assault, as opposed to other aetiologies. Although, in the present study, the incidences of differing traumas lacked sufficient parity for analysis, greater rates of avoidance may also be hypothesised to vary according to the aetiology of the original trauma. For example, social situations or may be avoided more if the participant's TBI was sustained after an assault.

Question 3. What kinds of situations are avoided owing to a loss of confidence (threatappraisals) after TBI? The ATAI sub-domains 'Personal Safety', 'Dealing with People' and 'Doing Things' represented general situations that may have been avoided (e.g., going out, avoidance of people and avoidance of doing things). It was found that the category, 'Doing Things' had the items with the greatest proportion of the sample reporting threat-appraisals and also the highest proportion of the sample reporting avoidance. However, when avoidance was calculated as a proportion of the threat-appraisals reported, no statistical differences were found when compared to the sub-domains of 'Personal Safety' and 'Dealing with People'.

When the 'Particular Activities' measure was examined (as opposed to the more global areas in sub-domains 1-4) 'doing paid work' and 'being in crowds', reported at 38% each, were the activities that people most often reported have less confidence for and did less of. 'Doing housework' was not reported to be a difficulty by any of the participants from this part of the ATAI.

Question 4. What is it about these situations that people appraise as potential threats? This discussion cannot do complete justice to the full range of threat-appraisal and related avoidance scores shown in Table 3. However, the highest rates of reported avoidance may

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indicate the extent of difficulties that were related to each sub-domain when threat-appraisals were endorsed.

For example, for the issues of 'Person Safety', the item: "Sometimes I feel home is the only place where I'm safe," (no. 3) implies perceptions of increased vulnerability to potentially dangerous situations when in public. This interpretation is supported by the item ranked third in terms of its frequency: "Sometimes I worry that, if I'm attacked, I won't be able to stick up for myself," (no. 4). In the section, 'Dealing with People', the most frequently reported avoidance of people due to a threat-appraisal was: "I sometimes worry that people will patronise me or talk down to me," (no. 9). This may imply tendencies for perceptions following TBI of negative evaluations made by others.

In the ATAI sub-domain, 'Doing Things', the threat-appraisals that had the highest proportions of avoidance were the items: "If things go wrong when I'm doing something, I sometimes feel useless and stupid," (no. 38); and "It sometimes bothers me I can't do things like I used to," (no. 36). These items echo, to some extent, the processes within Goldstein's (1939;1952) catastrophic reaction model whereby specific emotional difficulties after TBI are caused when it is realised that tasks that were easily accomplished before an injury are more difficult after. Goldstein, however, emphasises that it is not just the difficulties in accomplishing a task that may upset emotional stability, but the threat that this represents to one's core-concept or identity (described in context of existential theory) that is based on premorbid levels of ability. Weight is perhaps added to this contention by the 'Doing Things' item with the forth highest proportion of avoidance (42.4%) in the section: "Sometimes when things go wrong, it reminds me of the brain injury and all the problems it's caused me," (no. 37).

As discussed in the results section, the sub-domain 'Awkward Situations' did not produce an adequate internal reliability and its status as a unified category was therefore considered to be in some doubt. Question 5. What might mitigate the effect of these appraisals on avoidance? Specifically, are those who employ approach coping strategies less likely to avoid, despite their appraisal of threat? An inverse relationship between the Active Coping strategies on the Coping Schedule, and avoidance as measured by the ATAI was not evident from the correlation analysis. It would therefore appear that avoidance coping in the present study was not mitigated by approach/active oriented strategies. This finding echoes the contention put forward by Cassidy (1999) that the presence of avoidance coping does not necessarily indicate the absence of approach coping, or vice versa.

Other factors must therefore moderate rates of avoidance. For example, the presence of secondary appraisal processes (Lazarus & Folkman, 1984), that is the evaluation of one's coping options in meeting a threat-appraisal, was not explicitly assessed by the present study. These were however assessed by Kendal *et al.* (2001) who established a relationship between lower self-esteem and avoidant coping strategies. Future studies of individual differences after TBI should investigate why a threat-appraisal is an antecedent of avoidance. For example, do individuals' levels of self-esteem, sense of control over a particular situation or levels of social support moderate stressors, rates of avoidance and therefore predict better adjustment? These are factors that have been typically postulated by the stress-appraisal and coping theory (e.g., Lazarus & Folkman, 1984) and further proposed in context of adjustment to TBI (Kendal & Terry, 1996; Godfrey, Knight & Partridge, 1996; Martelli, Zasler & MacMillan, 1998) but rarely tested. Secondary appraisal of coping resources may, first, explain why, as found in the present study, some individuals report particular threat-appraisals but others do not, and second, why some individuals report threat-appraisals and do not avoid whereas other do.

In relation to question 5, the Coping Schedule found paradoxical results for the coping strategies measured. Avoidance Coping and Active Behavioural Coping, both measured on the Coping Schedule, did in fact correlate positively; a higher frequency of avoidance was therefore related to higher frequencies of active behavioural coping. This appears to replicate the unexpected relationship found by Finsett and Andersson's (2000) acquired brain injury sample for approach and avoidance oriented coping, as opposed to their non-clinical control

group where the corresponding relationship was negative, as might be hypothesised. Thus, in line with Finset and Andersson, and as suggested by Moore, Stambrook and Peter's (1989) study with people with TBI, the present sample appeared to report an 'indiscriminate' pattern of coping strategies as measured by the Coping Schedule. However, given that the Coping Schedule requests the participant to consider just one stressful situation, the so-called findings of indiscriminate coping may be an artefact explained by the limited contextual analysis of such coping measures, as proposed by Kendal *et al.* (2001). Kendal *et al.* found that frequencies of reported active coping (labelled as active problem focused coping) were constant across scenarios but accompanied by varying frequencies of other coping types.

de Ridder and Schreurs (1996) proposed that coping, as formulated by the mainstream stress-appraisal and coping literature, has been demonstrated to stop a bad situation from becoming worse, but tends not to improve a situation. This is contrary to the unexpected finding in the present study that Active Cognitive Coping was negatively correlated with depression; thus more cognitive coping was related to less depression. This is also contrary to previous research that has generally failed to establish a relationship between approach strategies and emotional well-being in ABI populations (e.g., Finset & Andersson, 2000; Curran et al., 2001; Malia et al., 1995). Finset and Andersson report finding a negative relationship between higher frequencies of approach coping and lower 'apathy' but not lower depression. Apathy is distinguished by Finsett and Andersson from the somatic and affective concomitants of depression, and is associated with right hemisphere lesions, reduced goal directed activity, lowered autonomic activity and lowered motivation; its relationship to less frequent reports of approach strategies may not therefore be surprising. However, Kendal et al. (2001) consistent with the present finding, also found a positive relationship between higher frequencies of reported approach coping strategies and positive effect, as measured by the Bradburn Affect Scale (Bradburn, 1969). It may be that the different measures employed between studies, and the conceptual differences between measures of depression and negative 'affect' may, at least in part, account for these mixed findings. As the ATAI did not assess approach strategies in context of reported threat-appraisals, the jury is still out with regards to their relationship to positive factors of emotional adjustment. As suggested by Kendal et al.

approach strategies should therefore also be investigated within more contextually sensitive analyses. Furthermore, as the high number of analyses employed within the present study's relatively small sample is vulnerable to a greater incidence of significant results, findings such as the relationship between Active Cognitive Coping and depression require extreme caution in their interpretation.

Question 6. What is the relationship between appraisal of threat, avoidance, emotional adjustment and quality of life? On the basis of previous research it is hypothesised that, overall, higher frequencies of threat-appraisals and avoidance will predict negative indices of anxiety, depression and quality of life. This prediction will however be weaker for those in the earlier stages of adjustment to the injury. As hypothesised, more reports of threat-appraisal, as measured by the overall ATAI scores and those of the sub-domains, 'Personal Safety' and 'Dealing with People' was substantially related to lower quality of life, and raised anxiety and depression. Similarly, more reports of Avoidance, as measured by the overall ATAI scores and the sub-domains, 'Personal Safety', 'Dealing with People' and 'Doing Things', were substantially related to lower quality of life, and raised anxiety and depression. The 'Particular Activities' measure in the second part of the ATAI was similarly predictive although its relationships to depression, anxiety and quality of life were comparatively weaker than for the sub-domains I-4 in the first part of the ATAI.

The relationships between the ATAI and adjustment factors were found in the direction that was hypothesised on the basis of previous stress-appraisal and coping research. These studies have typically employed measures of coping strategies akin to those of the Coping Schedule. However, although Avoidance Coping as measured by the Coping Schedule was substantially related to anxiety, this, contrary to the measures of Avoidance on the ATAI, did not bear any significant relationship to depression and quality of life. The Coping Schedule was therefore generally less predictive than avoidance, or for that matter threat-appraisal, as measured by the ATAI. Evidence of any convergent validity between Avoidance Coping on the Coping Schedule and the ATAI was also limited to a significant correlation with the 'Dealing with People' Avoidance sub-domain. It is suggested therefore that the two measures of avoidance are to some extent distinct. The ATAI assessed gross and specific situations that

are avoided due to specific threat-appraisals. The Coping Schedule does not however assess situations, but the methods by which situations may be avoided. As stated in the introduction, the questions, why or what situations are avoided are not informed by such measures of coping and this may explain why only a limited convergence was found between the two measures of avoidance.

Some caution in this interpretation is however required as the Coping Schedule may not have been the most appropriate measure to test for convergent validity. Tyler and Cushway's (1995) Coping Schedule was an adaptation of the Coping Responses measure from the Health and Daily Living Form (Moos, Cronkite, Billings & Finney, 1984). It was included in the present study for its brevity in comparison to the other, generally far longer, coping questionnaires. However, as it was adapted and re-factor analysed for a different research population, it may not have been the most suitable coping measure for people with TBI. A factor analysis was not possible in the present study due to the insufficient sample size. It is possible that other measures, demonstrated within TBI populations, may therefore have revealed stronger relationships to Avoidance on the ATAI, such as the re-factored Revised Ways of Coping Scale reported by Malia *et al.* (1995). Furthermore, some of the Avoidance questions may, in retrospect, have been inappropriate for a TBI population. For instance, the items: "Tried to reduce the tension by drinking more, or exercising more," (nos. 20a & 20c; Appendix F) might be activities that, in the case of drinking alcohol, are advised against, or in the case of exercise, might not be possible due to physical difficulties after an injury.

Out of the ATAI sub-domains, regression analyses suggested that threat-appraisals of 'Personal Safety' were the most predictive of quality of life and anxiety, but depression was not more significantly associated with a particular sub-domain of threat-appraisals over any other. To the author's knowledge, little empirical attention has so far been given to perceptions of increased personal vulnerability after TBI and this would therefore warrant further clinical and research attention. For example, how realistic is one's perception of threat in relation to their environment, and is this moderated by the secondary appraisal processes described above?

'Dealing with People' Avoidance was significantly more predictive of quality of life, anxiety and depression than the other Avoidance sub-domains. Thus, reported avoidance of social situations, on the basis of negative appraisals of threat, was generally the most significant predictor of adjustment. The 'Dealing with People' threat-appraisals themselves were not as predictive of adjustment.

Two aspects of this finding are of particular note. First, these results are striking considering that it was the sub-domain 'Doing Things', not 'Dealing with People', that generated the highest rates of reported threat-appraisals and avoidance. The 'Doing Things' sub-domain was not however as predictive of adjustment. Second, as informed by the initial qualitative phase of the research, the 'Dealing with People' items are largely characterised by the concern of those with TBI that others may evaluate them negatively. Exceptions to this rule may be the items 24. ("I sometimes feel I am not very good company,"), 25. ("I sometimes feel less sexually attractive since the injury,".) and 14. ("I sometimes lose my temper with other people,".) where the difficulties may also be, at least, partly attributable to organic or physical deficits.

To the author's knowledge, the present study is one of the few quantitative explorations of the negative perceptions of social information in people with TB1. Other examples of assessments of social adaptation difficulties have included The Head Injury Family Interview (Kay, Cavallo, Ezrachi & Vavagiakis, 1995) and the European Brain Injury Questionnaire (Deloche, Dellatolas & Christensen, 2000). These have, however, tended to focus on the individual's self-dissatisfaction in social situations rather than on the effect of perceived social threat. Elsewhere in the TBI literature, the deleterious effect of the perceived negative evaluation of others has received some discussion and/or qualitative investigations (e.g., Godfrey, Knight & Partridge, 1996; Nochi, 1998; Krefting; 1989; Crisp, 1993; Nadell, 1991; Willer, Allen, Liss & Zicht, 1991). Nadell, for instance, from an existential perspective proposes that the internalisation of other's negative appraisals can contradict one's own self-concept and thus lead to self-alienation. Additionally, psychological models outside of the TBI literature have demonstrated that negative self-evaluation through comparison to others can mediate depression (Festinger, 1954, Allan & Gilbert, 1995; Swallow & Kuiper, 1988;

Dagnan & Sandhu, 1999), particularly when personal resources conducive to self-worth are limited or absent (Champion & Power, 1995). Future investigations, with a greater focus on these processes, would therefore be merited. For example, hypotheses may be generated to test whether the negative evaluations made by others are sufficient for one's self-perception to be affected, as proposed by Nadell (1991). The present findings perhaps also suggest a particular need to establish socially based interventions that target both the individual's understandings of others' evaluations, and the effect that others' approaches to an individual with TBI may have, in order to address related appraisals of social threat and avoidance.

As the ATAI sought to assess avoidance in context of antecedent threat-appraisals, it is unlikely that the range of threat-appraisals included were exhaustive. Kendall and Terry (1996), for example, highlight research outside of the TBI literature that has identified an apparently distressing effect of uncertainty about one's future (e.g., Yarcheski, 1988). As the ATAI primarily sought to identify situations that may lead to avoidance, such areas of appraisal have probably been excluded and would deserve further investigation in their own right.

A post hoc exploratory path analysis provided an opportunity to explore the relative predictive relationships between each of the variables: anxiety, depression, overall threat-appraisal and overall avoidance scores on the ATAI, and that of quality of life, assigned as an outcome variable. This helped to unmask a more refined analysis from the, otherwise, many significant correlations evident. Of note, anxiety did not predict quality of life directly.

Anxiety did, however, strongly predict both avoidance and depression, which both in turn predicted quality of life; the strongest relationship with quality of life was held by depression. Interestingly, threat-appraisals did not relate directly to anxiety, depression, or quality of life, but rather their relationship to adjustment appeared to be mediated by avoidance. Given the difficulties that were described in the introduction section on previous research's conceptualisation of outcome, the finding that anxiety was predicted by avoidance, and vice versa is not surprising, and is consistent with Mowrer's (1939) two-factor theory of anxiety. A similar reciprocal relationship was suggested between threat-appraisals and avoidance. Furthermore, the hypothesis that higher avoidance was related to lower quality of life is also

intuitively plausible given the individual's limited exposure to sources of satisfaction brought about by avoidance. However, from contemporary cognitive-behavioural therapeutic perspectives (Beck, 1979; Wells, 1997), threat-appraisals might have been expected to have directly predicted both anxiety and depression, if not quality of life. Instead, threat-appraisals in the present empirical model appear to be mediated by avoidance and would therefore imply that the behavioural reaction of avoidance is of particular importance, especially when considering that avoidance did not follow a threat-appraisal on all occasions. It may also be surprising that anxiety did not directly predict quality of life but appeared to occupy a more central role by predicting depression and avoidance. In particular, anxiety's relationship to depression in the model perhaps faintly reflects that espoused by the learned-helplessness model of depression, described previously (Abramson, Seligman & Teasdale, 1978), whereby anxiety to accomplish an outcome is eventually joined by passivity in the event of perceived failure. However, passivity here might also be expected to be associated with avoidance but no direct relationship was suggested. The central role of anxiety, as suggested by the path analytic methods, would additionally echo that proposed in the models of coping and emotional reactivity by Goldstein (1939; 1952) and van Zomeren and his colleagues (1984; 1985). Particular clinical emphasis upon a routine screening of avoidance and anxiety difficulties after TBI may therefore help to identify vulnerabilities to depression, lower quality of life, and inform the timing of required interventions that target anxiety difficulties.

This empirical model of emotional processing is, however, based on a method of correlational analyses, is therefore exploratory, and the interpretation above is to some degree speculative. Although it appears to echo established clinical models and thus provides some cross-validity for the present data, the causal direction of which variable precedes which cannot be confirmed by the present study. Longitudinal analyses, particularly through case study methods (Kendal *et al.*, 2001) are therefore required to test further the dynamics of coping after TBI. The stability of the path analytic method presented is also in question without a replication of the results, preferably within a substantially larger sample than that in the present study. Caution therefore needs to be exercised in its interpretation.

The final analysis investigated the hypothesis that, based on previous reports (e.g., Malia, Torode & Powell, 1993), avoidance may relate to more difficulties in the later stages after injury. Support was found in a relationship between avoidance and quality of life in the late group (16-32 years since injury). Avoidance bore no relationship to any adjustment factors in the earlier group. As the relationship between avoidance and quality of life was not significantly stronger in the late group than for the early group (0.83 – 2.16 years since injury), only marginal support has been found for this hypothesis. Again, longitudinal analyses would be a more appropriate methodology to assess the longer term impact on avoidance coping. The small numbers in the early and late groups, and the imbalances in their respective ranges of years since injury limit the power of this analysis. Nevertheless, the present findings add partial weight to the contention of a negative relationship of avoidance coping to factors of adjustment in the longer term and would therefore merit further, and more comprehensive, investigation.

It should be noted that, apart from the identification of less avoidance and threatappraisals, the present study has not fully explained what is related to better adjustment after TBI. It is necessary therefore for future research to study those individuals who reported less threat-appraisals, and less avoidance after TBI, and to identify factors that relate to their better adjustment. This might, in a contextual analysis of coping, relate to approach based strategies, or flexibility of coping patterns as indicated by Kendal et al. (2001), or perhaps to the presence of social support. Alternatively, the answer may lie outside the factors investigated in traditional coping research. For example, personal resources conducive to a sense of hopefulness, gained through achieving new and realistic goals after brain injury may. as put forward by Prigatano (1999), relate to better adjustment. Relating to this, the reevaluation of one's goals after injury may help the individual integrate their new circumstances into a new self construct (Yoshida, 1993; cf. Kendal et al., 2001) and therefore manage intense emotions after TBI more effectively. In coping research elsewhere, the potential role of optimism in health related models of coping has begun to be delineated by Schwarzer (Health Action Process Approach; 1999). Here, self-efficacious optimism, that is when one trusts in their competence to achieve a goal after a setback or failure, is considered

'functional'; i.e., the belief that one can return to work after brain injury. Although not discussed by Schwarzer, this may perhaps also determine whether the individual's appraisal is one of threat, or alternatively, one of 'challenge'. Challenge appraisals are defined by Lazarus and Folkman (1987) as being fused with the individual's sense of control over what is at stake. Thus, although the present study has assumed that the appraisals accessed in the preliminary and main studies are threats, some people with TBI may however, consider them challenges, particularly those who did not report avoidance despite having endorsed a threatappraisal. This may therefore be another factor that determines whether the enactment of a consequent coping strategy is avoidant or not. Schwarzer, however, distinguishes optimistic self-beliefs from 'defensive' optimism. This is considered to be of benefit in regulating threatappraisals through maintaining a positive outlook, and allows the individual to go through daily routines without being hindered by constant worry, i.e., believing there will not be any difficulties in returning to work after TBI. Optimistic self-beliefs, rather than defensive optimism, are however required for behavioural intention, more realistic appraisals and goal setting, and may therefore be the beneficial counter action to avoidance. Alternative models such as these have received few empirical tests in an, as yet, thin evidence base for the aetiology of adjustment after TBI. How such a model of optimism might operate in a TBI population would, for instance, require specific investigation for the effects of cognitive deficit.

As the ATAI was developed specifically for the present study, its psychometric properties have a limited scope of extrapolation due to the modest sample size in the present study.

Although sufficient internal reliabilities for most of its measures were found, no factorial analysis was possible to confirm the structure of sub-domains that were largely based on face validity and the data provided by the preliminary focus group study. Additionally, no assessment of test-retest reliability was conducted and therefore the stability of the ATAI's responses over time is unknown. Furthermore, the self-report method used by the interview is subject to some of the same criticisms of standard self-report coping questionnaires. For instance, Gosling, Oliver, Craik and Robbins (1998) argue that the link between stated and actual behaviour is tenuous from such assessments, and this is considered to be a particular

O'Brien, 1990). However, it is not unreasonable to surmise that the substantial predictive validity of the ATAI to the adjustment factors in the present study was aided by the preliminary qualitative study in its development. The findings of such self-report studies of coping and behaviour should not be viewed in isolation however, but should be combined with other methodologies, such as the single case behavioural design demonstrated by Alderman (1991) and Youngson and Alderman (1994), the video based vignettes demonstrated by Kendal *et al.*, (2001), or by the case study diary method to trace phenomenological decision making processes and observations (Leonard-Barton, 1990, cf. Kendal *et al.*, 2001).

#### Conclusions

The present study has attempted to address the lack of attention given by previous research to the individual's subjective appraisal of the threat that may lead to avoidance strategies of coping following TBI. To summarise, the findings here have provided evidence about the kinds of threat-appraisals made by people following TBI. Specifically these have related to social issues, personal safety issues and the impact upon self-confidence from losses of activities and skills. It has been suggested that such threat-appraisals are fairly common after TBI and, what is more, they often lead to avoidance of situations. The most frequently reported ATAI category of threat-appraisal and avoidance was the section 'Doing Things'. All the categories of threat-appraisal and related avoidance appeared to correlate significantly with factors of adjustment, as represented by quality of life, depression and anxiety. In particular, threat-appraisals about 'Personal Safety' appeared to predict quality of life and anxiety more than any other category of threat-appraisals measured. However, the variable with the strongest and most consistent relationships to adjustment factors was social avoidance, as measured by the 'Dealing with People' sub-domain. A post hoc exploratory path analysis suggested that rates of avoidance are directly predictive of anxiety and quality of life. The relationship of threat-appraisals to adjustment, however, was suggested to be mediated by avoidance. Partial support was found for a weaker relationship between avoidance and quality of life in the earlier stages of injury than for those whose time since

injury was more advanced. The present study has not, however, accounted for why some people reported avoidance after reporting an appraisal of threat, whereas others did not. This would therefore warrant further investigation though, for example, stress-appraisal and coping models of social support processes, self-control beliefs or self-efficacious optimism. Further, it is recommended that future studies provide particular emphasis to the concerns of people with TBI about others' negative evaluations, and of their own personal safety.

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### Appendix A

Journal specifications: Contribution guidelines for authors

Clinical Psychology Review

Neuropsychological Rehabilitation

[Not available in the digital version of this

### Appendix B

Letters confirming ethical approval for research

[Not available in the digital version of this thesis]

### **Appendix C**

**Consent forms** 

Consent to Audio Tape

Consent to Interview



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Head of School

Professor G. W. Humphreys
PhD FBPsS CPsychol

Email

Direct Line 0121 414

#### Consent to audio-tape

This form asks you for your permission for the following session to be audio-taped.

I understand that the group discussion I am about to take part in is to be audio taped. The tape will be used to later analyse the discussion. This will be treated with the same confidentiality ensured for all other records used in this research.

Participant's signature	Date		
Researcher's signature	Date		



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#### **CONSENT FORM**

If you are happy for Andrew Brennan (Clinical Psychologist in Training) to interview you,

Researcher's signature.....

please sign this consent form.

Date.....

### Appendix D

## Letters and correspondence sent as part of the recruitment process for both preliminary and main studies

Information sheet (preliminary study)

Letters to participants with acquired brain injuries (preliminary study)

Letters to family members of people with brain injuries (preliminary study)

Information sheet (main study)

Letters to participants (main study)

Letters to service managers (preliminary and main study)



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### UNIVERSITY of BIRMINGHAM, SCHOOL of PSYCHOLOGY INFORMATION LEAFLET

# Research Outline: Coping with, and approaching everyday activities after a brain injury

#### Researchers

Andrew Brennan, Clinical Psychologist in Training Dr. Gerry Riley, Clinical Psychologist Dr. Theresa Powell, Clinical Psychologist

#### Introduction

The World Health Organisation has recently recommended that psychological problems should be added to physical and organic problems in the overall meaning of disability. This has given rise to new questions and challenges for researchers, clinicians, carers and policy makers.

It is well known that how people cope with everyday activities can greatly affect their quality of life. This is especially true for people who have had a major life event that has in some way made their everyday routines more difficult.

This project aims to help understand how people cope with and approach everyday activities after they have suffered a brain injury. It is hoped that its findings will help guide future therapy for people with brain injuries.

#### **Participants**

Three groups of 5-8 people each will be invited the take part in a discussion about people with brain injuries and how they cope with everyday activities. The groups will include:

- One group of people with brain injuries.
- One group of family members of people with TBI.
- One group of professionals (e.g. occupational therapists, support staff).

#### **Procedure**

Andrew Brennan, Trainee Clinical Psychologist, will consult with support and treatment centres for people with brain injury with regards to inviting people to take part in the discussion groups. Each group is expected to last for maximum of about one hour. These interviews will be audio tape recorded so that the information gained during the discussion can be later analysed. All the discussion groups will take place in April.

#### Ethical Considerations

The following points will be fully covered throughout the research:

- All discussion groups will take place within the treatment or support setting attended by people with brain injuries.
- A name and address of a contact will be left with staff in the treatment or support setting in the event that any participants would like future discussions about the research.
- Participants can withdraw at any time from the discussion groups.
- People will be reassured that declining to participate in the study at any time will in no way affect their future care or status.
- It should be noted that this research is unlikely to be of any direct benefit to its participants. Participants do not therefore have to take part.
- Confidentiality will be maintained by anonymity in all later reports.
- The participants' psychological and physical well being, feelings and wishes will be respected at all times, above and beyond the needs of the research.
- Data gained from the discussion will be transcribed onto a computerised database, and protected by a password. All raw data will be kept in a locked cabinet.
- The results of the research will be circulated from September, 2002.

#### Contact

Any queries regarding the research can be discussed with:

Dr. Gerry Riley or Dr. Theresa Powell School of Psychology The University of Birmingham Edgbaston Birmingham B15 2TT

Please quote reference: Doctoral thesis - Andrew Brennan.

The West Birmingham Local Research Ethi	cs Committee has a	pproved this
study. If you have concerns about this study	y and wish to conta	ct someone
independent, you may telephone	on	I.

#### Date 15/01/2001

#### Dear

#### Coping with, and approaching everyday activities after a brain injury

My name is Andrew Brennan and I am a Trainee Clinical Psychologist studying at the University of Birmingham. I am writing to ask for your help with some research into adjustment to brain injury that I am carrying out.

#### About the Study

The study aims to investigate any possible relationship between the ways that people with a brain injury cope with and approaches everyday activities and their overall adjustment to the injury.

#### In what ways will this research help people?

It is hoped that this research will eventually help to improve psychological therapies used to aid people's ability to cope with their injury.

#### What would I need to do?

I am looking for three groups of people to take part three discussion groups.

- one group of people with head injuries.
- one group of family members of people who have head injuries.
- one group of professionals who work with people who have head injuries.

The discussion groups will take place in a local centre for people with head injuries. These will not take any more than an hour to complete. You will be asked about your views on how people who have had a brain injury approach everyday activities, how they have managed to cope with these, and the impact that this has on someone's quality of life.

#### What about confidentiality?

Any information given will be treated confidentially. Any names, addresses or telephone numbers will only be used to contact you and will be destroyed later.

#### What will happen to the findings of the study?

A summary of the findings will be made available to all participants. In addition, it is hoped that the results will be published in a journal, thus informing other health professionals of the findings. No individual will be able to be identified from this study.

I have enclosed a detailed information sheet for you. However, if you have any more questions regarding the study I will be very happy to answer them. I, Dr. Riley and Dr. Powell can be contacted at the School of Psychology, University of Birmingham, on .

If we are not there please leave your name and number and you will be rung back.

If you have agreed to be contacted this does not commit you to anything and you are free to withdraw from the study at any stage.

Many thanks for your time and help.

Yours faithfully,

Andrew Brennan
Trainee Clinical Psychologist

#### What about confidentiality?

Any information given will be treated confidentially. Any names, addresses or telephone numbers will only be used to contact you and will be destroyed later.

#### What will happen to the findings of the study?

A summary of the findings will be made available to all participants. In addition, it is hoped that the results will be published in a journal, thus informing other health professionals of the findings. No individual will be able to be identified from this study.

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If we are not there please leave your name and number and you will be rung back.

free to withdraw from the study at any stage.

If you have agreed to be contacted, this does not commit you to anything and you are

I would like to hold the discussion group at -----at -----at -----at one will try to rearrange if this does not suit the majority. Please reply on the slip below. Travelling expenses will be refunded. I will look forward to talking to you. Many thanks for your time and help.

Yours faithfully,

### **Andrew Brennan**Clinical Psychologist in Training

ou are able to attend, please return this part of the letter to/elope provided.	in	the stamped	
in attend(please tick)	YES	NO	
unnot attend on the, but if the time could be inged I would be able to attend (if this he case we will contact you in the next few weeks)	YES	NO	

me			

12<sup>th</sup> May, 2001

Dear

#### Coping with, and approaching everyday activities after a brain injury

My name is Andrew Brennan and I am a trainee clinical psychologist studying at the University of Birmingham. The staff -----are helping me to identify family members of people with head injury for a research project, and has sent this letter to you. I am therefore writing to ask for your help in researching adjustment to brain injury.

#### About the study

The study aims to investigate any possible relationship between the ways that people with a brain injury cope with and approach everyday activities and their overall adjustment to the injury.

#### In what ways will this research help people?

It is hoped that this research will eventually help to improve psychological therapies used to aid people's ability to cope with their injury.

#### What would I need to do?

I am looking for three groups of people to take part three discussion groups.

- one group of people with head injuries.
- one group of family members of people who have head injuries.
- one group of professionals who work with people who have head injuries.

The discussion groups will take place in-----. These will not take any more than an hour to complete. You will be asked about your views on how people who have had a brain injury approach everyday activities, how they have managed to cope with these, and the impact that this has on the quality of life of people involved.



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#### UNIVERSITY of BIRMINGHAM, SCHOOL of PSYCHOLOGY INFORMATION LEAFLET 18/11/2001

Research Outline: Coping with, and approaching everyday activities after a brain injury

#### Researchers

Andrew Brennan, Clinical Psychologist in Training Dr. Gerry Riley, Clinical Psychologist Dr. Theresa Powell, Clinical Psychologist

#### Introduction

The World Health Organisation has recently recommended that psychological problems should be added to physical and organic problems to the overall meaning of disability. This has given rise to new questions and challenges for researchers, clinicians, carers and policy makers.

It is well known that how people cope with everyday life can greatly affect their quality of life. This is especially true for people who have had a major life event that has in some way made their everyday routines more difficult.

This project aims to help understand how people cope with and approach everyday activities after they have suffered a brain injury. It is hoped that its findings will help guide future therapy for people with brain injuries.

#### **Participants**

Fifty people with closed head injuries will be invited to answer questions in an interview and to complete three questionnaires.

#### Procedure

Andrew Brennan, Trainee Clinical Psychologist, will contact professionals or family members with regards to inviting people with brain injuries to participate in the research. He will conduct each interview in line with the person's abilities. Interviews should last approximately half an hour for each person. Additional questionnaires should take around half an hour also. All interview and questionnaire data will be collected between October 2001 and May 2002.

#### Ethical Considerations

The following points will be fully covered throughout the research:

- All interviews will be conducted at the centre attended by, or home of a participant.
- A name and address of a contact will be left with participants or family members/professional staff in the event that any participants would like future discussion about the research.
- It will be made clear to all participants that they can withdraw from the interview at any time.
- Deciding not to take part in the study will in no way affect current or future care and status.
- Confidentiality will be maintained by anonymity in all reports.
- The information obtained from the research will be handled in compliance with the Data Protection Act, 1998.
- There is unlikely to be any direct benefit to participants.
- Participants do not have to take part.

- Participants' psychological and physical well being, feelings and wishes will be respected at all times, above and beyond the needs of the research.
- The results of the research will be circulated from September 2002.

#### Contact

Any queries regarding the research can be discussed with:

Drs. Gerard Riley or Theresa Powell School of Psychology The University of Birmingham Edgbaston Birmingham B15 2TT

Tel.	

Please quote reference: Doctoral Thesis - Andrew Brennan



### THE UNIVERSITY OF BIRMINGHAM

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#### University of Birmingham, School of Psychology Information Leaflet

#### 29/01/2001

#### Research Outline:

Anxiety and avoidance in the aftermath of traumatic brain injury: An exploration of its nature as an emotional sequela of impairment and its relationship to adjustment

#### Researchers

Andrew Brennan, Clinical Psychologist in Training Dr. Gerry Riley, Clinical Psychologist Dr. Theresa Powell, Clinical Psychologist

#### Introduction

Traumatic Brain Injury (TBI) profoundly affects the quality of life of the person who has suffered the injury as well as the lives of caregivers, causing disruption and considerable distress to family life (Semlyen, 1998). Although the consequences of TBI are generally well recognised, psychological factors beyond the standardised ratings and profiles based on the reduction of intellectual functioning due to organic damage are largely underrepresented in the literature.

#### Project Rational

The present study broadly aims to build upon the current body of literature dealing with the emotional impact of TBI, and its relationship to post injury outcome. The initial experience when attempting to cope with a reduced rate and efficiency of information processing has been considered to result in an adverse emotional impact upon the individual. Anecdotally this has been characterised in the clinical TBI literature by a reduction of confidence and increased anxiety and avoidance of social, work, leisure and domestic activities. This is also consistent with a prominent feature

of the 'catastrophic reaction' formulated by Kurt Goldstein (1939; 1942; 1952). The individual therefore displays levels of disability beyond those predicted by a reduction in intellectual functioning alone (Montgomery, 1995; van Zommeron *et al*, 1984; Prigatano, 1984).

This formulation is consistent with, and has been partially supported by, investigations of the coping style of people with TBI where avoidance is predictive of greater emotional distress after TBI (e.g. Malia *et al*, 1995). Such studies have not, however, employed measures tailored for people with TBI, and their subjective beliefs on the matter have therefore not been investigated. The beliefs associated with anxiety and avoidance behaviour have been well established as maintaining cognitive factors within a number of other psychological difficulties ranging from phobias (e.g. Salkovskis, 1991) to exacerbated levels of pain (e.g. Rachman, 1991), and a variety of health related difficulties (Moos & Scheafer, 1993). It is therefore worth considering the pervasive effects of such processes in post-TBI adjustment which, so far, have received attention from just a small section of the literature (e.g. Kendal & Terry, 1996; Moore & Stambrook, 1995; Cicerone, 1991).

These proposed emotional consequences are regarded as a 'psychogenic' rather than direct organic sequela of TBI. This more complex interaction between organic impairment, emotional factors and disablement after TBI is consistent with the World Health Organisation's (1999) recent promotion of biopsychosocial models in their international classification of impairments, activity and participation (ICIDH-2; WHO, 1999).

#### Project Aims

The specific aims of the present study are:

- To use qualitative methods to classify what makes people anxious about participation in different everyday activities and to explore in more detail why they avoid them.
- To devise a structured interview to measure the activities that people avoid, and, based on the qualitative data, their reasons for avoidance.
- To apply this measure to a well defined sample of people who have sustained a TBI, in order to establish the frequency of anxiety-related avoidance of activities.
- Additionally, to provide some evidence for the validity of the measure by correlating it with established standardised measures of emotional adjustment to acquired disability (Hospital Anxiety and Depression Scale) and general measure of quality of life (Quality of Life Index).

#### Hypotheses

The present study will test the following hypotheses and exploratory question.

• Anxiety and avoidance is hypothesised to have a 'mediating' effect on outcome after traumatic brain injury as measured by emotional adjustment. This hypothesis is to be tested by a correlational analysis between scores from the anxiety and avoidance structured interview (to be developed) and a generic measure of emotional adjustment to disability (Hospital Anxiety and Depression Scale). This is therefore expected to

yield a significant correlation whereby elevated scores relating to anxiety and avoidance after TBI is predictive of a negative index of emotional adjustment.

• Convergent validity of the structured interview will be tested by analysing the strength of correlation between its scores, and scores of avoidance on a measure often used to assess avoidance coping (Coping Schedule).

#### **Participants**

Phase One

Three groups of 5-8 people each will be invited the take part in a discussion about people with brain injuries and how they cope with everyday activities. The groups will include:

- One group of people with brain injuries.
- One group of family members of people with TBI.
- One group of professionals (e.g. occupational therapists, support staff).

#### Phase Two

Approximately fifty people with closed head injuries will be invited to answer questions in an interview and to complete two questionnaires. Following permission from the person with TBI, family or professional carers will be asked to complete a brief questionnaire on information about the person's activities and personal details (e.g. age, time since injury etc).

This phase is due to begin in September, 2001 and continue until March 2002.

#### **Procedure**

#### Phase One

Andrew Brennan, Trainee Clinical Psychologist, will consult with support and treatment centres for people with brain injury with regards to inviting people to take part in the discussion groups. Each group is expected to last for maximum of about one hour. These interviews will be audio-tape recorded so that the information gained during the discussion can be later analysed. All the discussion groups will take place in April.

#### Phase Two

Andrew Brennan will consult with services and professionals to discuss inviting people with TBI and family members or care staff to participate in the research. Testing time for the interview and questionnaires should take no more than forty-five minutes to complete.

#### Ethical Considerations

The following points will be fully covered throughout the research:

• All interviews will be conducted at the centre attended by, or home of a participant. This will be in a private room where the least possible interruption will occur.

- Name and address of a contact will be left with staff in the event that any participants would like future discussion about the research.
- It will be made clear to all participants that they can withdraw from the interview at any time.
- People will be reassured that if they decline to participate in the study, it will in no way affect their current or future care and status.
- It should be noted that this research is unlikely to be of any direct benefit to its participants.
- Participants do not have to take part.
- Confidentiality will be maintained by anonymity in all later reports.
- The participant's psychological and physical well being, feelings and wishes will be respected at all times, above and beyond the needs of the research. If at any time distress is caused by the research, it will be stopped until the situation is resolved.
- Interview data and data from questionnaires will be coded and entered onto a computerised database, and protected by password. Back-up data will be saved on a floppy disk, and protected by password. All raw data will be kept in a locked cabinet.
- The results of the research will be circulated from September, 2002.

#### Contact

Any queries regarding the research can be discussed with:

Dr. Gerry Riley or Dr. Theresa Powell School of Psychology The University of Birmingham Edgbaston Birmingham B15 2TT

Tel.		
Please quote referen	ce: Doctoral Thesis - Andrew Brennan	

The West Birmingham Local Res	search Ethics Commi	ttee has approved this
study. If you have concerns abou	it this study and wish	to contact someone
independent, you may telephone	on	1.

#### Date

### Person with TBI's name Address

Dear

Coping with, and approaching everyday activities after a brain injury

My name is Andrew Brennan and I am a Trainee Clinical Psychologist studying at the University of Birmingham. I am writing to ask for your help with some research into adjustment to brain injury that I am carrying out.

#### About the Study

The study aims to investigate any possible relationship between how somebody with a brain injury copes with and approaches everyday activities and their overall adjustment to the injury.

#### In what ways will this research help people?

It is hoped that this research will eventually help to improve psychological therapies used to aid people's ability to cope with their injury.

#### What would I need to do?

I am looking to invite people with head injuries to interview and to fill out some questionnaires. These will ask you about how you have coped with everyday activities since having had the injury, and the impact this has had on quality of life. It should take about an hour to complete everything.

#### What about confidentiality?

Any information given will be treated confidentially. Any names, addresses or telephone numbers will only be used to contact you and will be destroyed later.

#### What will happen to the findings of the study?

A summary of the findings will be made available to all participants. In addition, it is hoped that the results will be published in a journal, thus informing other health professionals of the findings. No individual will be able to be identified from this study.

I have enclosed a detailed information sheet for you. However, if you have any more questions regarding the study I will be very happy to answer them. I or Dr. Riley and Dr. Powell can be contacted at the School of Psychology, University of Birmingham, on .

If we are not there please leave your name and number and you will be rung back.
If you have agreed to be contacted this does not commit you to anything and you are free to withdraw from the study at any stage.
Many thanks for your time and help.
Yours faithfully,
Andrew Brennan
Trainee Clinical Psychologist

### Appendix E

#### **Preliminary Qualitative Study Description**

Rationale and procedure

Categorised raw data: Dealing with people after acquired brain injury

Issues of personal safety after acquired brain injury

Particular activities where confidence may be lacking

Issues about doing things

Awkward situations

Example transcript: Focus group of 3 men with acquired brain injuries

Appendix E

Preliminary Qualitative Investigation

Rationale

An initial qualitative investigation was employed for the development of a questionnaire. This specifically aimed to identify the types of difficulties that people with ABI might appraise as difficult since their injury and may therefore go on to avoid. Focus groups have been proposed to be of benefit to the design of questionnaire based measures (O'Brien, 1993a; 1993b), particularly for the uncovering of complex motivations and behaviours (Morgan, 1998;1993). Kreuger (1994) states that focus groups serve primarily as a means of raising issues and considerations not included before and for generating testable hypothesis. Furthermore, qualitative data allow for the language and meanings provided from an insider's perspective to be considered in subsequent

1991; Skevington, MacArthur & Somerset, 1997).

Qualitative Investigation: Appraisal of Difficulties Following ABI

descriptions of the data and for the design questionnaire measures (Hyland, Finnis & Irvine,

**Procedure** 

In order to elicit information on individuals' perspectives of difficulties after ABI, open-ended questions were arranged into an interview guide. These broadly aimed to cover the following areas.

- Situations and activities of daily living that are considered difficult.
- What people found threatening about these situations.
- What may be avoided due to a lack of confidence.

These areas were selected on the basis of the literature on the topic and the researchers aims.

The first author moderated the groups. A colleague sat in to act as a scribe, and to note first hand

the emergent themes. The interviews and groups were taped recorded for later transcription (see

Appendix C for audio consent forms). The groups lasted approximately an hour in duration, as did the individual interviews.

#### **Participants**

Four focus groups were employed. The data from the focus groups were supplemented with one to one interviews and also with themes taken from first hand accounts of people with ABI (Buck, 1983; Freedman, 1987; Linge, 1980; 1990; Newborne, 1997; Quinn, 1998: included in main appendices). two groups of people with ABI (n = 3 & 2 [all male]), one group of professionals working in an ABI rehabilitation service (n=10) and one group of family members of people with ABI (n = 9). The injuries of the participants and relatives of people with brain injuries were of mixed aetiologies, either cerebral vascular accidents or closed head injury. One additional interview with rehabilitation professional was also conducted.

#### Coding Process

Audio tapes of the discussions were transcribed verbatim (see example transcript in this Appendix). Two analysts reviewed the scripts independently to identify key areas of difficulties that were experienced. Thematic analysis was used (Dey, 1993) to encode the data. Each emergent theme was noted in the text across the transcripts and given a code. Themes were constructed using the 'cut and paste method' recommended by Dey. Themes might take the form of a word, sentence, phrase or anecdote. The themes were then collected and broadly categorised into the four main areas listed below.

- General difficulties experienced when taking part in activities.
- Issues relating to personal safety
- Difficulties in social situations.

These categories were used to inform the structure of themes within the ATAI interview used in the main study. The raw qualitative data and categories gleaned are included in the following section. The themes and items of data that were included in the ATAI have been cross referenced with the example of the interview in Appendix E. The section on data categories is followed by an example of a transcript from one of the focus groups.

#### References

- Hyland, M.E., Finnis, S., & Irvine, S.H. (1991) A scale for assessing quality of life in adult asthma suffers. <u>Journal of Psychosomatic Research</u>, 35(1), 99-110.
- Kreuger, R.A. (1994). <u>Focus groups: A practical guide for applied research</u>. Newbury Park, C.A.: Sage
- Morgan, D.L. (1988). Focus Groups as Qualitative Research. Newbury Park, C.A.: Sage.
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- O'Brien, K. (1993a). Using focus groups to develop health surveys. <u>Health Education</u>

  <u>Quaterly</u>, 20, 361-372.
- O'Brien, K. (1993b). Improving Survey Questionnaires Through Focus Groups. In Morgan D.L. (Ed.) <u>Successful Focus Groups</u>. Sage Publications. Newbury Park: London.
- Skevington, S.M., MacArthur, P., & Somerset, M. (1997). Developing items for the WHOQOL:

  An investigation of contemporary beliefs about quality of life related to health in Britain.

  British Journal of Health Psychology, 2(1), 55-72.

#### **Identification Codes**

The following explains the meanings for the qualitative codes. Used in the following analyses, and example transcript to track the sources of each item included in the categories. These have also been used to cross reference the qualitative data with the Appraisal of Threat and Avoidance structured interview.

#### Focus Groups

F = Focus Group, 1 = Professional's Focus Group

2 = Family Members

3 = People with TBI (Three males)

4 =People with stroke (2 males)

P = Page Number

M = Male (number is to identify each male)

F = Female (number is to identify each female)

T = Transaction number

#### Individual Interviews

I = Individual Interview

I1 = Person with a closed head injury (female, lives independently now looks after first infant child)

I2 = Professional working with people with acquired brain injuries.

I3 = Individual with a closed head injury (male, attending rehab service)

I4 = Individual with a closed head injury (female, attends day service).

Items that have been taken from author's quotes are referenced by each item.

# Dealing with People after Acquired Brain Injury

#### Social Discrimination/Stigma

- F3 P3 M2 T2 ....if you hear somebody, something in a pub or a friend and he's had a brain injury you think, stay away from him, that's your immediate reaction.
- F3 P4 M2 T3 I suppose, its... just the stig...with any disability there's a stigma with it. Yeah it is. I think I was just as ignorant as anybody else in thinking I would be a nutter.
- F3 P4 M1 T7 Yes I think its ignorance as well.
- F3 P4 M3 T4 Yeah, yeah, yeah. I don't really know any people who have got a brain injury, so you think like that. Like I say, most people go out, just go out like and they think that just the way you talk, the way you watch people, they think, God, he isn't all there like, he ain't all there like, he's watching. I have loads of different problems I do like, I say to (therapist), how, how I haven't gone back to hospital yet like with a load of blokes who have got me like and give me a good smacking?

#### Social Rejection

- F3 P7 M3 T10 (in context of having been asked what has been the main change since the injury) You feel rejected don't you?
- 3. Newborne, B. (1997) The frightened lonely feelings came back to haunt me as nightmares. But the worst nightmare was waking up to find that I did not feel or look or act myself any more. I had gone from healthy to handicapped in an instant, from "one of us" to "one of them," from being a full member of the human race to being an outsider, a reject. That was the source of my deepest terror.
- F2 P4 M1 T15 .....because they feel, now this seems strange, they feel neglected, they feel as though they've been forgotten, they are the forgotten people.
- F2 P1 MI TI/T2 (interrupting) It's always the same. Because when I took my son to see the surgeon, he said "I suppose you feel you're with the losers,". (Fac;

  The surgeon said that?). Yes. I'm not going to mention no names, I mean he was for the other side. He said, "I suppose, Arthur, you think you're with the losers,". He said, Yes, I do. Because all these people that he associated with while he was at college went about their business, not that they were avoiding him, but that's life, y'know.
- F2 P5 M1 T16

  And, and I don't think, I don't think it's just a question of, like, being forgotten by a family, I think eh, they feel as though they have been more forgotten by society. I'm not saying going out, coming in... I mean I take my lad everywhere, football matches, you name it, all that. He sees that as a part of normal life. But where he was at college and he thought: I'd get somat' back or..... from.... the medical fraternity, I'll get somat' back.... No!.
- I3 P5 T23 Not seeing anyone and speaking to them, it's an easy way out isn't it? I suppose. If you don't confront anybody or the situation you're in, it's a lot easier I think.

- F2 P1 M1 T3

  If they go to colleges, go to different places and do different jobs. If you're not in that factory you lose track. I mean, you forget that most people are just ordinary working class, and when they're out of work that's their social life even though they don't want to admit it. They don't socialise at home, they socialise there. So their social life goes and that person then becomes isolated. Always I think, even today they become paranoid when they become isolated, I had that with my son.
- F2 P15 F4 P29 I've got another sister and she phoned me and Ian answered the phone, she was very abrupt, I'll ring back when Beryl's in, slammed down the phone.

  She wouldn't say: "How are you Ian?" now that really is bad.
- F2 P1 F1 T2-4 Well it's the same with Jim really......He had this accident at seventeen......And he had loads of friends before that, and his accident was a motorbike accident. They all had motorbikes, so you know, they were always out. So then I mean they were all just young lads, like Ian, so they came to the hospital, you know, just sort of for a few weeks, came round...... (but when Ian organised a party) and you know, nobody turned up. Well, two girls turned up and there was nobody there so they went and Ian was left on his own..... But this is it you see, their lives (lan's friends) still goes ahead,".
  - F2 P2 M1 T5-7 And (inaudible) they can't sort of communicate. Because they do change when they've got a head injury....They can't quite......I think society, society changes, in all......I think people themselves change. If they can't communicate with ye. If you can't communicate.... If I can't communicate with that chap there, our relationship, even if it was on the best terms, it's going to change.

#### Difficulties with Questions Asked/Seeing Old Friends.

- F1 P1 F1 T1

  It sounds to me that this concept for one person rings a bell. They don't like going out because, because, they have to sort of go through the same thing and tell people,"Yes I've had a car accident, blah blah", they just can't be bothered to go through it all again, to tell people what actually happened, and I think he just, in itself, like he was wanting to put it past him and be reborn so he didn't wind people up.
- F1 P1 F1 T2

  I think if he hadn't been to his, erm, pub, erm, for quite a few months or something and people used to say "Oh I haven't seen you for ages, What sort of happened to you?". And then he has to go in and start telling them.

  Y'know it is a shock to them, yet he has always said he likes going to places where people don't know him, so people aren't laughing, they just take him at face value really rather than going on what he was before.
- Is P1 T6

  So on the whole I'm still a bit dubious of meeting old people who I hadn't seen for a long time. I'm not too bad now, because I've lost a hell of a lot of weight now, I'd lost about a quarter of my weight anyway (he had put a lot on after the injury)...I prefer not to meet people I knew from before the accident, y'know, who I hadn't seen for a couple of years. (Fac. What puts you off doing that?). I suppose from people I've been talking to here, it's probably embarrassment, I don't know why. You haven't got the confidence than I had, I mean I used to be in charge of a good amount of chaps and things like that, so. I always done my own thing and being in this situation I

can't do anything for myself and that y'know. I think it's worse. I shouldn't imagine it would be as bad as if I was more of a 'go with the one who leads you' sort of thing but I was always the one who did anything. Even with the lads y'know. But when you can't do it physically anyway or mentally I suppose I couldn't eh, it's a bit of a shock and obviously rather than accept it, its best to keep out of the way and so I wouldn't go out. I've only just started going out now but only to places where I know there's not going to be anybody I know there.

- 13 P2 T7 (Fac. I know some people have said they don't like old friends asking questions?) That's the worst thing y'know, well when they: "Oh Blimey what's happened to you?" It's embarrassing and I think I get fed up of it anyway because I know a lot of people. But if you stay in (at home) you don't have to confront people with it.
- I3 P5 T23 Not seeing anyone and speaking to them, it's an easy way out isn't it? I suppose. If you don't confront anybody or the situation you're in, it's a lot easier I think.

#### Not Fitting In.

- F2 P7 F1 T9 ......for the younger ones, at Ian's ages of seventeen, they've never had the chance, never had the chance actually to eh, form a relationship feeling cut off at the age of seventeen when they're going out with girls and what not, because all this has happened. They've missed that part of their lives. But by the time you, you know, are seventeen you feel you are alright, but you've lost contact with everybody and you've got nobody to go out with in the evenings you know. So they've none of their own. And to be honest, I'm afraid of Ian wants to go into the town where we live because there's so many pubs now that you can wander and go into another pub, so much, you know, these getting mugged and all sorts, that your afraid.
- F2 P9 M1 T26-28 ...one of the strongest things I find with most people in here is fear. (T28) I think it's fear of being alone, I think it's fear of not fitting in.
- F2 P7 F2 T16 Definitely with Mick it's going where there's a crowd of people he doesn't know. The day centre is fine because they're all like minded people, aren't they?.
- 4. Newborne, B. (1997) An analogy is to imagine yourself a stranger in a foreign land, not knowing the customs or language. Your vocabulary might be limited to a few words –not even enough to ask for food or ask for directions. Your first utterance would be a conscious, effort-ridden response. A native not comprehending what you were trying to say, would be apt to interrupt or even ignore you, and you would feel lost, alien and helpless as a result. Such is the case with aphasics. They are always strangers in a strange land.
- 5. Newborne, B. (1997) I suppose that parents taught their children to fear anyone or anything that was different; they dared not question the underlying truth. Linda and Charley needed friends and compassion then more than at any other time in their lives. Instead people only saw their external scars and reacted by ostracizing them. They refused to acknowledge the vulnerability felt by

those affected by the disease, disaster and difference. In their refusal, they prejudged people who were not as "normal" as they were.

- 7. Newborne B. (1997) Inside the building it was noisy and closed in, and the people frightened me. I was already trying to adjust to too many things at the same time. I felt that some sort of plastic barrier, like a bubble, was separating me from other people. It was as though I was walking in a strange dream state, with all those people staring at me. In the past I had known that they were staring for a better reason. I was attractive and full of life. Now I imagined that those stares were looking inside me, believing there was nothing there. I felt choked, suffocated; I needed to get out. I wanted to go home or back to the hospital where I was safe and secure, where people were like me or worse. They were the only ones who understood me now.
- Buck, M. (1963) It is important to be continually aware of the fact that the patient can have an extreme inability to recall both current and past events. The stricken patient can suffer drastic emotional disturbances all too suddenly when we do not have a thorough understanding of this behavior. If he is subjected to a continuous sequence of unreasonable demands, he has no choice but to voluntarily remain silent and completely withdraw from any social situation. When this occurs, the depressive psychological overlay may stimulate extreme suicidal plans and/or actual attempts.

...behavior of this type is not readily understood by personnel outside of the family; we as professional persons, must keep in mind that the patient usually has an immediate recall of events if they are noted in a kind and easy manner by those within the situation. This kind of behavior is usually not pursued merely to attract attention, for it is most often a result of an extremely short memory and self-disgust.

When the patient begins to initiate obvious symptoms of insight, it is necessary that we remember he is bound to have some internal disgust concerning his failure in recalling current activities.

#### Social Disempowerment/Depersonalisation

- 2. Newborne B. (1997) I chose not to be a victim. From my experience, this word conveys the negative connotation that the person is helpless and passive, and reinforces the belief that illness is only a negative phenomenon.
- 6. Newborne, B. (1997) I had longed for people to see beyond my disability.
- F1 P4 F5 T3 It's the experience of the injury and kind of what's happened in the recovery up until this point, i.e. being hospitalised and all the conditions (inaudible). I think they probably get disempowered really being used to a very medical model and they would be looking to the doctors or whoever to be very directive.
- It's a bit annoying when I, erm, say I've know people in the past and they've known I have a head injury and all that. But I make a mistake and do something wrong: "Oh it's your head injury". Everything is blamed on the head injury. Hold on everyone makes mistakes, why does it have to be because I've had a head injury?.
- Having people tell me to do things is a no no for me you know. I didn't want to come here and have people tell me what to do. Y'know when I worked for

people, contracting, I used to tell them how I'm going to do it, not how they want it, they'll get someone else. With my personality I'm a bit strong with that sort of thing. So with coming here there's a reverse of the situation.

II P8 T55 Sometimes, I think people who I meet, I think, 'You're just labelling me'. just 'Head Injury,'. Because I do some thing wrong, it's "Head injury,". Y'know what I mean, sometimes I wonder, are they always going to think of me, associate me with the accident, or y'know, or just leave it, if I make a mistake I make a mistake. Y'know I've done so well but I think I'm always labelled with a head injury, that's why I think I wonder sometimes, am I told everything that's going on around the family? Y'know is it kept quiet?

#### People Watching Me

- I4 P4 T27 (I was just wondering about the possibility about going into employment?)
  ...No because I don't like people staring or watching me and I might lash out then.
- I don't like people staring at me. I'm very self-conscious. I mean they're only looking at me because they're speaking to me. Sometimes I think to myself, what are they looking at? I know it's wrong of me but sometimes I can't help it...I do it (go to the pub) on very, very rare occasions...I think they're eejits. Probably only for my benefit they're doing that, that's what I'm supposed to think, but I don't think that. They're eejits. I mean I can't help doing things wrong. If they wanted to get to know me, or be my friend then they've got to understand me. Not everybody (understands) especially if they don't know me. Of course they're not going to understand me are they...They should be locked away or something...They see the wheels (wheelchairs) they don't see the person in the chair, they see the wheels...It rubs me up the wrong way.
- Quinn D.A. (1998) (diary entry) I woke up in a good mood, but when Mom showed up unannounced whilst I was exercising because I didn't answer the phone, I felt more depressed than ever. Just seeing Mom made me feel even more keenly how much I had lost my independence and privacy, because people have been constantly worried about me and checking up on me. They don't trust me to take care of myself properly.
- If I get on a bus now I feel a bit awkward. I'm still a bit unsteady on my feet anyway, but I'm watching all the time just in case I miss my stop or anything silly, you don't want to look the odd one out. I'm sitting there thinking: 'Is everyone looking at me?' They're probably not but I can't help the way I am.
- F4 P3 M1 T6 You're always conscious of how other people might see you, how you're speaking how you're walking.
- In the early days I could not accept my disability even though I was in a wheelchair, if I couldn't do it I would throw a tantrum just because I didn't want to admit I couldn't do it no more. I locked myself away, I was that embarrassed, I didn't like people looking, talking or doing anything with me. I could not accept it. It took (acceptance) about six years in all. After about six years I could understand then a little bit. They used to say I can't do that, but I said I can. But after six years I realised I couldn't do that or it was impossible to do that, but I learned to accept.

#### Negative Perceptions of Other's Evaluations

- F1 P1 F2 T1 ...our clients particularly are often, erm, mislabelled by the general public so assumptions might be drawn for example to a, to a brain injury, is drugs for example, and that can affect social, I think, erm social situations, and obviously the person is kind of receiving those kind of cues, and and, and, y'know the result will be something affecting the self-image really. And the confidence we're trying to build is affected by that.
- F1 P4 F5 T4 ...the people around them can cause them to lose confidence as well......with their relationships with carers and that can be erm, pessimistic in what they are able do.
- I4 P7 T34 People think just because I've got a head injury, I'm in a wheelchair, I can't think properly myself. They're sadly mistaken. I can think better than a lot of people.
- F1 P1 F2 T2 Clients express difficulties that, because the disability is hidden especially if it's a mild cognitive difficulty that without the erm physical disability there's no obvious erm, erm features. Which sometimes if someone's, in a wheelchair, for example, erm, some members of the public might give a little bit more leeway or might be a little bit more helpful because it's a bit more obvious what some of their problems are. But if its somebody just with a cognitive impairment erm maybe with slightly slurred speech who is having difficulties erm, processing information, the speed of information, thinking things through, getting distracted by the erm different stimulus things in the environment. I think, people, the general public can often jump to assumptions.
- F4 P6 M3 T9 Sometimes in your own mind it may seem level why you were saying it or thinking it, and then somebody is trying to understand it, and sometimes you can take it on and it's an insult to yourself. You think: 'What am I going to do?' Am I going to just sit and not say anything?'. But you've got to get up and beat yourself at that and try. It's better than giving into it.
- It's always been, y'know, say I haven't seen anyone for a number of years, old friends "How are ya?". Or they'll, if anyone finds out I've had a head injury its always talk to my husband kind of thing, y'know if I meet people. I suppose it's just the label of head injury people think "oooh", that's why they always talk to the person with us.
- Yeah, they start to look at you in a different light, they start to talk slowly, y'know. Things are a bit patronising.
- F1 P7 F4 T6

  At the moment I've got a client who wants to go back to college where he was training to do hotel management and he wants to go back to do reception. But he said that he couldn't go back on reception 'because of the way I (the client) talk(s)'. But he's a hundred per cent intelligible. We got into discussions about the way people perceive the way he talks and it is very much an attitudinal barrier, isn't it, he'll clam up when he's on the phone but its nothing to do with intelligibility. He perceives that he doesn't speak normally. (also in Particular Activities).

- F1 P2 F3 T1 It's a negative perception, they could have previously misinterpreted, I think from pre-morbid views, also things about other people, and now they're like them (i.e., the transition from misperceived member of the public to person with a brain injury).
- 1. Newborne, B. (1997) For the first time in my life, speech became a conscious and deliberate act, filled with errors, including stuttering, mispronunciations and nonsense words. I became extremely anxious whenever I had to talk to strangers and even good friends; I thought that society now presumed my intelligence to be lessened or retarded. I could no longer convince anyone that only my speech had become impaired and not myself.

#### Other's Negative Reactions.

- (Fac. About independence, Is there any other aspect of it that puts you off doing things?) Only when people shout at me. (People shout at you?). Yeah if I've done something wrong then bugger it, I'll leave it. (Right, because you were asking me not to shout at you (to begin with) if you got this wrong. There's no right or wrong answers for this, and I wouldn't shout at you anyway. But in which kind of situations would that actually happen?). If say I'm cooking and I put the wrong ingredients in it'll be: No: Don't do that! And I'll say, Oh bugger it and throw it at them, walk off.
- People laugh, that bugs me as well, people laugh and I start shouting then, and then when I start shouting then that's the time to run (laughs). People should realise that I can't do everything, they gotta take the time to explain to me that I can't say I'm the fastest speaker in the world, they have to slow right down to me.
- ... before the accident I might have looked at the person in the wheelchair and perhaps had a little laugh, my mum noticed some time ago: Before the accident you would have laughed! Y'know, but now I can relate to people in wheelchairs I've got a lot more patience with people, it's not kind of turn you're cheek.
- People laugh, it hurts me that people laugh at me because they don't understand me.
- FI P2 M2 T1 I think if it's a, it's a younger person who's had a head injury, I mean I have a client who used to get a lot of stick from neighbours and stuff like that, and some of the kids would throw stones when he was y'know, just like walking through the estate, just like a ... year or so ago, and that's led to an awful lot of problems, socially. (also in Personal Safety)

#### Losing One's Temper with People.

- F4 P5 M2 T6 Or if you're trying to explain something to somebody, they don't seem to understand, which is probably your fault if you didn't explain properly, you're getting worked up.
- F4 P5 M2 T5 I've got a shorter fuse now. Before I had the stroke people say I was a nice laid back guy. I snap!

F4 P5 M1 T10

The other day I asked the wife to the cancel the ambulance. Sorry not to cancel, to order the ambulance to pick me up to take me to the hospital. And eh, the long and the short of it, it wasn't (didn't arrive) and I blamed the missus and I shouldn't have done really, it was nothing to do with her and I just snapped. I was shouting at her: "Where's the bloody ambulance?" It wasn't her fault, there was nothing she could have done about it anyway like.

F2 P3 M2 T1

When my wife comes here (*day centre*) she is a different person. When she was at Landudno she was a different person. And at home you've got to have it day in day out you get the aggro......

- F2 P4 M1 T14 (in context of a discussion upon anger difficulties) I think their tolerance level loses, diminishes greatly....
- F2 P10 F4 T23 I honestly think anyone with a head injury has got a very short fuse, haven't they?
- F3 P4 M2 T5 Then you have behavioural problems when you have a brain injury which I've experienced and had, since I've seen a psychologist and that happens, then you start questioning yourself. I've been been out reacting and shouting in the streets at people in a queue but, in a way, my anger is, so I'm aware I will start to have sort of behavioural problems I'll get annoyed and aggressive if people get in my way. That's now being dealt with, that's twelve months after, you know, it takes, I don't know how long its takes. It takes time for these these things to be resolved at various levels, at the, the early stages of, after the initial injury. They may not come out immediately but... obviously its happened and I think that's what's happened there and then, the actual sort of effects might not come out until later which I found. Like this, this behavioural thing didn't start until the last few months as I've been more adventurous and going out further.
- F3 P6 M2 T7 Obviously as I've been seeing my psychologist, I am having problems with sort of like, temper rages, over silly little things that wouldn't have happened before. I find it very hard to control that y'know. I can't physically do things, but verbally I can still scream and shout. That's how I feel, it's like a rage inside that wants to get out, why can't I sort of change this?
- F3 P4 MI T8 No I was just going to...I haven't got the problem out in the street like that, but one of the problems I have that I liken to that is the fact that I haven't got the strength with my one son in the sense that he knows just how to wind me up. I'm not able to curb my, its odd, my patience. He knows how to push that button as it were, and it annoys me that (I can't) control him in the sense to discipline him, and I can't curb my...it's a catch 22.
- F1 P4 F5 T4 ...the people around them can cause them to lose confidence as well......with their relationships with carers and that can be, erm, pessimistic in what they are able do.

## Issues of Personal Safety After Acquired Brain Injury

#### Vulnerability to Physical Attacks

F3 P13 M2 T31 I think if you get negative things happening that might put you back when those things happen. It would impact probably more so when you have an injury like ours because you're sort of looking for hope aren't you. So when something good happens in life, say like me, I've passed my assessment, its wonderful so I'm learning to drive now and that's something to strive for. But being sort of robbed for my wallet, it's a very negative thing and I didn't want to know. I wanted to go forward. (Fac. Did that give you doubts about yourself?) (T32) Yes because I couldn't defend myself. Physically I'm not able to defend myself so that made me feel extremely vulnerable. (Fac. And what would worry you most about that?) That society in this day and age y'know, the way it is there's just no morals out there with the youth of today and no principals, like an old lady I was an easy target.

F3 P13 M2 T29 I was robbed not so long ago.

- F4 P1 M1 T2 Occasionally I get worried about how I'm going to handle myself, and worry about what would happen if I got in a ruck or something. I live in a fairly rough area like. You have to think about the realities around you.
- F1 P2 M2 T1 I think if it's a, it's a younger person who's had a head injury, I mean I have a client who used to get a lot of stick from neighbours and stuff like that, and some of the kids would throw stones when he was y'know, just like walking through the estate, just like a ...year or so ago, and that's led to an awful lot of problems, socially. (also in Dealing with People)

#### **Kitchens**

Part of the task that you're (rehab professional) doing, erm, might be to do with showing the person you can do it, or or showing family members that they can do it when they're actually able to support the person to continue to do it, to continue the package. So eh, common things that come up is, Fred Bloggs couldn't possibly do things in the kitchen because it would be dangerous, he's got a memory problem. How could they possibly be safe when actually pretty simple strategies can be used? (also in Particular Activities).

#### Dealing with Traffic

- F3 P8 M2 T14...there's dangers in going out into the road as a pedestrian.... (T15)
  You get to lights and problems with cars coming passed and they
  changed. That is a major problem for me.
- F3 P8 M2 T17 I've walked across lights, like, and cars have just gone straight through the light, and I've got a little girl and pushed her out into the road so

you know its like they can't rely on me to be out on me own. Understandable, the light's green to walk and cars are coming from left and right. I've got a problem with vision. As M3 like said it's a problem.

- F3 P13 M2 T29 Eh well it's just the danger of falling and your unsure and unsteady, and you're disorientated with the traffic.
- F4 P1 M3 T3 I worry about doing the right thing at the right time, and as you've just heard, it's what you think in yourself. Well what if I was walking down the street and such and such happened or I went dizzy or something like that. I've never ran. If you were in the middle of the road and you had to run across and something went wrong, you could be over. And what I've always found, self-confidence is the main thing. If that isn't there on that day, you could be in for a rough day.

## Particular Activities Where Confidence may be Lacking

#### Filling in Forms ect.

F3 P14 M2 T25 (In context of discussion on benefit entitlements and filling in forms) But if you've got a brain injury and you've got to figure out all this stuff, it was headache stuff for me, you feel like banging you're head against the wall. I really wanted somebody to do this for me. I had a social worker who basically led me down the wrong bloody path, and I ended up going down a blind alley. You can't reason it out in the early days.

#### **Employment**

- F1 P7 F4 T6

  At the moment I've got a client who wants to go back to college where he was training to do hotel management and he wants to go back to do reception. But he said that he couldn't go back on reception: 'because of the way I (the client) talk(s)'. But he's a hundred per cent intelligible. We got into discussions about the way people perceive the way he talks and it is very much an attitudinal barrier, isn't it, he'll clam up when he's on the phone but its nothing to do with intelligibility. He perceives that he doesn't speak normally. (also in Dealing with People).
- Newborne, B. (1997) I was really in a mess this time. My insecurities about not having the same connection with the students made me anxious. During my two months as a student teacher the previous year, I was able to break through to the kids. Now, however, my confidence had been shaken...Most of the kids stared in disbelief. Some laughed. Many thought I was from another country, having an odd foreign accent. It was so embarrassing I wanted to scream.
- F2 P11 M1 T22 But there's not many that want to get back to work, after a head injury.

#### Making Meals & Snacks

- F1 P7 F3 T14 ...he's underestimating his current abilities at this level because he doesn't want to do things that a disabled person does. I mean he might say I don't see the point in sitting making a cup of tea while I'm in a wheelchair, I'll wait until I can walk and I can make a cup of tea when I'm standing. It's been really hard to understand why he won't make a cup of tea in the wheelchair.
- F1 P 8 F3 T18 I think it's a challenge enough anyway to someone's self-esteem to be asked to do something different, because before obviously it was such a basic task, y'know, and to make a big deal of it, like to make a cup of tea, it must, must destroy you to some degree. Because in essence every time you kind of treat someone you're always again bringing up this, ...things like the way they were before.
- Part of the task that you're (rehab professional) doing, erm, might be to do with showing the person you can do it, or, or showing family members that they can do it when they're actually able to support the person to continue to do it, to continue the package. So eh, common things that come up is, Fred Bloggs couldn't possibly do things in the kitchen because it would be dangerous, he's got a memory problem. How could they possibly be safe when actually pretty simple strategies can be used. (Also in Personal Safety)

#### Childcare

I1 P7 T48

(In context of a discussion about childcare) When the baby was first born it was erm, you know, it was not enough confidence in myself. And if I got something wrong, it was: No you don't do that! I'm thinking y'know, erm coping with lots of things at once or if there's too many people I don't cope.

#### Crowds

Quinn D.A. (1998) Also I found I can't carry on more than one conversation at once, although such conversations are common in such big gatherings. As a result, I'm not comfortable around a lot of people anymore. At least, not yet. So I felt relieved and relaxed when I came home after the get-together, watched T.V. and went to bed.

#### **Films**

F3 P9 M2 T21 I can't watch a full-length film because it's too long.

- F1 P9 M1 T28 Yeah, I've seen a couple of cinema films and eh, with the kids, the first couple were more sort of cartoons things like toy story and that sort of thing. And eh, because its warm and cosy and when the lights go dim and what not, and eh, I doze off. Then we went to see this Return of The Mummy thing and the the effects are very good, I didn't think I would like it at all because I don't normally like those sort of films, but I must admit I quite enjoyed it because of the special effects and towards the end Wifey says, "you stayed awake all the way through you did ever so well" I thought to myself I haven't really because I did fall asleep ten minutes ago, she said "did you?".
- F3 P9 M3 T8 I remember they tried to get me em, to the cinemas like. I'd go to the cinema and it was erm, I didn't really want to go in there like anyway like, and I said to her, what's this cinema for anyway? And it's some bloke who's chopping someone up like (laughs) I got out straight away like and got back to the beer. They kept saying to me just that it's just the way that you're thinking. They said you will want to be able go back to the cinema like but I haven't been back to the cinema since before the accident. I don't really want to like..(T9).. I don't really want to look at anything where something's happened and, even with cars (crashing) I don't like to see them, even when I see a magazine or a newspaper, when I see something that looks really not very nice, nah! (also in Particular Activities).

#### <u>Telephones</u>

- F3 P10 M1 T32 I find using the telephone difficult er, because, I can't, I haven't mastered writing with my, I can't hear with my left ear, but I haven't mastered using my left hand. I have to hold the receiver with my right hand to my right ear. And then of course its what happens to your right ear. So it's a bit mmm mmm mmm what do you do with your hands?
- F3 P10 M2 T26 I wouldn't answer it for a long time because I couldn't deal with what they were saying, people speaking, I suppose, because of the speed, the volume of it, I couldn't take it in. A lot of the time you're saying to people, Slow it down!.

- F3 P10 M3 T11 Yeah, I had a lot of problems with numbers and everything and with the telephone like, "What is it,"? they'll tell me and I'll say "What is it again"? and they say "I just told you,". And I say "Yeah I know, tell me what it is,". And then it is as if though, they thinking (laughs) this is messing around like and everything like you know. And I've just put it down like.
- Newborne, B. (1997) Every time the phone rang when my parents were at home I would become anxious. Often I would just let it ring. The few times I had the courage to pick it up, I couldn't remember what the message was or even write it down. If the call was from a friend our reactions would make both of us feel uncomfortable. If a stranger telephoned, they thought I was stupid because I didn't speak intelligently.

#### **Shopping**

F3 P12 M1 T37 (context: discussing shopping) I'd do it but only with Wifey. The idea of working from a list at the moment, its eh, (Fac. That's not a nice idea) (T38) Well I know I've got to work from a list because, eh, the one time I went down there and eh I had to buy one thing, I come back with some special offer salmon which I thought was a marvellous offer, about three quid for a punt of salmon it was on offer. I thought that's pretty good value that is, I'll get some of that. But I come back with about nine cartons of it. And she says what the hell are you playing at? Are we going to be eating salmon for the next six weeks? You can stick it in the freezer can't ye?.

#### Being Alone

F2 P8 F1 T12 With Ian now, at night, if the television's on and it's a bit latish, I, I'll say I'll have to go to bed. I might as well be married to him, because he wants to stay up and watch a certain programme, but if I go bed he wouldn't stay up, he'll go to bed. He's got to follow me upstairs, he will not stay up.

#### Housework

F4 P1 M2 T1-T2 It's very hard for me to originate stuff, reply to things...That puts me off doing things around the house where you've got to arrange to do something.

#### Going Out

F4 P2 M1 T3 I've just started going into a local pub now like, but that's after three years like y'know what I mean (Fac: What was stopping you beforehand?) Nothing really, just eh, my self-confidence I think. I just felt vulnerable I think.

#### Study

F2 P8 M1 T25 Now he goes to college and, and I say to him does he want to sit an exam?, he comes home and does all this paperwork. I say to him you might want to take another A'Level again? No, no. And he'll talk to me, rattles to me about it, he talks very level headed. You know he's talking about psychology, and the way he's talking about it, the full monty, slightly above me. An obviously, well you know, what are you doing next year? He just wants to be in college, because he wants to be around them people that was the circle he

got left out of, do you know what I'm saying. I said well you've got to be careful, you can't always be a student.

#### Taking Part in Sports

F1 P8 F3 T19 Yes, I've a client who played golf and he couldn't play golf the way he played it before. So then there was no point in playing golf, even though he could play golf quite easily.

#### **Driving**

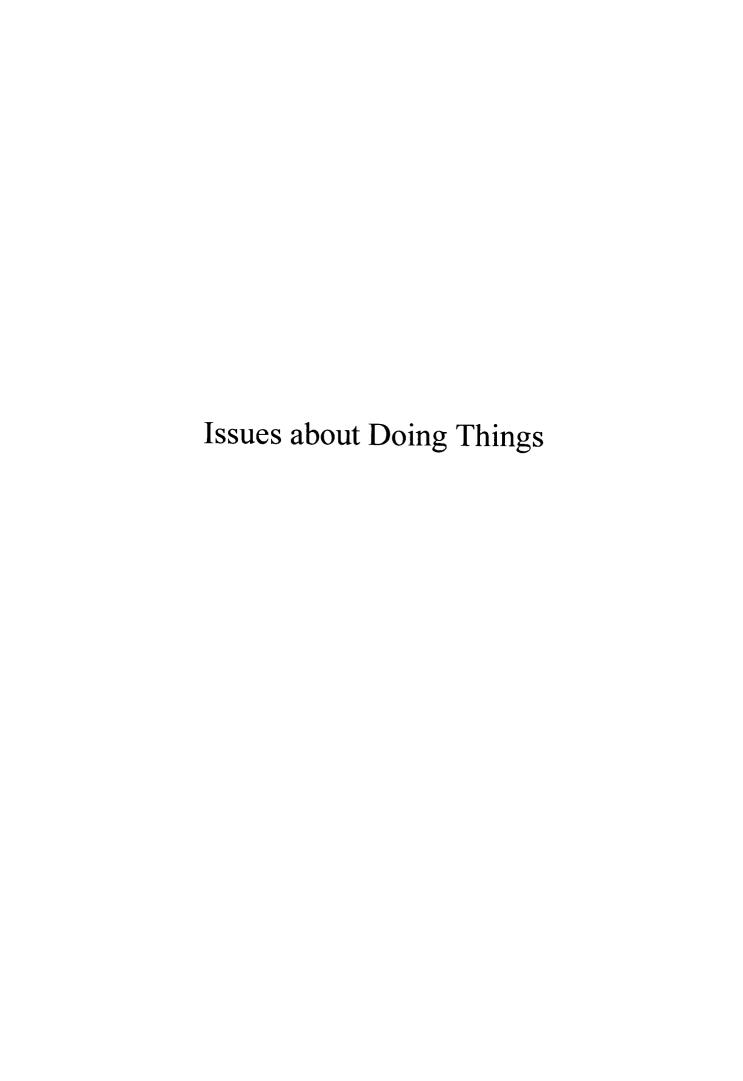
F3 P7 M3 T7 Taking, most of the time, taking, taking the family out properly like. Say the kids want to go the to Alton Towers or something like. I haven't got my car no more like. That's what, that is a really, it's a big thing to me that, like most people who have got a car like, if they haven't got it, its like.....

Single Exchange F3 P7 M2 T13
Between you used to.
Participants

F3 P7 M2 T13 Your social life stops in effect, you can't socialise like you used to.

F3 P7 M1 T22 It's like losing your shoes isn't it? Because most, most of us pass the test when we're 17, 18 so we have been longer with a car than we have as pedestrians. I mean I'm learning to be a pedestrian now because I was longer as a car driver than I was as a pedestrian.

Quinn D.A. (1998) (Trying to drive for first time since the injury) I was so afraid of another crash-and the fear was even stronger, because it brought back vivid memories of the crash with Bob.



- F4 P5 M1 T9 (in context of frustrations when trying activities) It's exasperating! It totally vexes me...You're the only one who you can get annoyed with, y'know what I mean. It makes me short tempered, a short fuse.
- Linge, F.R. (1980) I cannot cope with anger as well as I was able to before the accident. Rage related to my losses, does not lie just under the surface waiting to explode as it did earlier in my recovery. Yet, like any other person living in the real world, situations arise which makes me justifiably angry, and I am still, today, slow to anger. The difference is that now, once I become angry, I find it impossible to 'put the brakes on' and I attribute this directly to my brain damage. It is extremely frightening to me to find myself in this state, and I have not worked out a truly satisfactory solution, except insofar as I try to avoid anger-provoking situations or try to deal with them before they become too provoking.
- F3 P7 M1 T21 No what makes me cross about my injury is the fact that I always felt head of my household. I always felt that I could achieve whatever I wanted to achieve, and also the skills I had learned put me in my stake in society. And also beside the skills I had learnt, the skills I was about, I used to enjoy art, I used to be. I was, if for example......I said to you .See that house over there? You would say yeah, I would go; To get to that house. And I would say right O.K. Andrew. And a bit later on in the day I would say; Here you go Andrew there's that house we discussed. And you would know which house we was talking about. That was my ability in art. I haven't got that any more now. I can't draw a straight line with my right hand. I can't draw because of that, what I want to draw. I mean it sounds nothing but it's a lot.
- Quinn D.A. (1998) Soon the more I tried participating in everyday activities, the more I discovered I couldn't do. This is what happens with a brain injury. On the surface, one seems fine, but then one discovers one can't do the everyday things one takes for granted.
- Freedman, L.R. (1987) The first talk (*lecture*) I had to give, about three months after the accident, was accompanied by a lot of anxiety. I took a long time in preparing it and worried about the most unlikely aspects of it. When the talk went easily and well. I realized that the main difficulty at this point was most likely due to the uncertainty and anxiety related to the thought of doing something rather than an inability to actually do what I contemplated doing. Guessing the probable source of my difficulties did little to help resolve them. I realised that my physicians had not addressed the psychological consequences of my injury, nor had they prepared or advised my family of the inevitable anxiety that would accompany recovery. I felt intensely alone with my worries, too frightened, too protective, and too insecure but to worry more.

# Awkward Situations after Acquired Brain Injury

#### Reminders of Injury in Films

F3 P9 M3 T8 I remember they tried to get me em, to the cinemas like. I'd go to the cinema and it was erm, I didn't really want to go in there like anyway like, and I said to her, what's this cinema for anyway? And it's some bloke who's chopping someone up like (laughs) I got out straight away like and got back to the beer. They kept saying to me just that it's just the way that you're thinking. They said you will want to be able go back to the cinema like but I haven't been back to the cinema since before the accident. I don't really want to like..(T9).. I don't really want to look at anything where something's happened and, even with cars (crashing) I don't like to see them, even when I see a magazine or a newspaper, when I see something that looks really not very nice, nah! (also in Particular Activities).

#### Being Around People With Disabilities

F1 P10 F1 T11-T12 I had a recent experience with a client who was extremely verbal in stating that she didn't want to be here and I was really kind of surprised that actually though negotiation, exploring those issues and actually getting her to reflect on that it wasn't actually coming here that she disliked because she was actually saying that isolated activities and sessions throughout the day she actually enjoyed, and the one-to-one work she kind of enjoyed as well. So I got her to think about it's the fact that she didn't like she had to be here because of the accident,". (Fac: Would coming here remind her of the accident?) (T12) Absolutely, and being around other people with disabilities.

#### Use of Aids that Signify Disability

F1 P11 F1 T18 I think sometimes with clients, even if they use diaries, whatever they're using is unacceptable sometimes they resist using it because it points out that they need to use it, I think that tends to be the case .....So sometimes it's not the appearance it's the thought of having to use a diary.

F1 P11 M2 T2 She's refused to bring a walking stick in with her.

I2 O3 TI2 "But there's a guy I've been working with and he was late forties, early fifties, he had quite a senior position in Royal Mail, and actually he was just telling me the other day a little bit about his background I do think that it's very important for clients to tell their story. And he was telling me that his father died when he was young at about thirteen and so he was the elder male in the family, and that they'd, erm, his mum had lived in a council house and that it was very clear that he was very very proud that he'd worked very hard to get to the point that he was erm, just before he had his stroke. And it just made a lot of sense about why the work ethic was so important to him. And this particular chap has significant issues with stamina, erm, even to the extent to which it affects his ability to carry out every day tasks, basic tasks like self-care and dressing, those kind of things. And this is someone whose being used to being in control and been used to delegating and working on a high cognitive level. And he's aware of those deficits and just because of his physical disabilities as well I think the basic things just take an awful lot out of him. He's has a huge, huge problem really in terms of adjustment. I think the other thing as well that's, that's important is that erm, someone's injury doesn't occur in a vacuum with, y'know there's other things going on in that person's life as well, the brain injury is just one of them. So for this

particular guy, his partner became pregnant very soon and, sorry, he had his stroke just before, he had his stroke just after his girlfriend became pregnant, so he had lots and lots of changes then. He describes it as quite a casual relationship before. So in a few months he had a stroke, moving in with someone he had not lived with before, and had a baby to kind of deal with. So there was huge issues there for him in terms of change and adjustment. And what still are things that are very important to him is that to some extent, say he's not asked for a certain set of circumstances it's maybe not what he's chosen but he's still wants to be able to provide and care for his new family and it's very difficult for him to be able to do that. And some of his behaviours are quite self-defeating in terms that he will try to...he over does it, he overdoes it and continually, from day day one, he has discussed this with him, he still gets into that kind of cycle of tiring himself out and and therefore becoming irritable and having problems managing his disability and stress, because he's so tired that significantly affects his social relationships and and so there's more stress at home

... there's loads of meanings and beliefs there about his work ethic and how his role as a provider and the status that he had before that he really hasn't got now in society to do with his job. Erm, he he is someone who would not accept things that would mean he is disabled or erm, it's best to just give you an example really so. Another professional had actually suggested that he has his downstairs garage converted and as like a bedroom with a shower and toilet areas, he has significant problems erm getting up the stairs, he's quite a heavy man so there's a risk of falling and incontinence issues so, an erm, even, even in the face of quite significant incontinence issues, erm, his initial reaction for some weeks was that there's no way because: That means I'm disabled, that means I'm disabled permanently. We're talking about major adaptation like that, and he would rather,....I was amazed actually that this this level...even though he had problems with double incontinence he refused to wear pads because that meant that he had a disability. And this is an intelligent man and he's masking the occasions when he is incontinent rather than wearing the pads. That, that just speaks volumes really.

F1 P10 F1 T17 She would say, "I don't know why I'm here" "These (disabled) people.

## **Example Transcript**

Focus Group 3 - 3 males with traumatic brain injury

Each participant has a numerical identifier and
a continuous numerical transaction sequence (T)

M1 T1 If you've read Trevor Powell's book, its, one of the problems that head injured's have J1 and M2 especially, eh, me not so much maybe, but erm, we look normal, if you're, like, to the average passer by. They wouldn't necessarily think that anything was wrong with us. I think Trevor Powell puts it as, were the silent.......

Fac Silent minority? Is that it?.

M1 T2 Yeah something like that.

Fac That's the red book isn't it? The Headway publication?

M1 T3 Puce or something. That's an excellent book. But, that's what he says. It's funny really because since my head injury, in Lichfield where I live, the amount of people that have been touched by head injures, head injury. My wive's boss, his daughter was involved in a head on incident,

Fac. In a car?

M1 T4 That's right, now before my injury he'd never been touched by an injury. Now all of a sudden his daughter has been rendered to a wheelchair, she's actually going to be coming here shortly. Ahh, and on the same stretch of road that she was injured my brother's son's teacher her daughter and son were both involved in a collision. Eh Luckily her daughter was eh, head injured, she, she's recovered and everything's OK now so it touches everybody in different ways. The point I'm trying to make is, that, I think what you were saying earlier about that gentleman who couldn't manage going out, what I've come to realise is as I've come to Moor Green and come to meet and see more people who are, especially for example like people who have been rendered to a wheelchair, eh, I had nothing to do with people who had been rendered to wheelchairs before, now all of a sudden I'm not so frightened about people in wheelchairs I'll go up to them, I'll talk to them, I'll, some people who are in wheelchairs are my friends now, I don't have a conversation with them at all about them being in wheelchairs, and yet before I had nothing to do with them. And a similar thing also you were saying about that gentleman being frightened about going out, that's funny because when I was in hospital, my living is selling motor cars, and it's funny when you're head injured you do a lot of living in your head, because that's , that's where all your living was, in your head so you tend to think to yourself, "Oh I can do that, because you always did it before,". So I was thinking to myself, right OK I know just how I was affected down my left hand side, suffered a bit like the effects of a stroke. O.K I know I've got a problem with, er, changing gears even though the vehicle's left hand drive. So effectively I'll be changing gear with my right anyway. O.K that's no problem I'll get myself an automatic car, that's solved that problem, sorted. So I just think to myself right get myself on the road, and drive an automatic car. When my Wife came to pick me up from the hospital we had to have at the time a little Fiat Bravo, which is smaller in comparison to the larger cars we've had in the past. The first thing I notice is how close I was to the, to the door and so close to the road. And all the road noise was drumming through the car and that really came home to me and frightened me, (cont.)

I thought to myself, Oh my goodness. And not only that, everything was going so fast, all the islands the traffic's going shum shum shum shum. I couldn't not cope with the way life is moving so fast. I thought to myself, how did I cope with that before my head injury.

- Fac Right so this was the first time you left the hospital.
- M1 T5 Right, and I just thought to myself, how am I ever going to cope with this. But time is a great healer. And that's what places like (his rehab centre) do for you. And that's why I say time is a great healer. They've seen it all before here.
- Fac It sounds like an overwhelming experience, that first time when you left the hospital....
- M1 T6 It can be overwhelming if you allow it to be overwhelming, if you've got a good family like I have and also your able to, I mean at the time it wasn't Moor Green it was a local hospital with a rehabilitation unit. So it was an OT unit who were able to talk to me.
- Fac What do you think, M2 and M3, about that very early experience after an injury, do you remember it being overwhelming in the same way?

my sessions with Robin I realised how the brain actually works and then I could piece together what had actually happened because he had explained what had happened so I didn't have to be so fearful. So I would'nt be in a situation where I'm thinking what's going on in my head? Y'know. Because the brain's such a complex bit of kit isn't it? And who who knows what it does and how it really works. So that was frightening. Physically I could see what's going and I could touch that. Mentally I couldn't, I couldn't see. It's taken probably twelve months for me to see, for it to come out actually. In the beginning I could see the physical problems that I had so they'd work on that. It was only like midway through the last twelve months was I beginning to realise that it was a brain injury. My situation, eh, there's that on top as well, if you get asked, y'know "it's not just a physical disability, I've got it mentally,". I'm not mental but obviously I've got a problem with my thinking. So then I started to realise I was getting these different sort of thoughts and reactions that I didn't understand, I'm going through the classics here, which was twelve months afterwards that I began to sort of realise that, y'know, that it was just a natural part of what happens to all of us. Y'know. Mine is in some ways sort of symptomatic, erm, (cont.)

similar to M3, similar to M1's, the brain's been starved in one way or another. So it's relevant then to all of us. We need to share that with other people.

Fac What do you think about that, those early experiences yourself, M3.

M3 T1 Erm, sorry what was that?

Fac. I think what M1 and M2 were describing was that they found things overwhelming to begin with. M2 was the saying that, erm, after some work with Robin he became less fearful of how things affected him, how he was then able to work around that. Can you remember a similar thing happening?

M3 T2 Yeah, yeah. Like when I first came out of hospital I, I kept thinking to myself that I wouldn't be able to talk properly. Most of the time I weren't bothered about the head thing, I was just thinking 'can't talk properly'. I didn't like that like that, erm, because when the family came round I was trying to talk and I didn't mean anything. And I couldn't drive properly like, and I didn't like that. Most people here probably aren't driving. It depends how you have the head injury. Mine was in a crash like, and I keep thinking about how, I always think about it like that. At the same time, at the same time though, I was lucky, lucky, I am lucky that a lot of, I've got quite a lot of family that, like when I came out of hospital, they knew I couldn't talk properly, I couldn't walk properly or anything like that, they were doing most things for me. I'm glad that they was there for me like because it was pretty scary.....

Fac Yeah M1 was saying something similar....

M3 T3 I wanted to get out as quick as I could, I mean I know they're there to help you like and everything, but I just wanted to get out of hospital as quick as I could. I had enough. I'd been there for about six, seven months like. I just wanted to get home like, kids like and everything.

M2 T2 The problem that I have now is that there's not just one part of it, there's several parts to this. There's my vision, my speech my face, my bladder, my bowels, do y'know what I mean. What's going on? I'm thinking what the hell's happened here? You don't know its all, my whole body's taken a massive blow, every part of it, head, chest, leg, arms it's a lot to have to deal with is'nt it? Y'know its like, how can I say it, just of being a...inaudible.... makes it easier, y'know. If you hear somebody, something in a pub or a friend and he's had a brain injury you think "Stay away from him" that's your immediate reaction. That's probably a bit daft, but of course when it happens to you "no I'm not daft" I'm still thinking OK! It might not be coming out the way I want it to, but its all in there, its just sort of all jumbled up at the moment inside, it going to be time until it settles down and it'll come out in a bit flowing way. Then you can explain your feelings and what's happening to you, the different emotions.

Fac. Is that the kind of thing that you might have thought before the injury, that you might not want to speak to someone else with a head injury.

M2 T3 I suppose, its... just the stig...with any disability there's a stigma with it. Yeah it is. I think I was just as ignorant as anybody else in thinking I would be a nutter.

Fac Sorry, M1, what did you say?

M1 T7 Yes I think its ignorance as well.

Fac. Ignorance.. Right.

M2 T4 Yeah. But until it happens to you, you don't know do you!

Fac Is that something you've experienced M3?

M3 T4 Yeah, yeah yeah. I don't really know any people who have got a brain injury, so you think like that. Like I say, most people go out just go out like and they think that just the way you talk, the way you watch people, they think, God, he isn't all there like, he aint all there like, he's watching. I have loads of different problems I do like, I say to (therapist), how, how I haven't gone back to hospital yet like with a load of blokes who have got me like and give me a good smacking. All I can say is like, friends, they've tried to stop it all like, because if I'd been on me own like I know I couldn't do much, most of the time you need someone, someone, family friends who are ready to help you. People who do know what's happened to you.

Fac. You've all kind of mentioned that there could be a problem with ignorance and stigma.....

M2 T5 Then you have behavioural problems when you have a brain injury which I've experienced and had, since I've seen a psychologist and that happens, then you start questioning yourself. I've been been out reacting and shouting in the streets at people in a que but, in a way, my anger is so I'm aware I will start to have sort of behavioural problems I'll get annoyed and aggressive if people get in my way. That's now being dealt with, that's twelve months after, you know, it takes, I don't know how long its takes. It takes time for these these things to be resolved at various levels, at the the early stages of, after the initial injury. They may not come out immediately but... obviously its happened and I think that's what's happened there and then, the actual sort of effects might not come out until later which I found. Like this this behavioural thing didn't start until the last few months as I've been more adventurous and going out further.

Fac. Were you going to say something there?

M1 T8 No I was just going to...I haven't got the problem out in the street like that, but one of the problems I have that I liken to that is the fact that I haven't got the strength with my one son in the sense that he knows just how to wind me up. I'm not able to curb my, its odd, my patience. He knows how to push that button as it were, and it annoys me that control him in the sense to discipline him, and I can't curb my....it's a catch 22.

Fac. Would you get angry in that situation.

M1 T9 Well..... it was not to the point of anger, but I try and think what would have happened before? And I think it probably wouldn't have arisen before because I don't he would of eh? I mean I've been quite frank, Y'Know what happened to the little boy who was before? Because we used to share so much. And he said "What happened to dad"? You know and I couldn't answer the quenstion because what did happen to dad? Y'know. He fell of the roof and that was it. He said, "you can't drive, you can't ride a bike". I said that's not my fault because unfortunately, I'm not allowed to hold a licence. As far as riding a bike goes, I'm doing my best but eh I'm just a little bit wobbly.

Fac Sorry, how old is your son, do you mind me asking?

M1T10 Twelve

Fac And he's having difficulty understanding what's happened.

M1 T11Yeah, but he's got a twin brother who's like chalk and cheese, it makes me really appreciate the other twin because he's so understanding I say to myself, yet the other one is so different. It's so difficult.

M2 T6 The difficulty with a brain injury, all your life you've gone on in your, like then all of a sudden until a minute of so when it's happened, and your life's been changed upside down and all your life you've sort of gone along with the way you've been until...what am I? forty three. So for forty three years I am this person and overnight I can't be that person any more. And I was fighting to get back to that person, I will beat this, I can't beat it because its happened, you can't change it. So I talked and started to adapt, started to adjust to a different way of doing things because you think why can't I be the way I was before, because you can't physically and mentally, its impossible.

Fac. Yeah. Can I just come back to you on that one in one minute. M3 can I just ask you if you've been out and somebody is ignorant of what's happened. Would you feel that you would have a problem with anger there.

M3 T6 Yeah

Fac Yeah. Can I ask all three of you. is losing your temper or getting angry something that would worry you if you were about to approach a situation?

M1T12 I'm very fortunate in the sense I've only had temper tantrums right in the early days when I came out, and that was like, at the time we were living in a an apartment and I can remember I can get to the point of thump a supeedy door, and the reason I would hit a supeedy door is because it was soft enough for my fist to bounce off so my fist didn't hurt.

Fac. Sorry, what kind of door was it?

M1 T13 Supeedy, y'know these modern...

Fac. No I don't, how do you spell it?

M1 T14S A P E L L E Y

Fac Right, so that's soft enough to have a good at?

M1 T15Yes, it's got a cavity in it. You wouldn't have, you wouldn't have them because they're a 1960's, cheap, interior door.

Fac. Aaah, yeah I know what you mean.

M1 T16This apartment had been built, built by erm, the construction firm as a caretaker's flat.

Fac Right,

M1 T17It was like, anything so long as they could save money.

Fac Yeah.

M1 T18I made a point of not punching my own house!

M2 T7 Obviously as I've been seeing Louise my psychologist, I am having problems with sort of like, temper rages, over silly little things that wouldn't have happened before. I find it very hard to control that y'know. I can't physically do things, but verbally I can still scream and shout. That's how I feel, it's like a rage inside that wants to get out, why can't I sort of change this? That's why I need to talk to somebody about it.

Fac. Is that something that worries you about going into situations?

M2 T8 Yeah, like the last few months I've lost my temper a few times, not physically, but verbally I have a tantrum that lasts ten minutes. Its happening a lot more.

Fac I was just reading something by a chap, the other day, his name was F.R. Linge. He was a psychologist who had a head injury himself. He was saying a similar thing, one he actually lost his temper, he found it very difficult to control afterwards.

M2 T9 Yeah, you feel sorry afterwards. I, I'm certainly very aware of it now and trying to deal with it.

Fac. Can I get back to the point you made a minute ago. Because you described this very rapid change that happened to you all of a sudden.....

Scribe. (interrupts). I think that's time, we need to go. I can probably extend the time. What are you all doing? (leaves room)

M1 T19I mean I'm trying to say half a dozen words to her one. But for me that's six of one and half a dozen of the other in the sense that she's inclined to and I'm just inclined to counter. She's inclined to counter my argument with some words and I'm inclined to counter before you know you've got into an argument so I think she's just not used to that situation. That's (different to) before when I would let it lie.

Fac. When everything changed, eh, as John described, can you describe what the main difference was after the injury.

M2 T10You feel rejected don't you?

Fac. Rejected?

M2 T11Yeah, immediately, you think I'll beat this whatever happens. Mine was a clot so it could be different from a car crash. So, M3, you probably wouldn't want to go near that road again would you?

M3 T6 No.

M1 T20No, for me. I don't remember mine, we took the bus down there. No for me its, the situation, its final, y'know. The damage is done. What .....

M2 TI2No, there's no going back.

MI T21No what makes me cross about my injury is the fact that I always felt head of my household. I always felt that I could achieve whatever I wanted to achieve, and also the skills I had learned put me in my stake in society. And also beside the skills I had learnt, the skills I was about, I used to enjoy art, I used to be. I was, if for example......I said to you ."See that house over there?". you would say yeah I would go "To get to that house,". And I would say right "O.K Andrew,". And a bit later on in the day I would say "Here you go Andrew there's that house we discussed,". And you would know which house we was talking about. That was my ability in art. I haven't got that any more now. I can't draw a straight line with my right hand. I can't draw because of that what I want to draw. I mean it sounds nothing but it's a lot.

Fac. In your every day life, what would your head injury effect. What things would be made difficult. Any thoughts M3?

M3. T7 Taking, most of the time, taking taking the family out properly like. Say the kids want to go the to Alton Towers or something like. I haven't got my car no more like. That's what, that is a really, it's a big thing to me that, like most people who have got a car like, if they haven't got it, its like....

M2 T13Your social life stops in effect, you can't socialise like you used.

M1 T22Its like losing your shoes isn't it? Because most most of us pass the test when we're 17, 18 so we have been longer with a car than we have as pedestrians. I mean I'm learning to be a pedestrian now because I was longer as a car driver than I was as a pedestrian.

Fac. I think we're going to have to wrap this up now because we're out of time.....

Scribe No you're O.K actually.

Fac. Right O.K. so the car's one thing.....

MI T23Well, just to say the car, people say well you can walk y'know. For example, my house now is ten minutes walk from town. Now I've never had a house which is ten minutes walk from town, but that's because I've always had a car so I didn't need a house that's ten minutes walk from town. Its silly but all of a sudden now, not having a car, because before, just walk out of the door, jump into the car, where do you want to go? You go anywhere! And yet library books, y'know, you want to nip down to the library, and you think you can just walk down the library in ten minutes. And yet I've paid more fines in library books since I've had a head injury...

Fac Yeah.

M1 T24Because I have not programmed my mind into thinking I just can't get into the car and go to the library.

M2 T14Certainly, there's dangers in going out into the road as a pedestrian....

M1 T25(interrupts) Yeah, I've got that.

M2 T15You get to lights and problems with cars coming passed and they changed. That is a major problem for me.

M1 T26I have to wait until Wifey says "I'll come with you". Or someone says "I'll come with you".

Fac Yes because M1 was describing how after leaving hospital for the fist time that overwhelming feeling of life on the road really when you were being driven in the car.

M2 T16I'm driving now now for the last six months, I can drive, that's helped my social life.

Fac. If you had to walk somewhere, would that play on your mind do you think? And you would avoid doing it?

M2 T17I've walked across lights, like, and cars have just gone straight through the light, and I've got a little girl and pushed her out into the road so you know its like they can't rely on me to be out on me own. Understandable, the light's green to walk and cars are coming from left and right. I've got a problem with vision. As M3 like said it's a problem.

Fac Is there anything else like that? That's really useful. Anything in your everyday conditions that might worry you to have a go at?

M2 T18Watching T.V. Using computers.

Fac. Does that worry you?

M2 T19In a way yeah, because its quite a mental, I feel the stress in the back of my neck, I felt the stress of it, and I think am I overloading myself?

Fac You'd actually feel it in the back of your neck because of the stress?

M2 T20Yeah, yeah...it's the concentration I worked on the computers but its only recently I've noticed that happened because of the concentration.

Fac. M3, is there anything like that for you?

M2 T21I can't watch a full length film because it's too long.

M3 T8 I remember they tried to get me em, to the cinemas like. I'd go to the cinema and it was erm, I didn't really want to go in there like anyway like, and I said to her, what's this cinema for anyway? And it's some bloke who's chopping someone up like (laughs) I got out straight away like and got back to the beer. They kept saying to me just that it's just the way that your thinking. They said you will want to be able go back to the cinema like but I haven't been back to the cinema since before the accident. I don't really want to like.

Fac. Is there something about the violence that might be in the film that would worry you do you think?

M3 T9 I don't really want to look at anything where something's happened and, even with cars I don't like to see them, even when I see a magazine or a newspaper, when I see something that looks really not very nice, nah!

Fac. M1, from your point of view is there anything that since the injury that you might find worrying and avoid?

M1 T27I was just thinking very similar, I have a problem in the cinema just staying awake.

Fac. Staying awake in the cinema?

M1 T28Yeah, I've seen a couple of cinema films and eh, with the kids, the first couple were more sort of cartoons things like toy story and that sort of thing. And eh, because its warm and cosy and when the lights go dim and what not, and eh, I doze off. Then we went to see this Return of The Mummy thing and the the effects are very good, I didn't think I would like it at all because I don't normally like those sort of films, but I must admit I quite enjoyed it because of the special effects and towards the end Wifey says, "You stayed awake all the way through you did ever so well" I thought to myself I haven't really (cont.)

don't have, you can't have no more" and you just say, oh shut up like and then you start swearing. Y'know, he supposed to be your friend like and he's telling me what to do, like, and I'm thinking I don't wanna, and he's supposed to be my friend like.

Fac. So do you think that having another injury might be another worry, do you think?

M2 T25Yeah. You do get scared of having another stroke.

Fac Is that another worry for you M1, or?

MI T30I don't know, because my stroke was brought on by the fall.

Fac. Right, do you worry about getting into another situation like that which might?

M1 T31No, because I would never, literally, even if I see other contractors coming to my, eh, business centre going up there with no hat on I'm straight up to them, "Lads can you get yourself a hard hat please,"? Y'know, so I'm actually .....the closest I've come to that now is, eh, the taking of my epilectic pills. Which I'm very totally fastidious about now because the other week I took eh a forward dive as it were and head butted the tiled floor at about five mile an hour, that wasn't very nice.

Fac. Can I just go through a list of things that em are supposedly at times difficult for people with a head injury or brain injury to go through. Tell me what you think, reaching and using the telephone.

M1 T32I find using the telephone difficult er, because, I can't, I haven't mastered writing with my, I can't hear with my left ear, but I haven't mastered using my left hand. I have to hold the receiver with my right hand to my right ear. And then of course its what happens to your right ear. So it's a bit mmm mmm mmm what do you do with your hands?

M2 T26I wouldn't answer it for a long time because I couldn't deal with what they were saying, people speaking, I suppose, because of the speed, the volume of it, I couldn't take it in. A lot of the time you're saying to people, "Slow it down".

Fac. How about you M3, any problems.

M3 T11Yeah, I had a lot of problems with numbers and everything and with the telephone like, "What is it,"? they'll tell me and I'll say "What is it again"? and they say "I just told you,". And I say "Yeah I know, tell me what it is,". And then it is as if though, they thinking (laughs) this is messing around like and everything like you know. And I've just put it down like. Most of the time like, when I'm at home like and someone else is in, I've had to say "Hang on a second, get this number for me like,"?

M1 T331 find under those circumstances, when I have to take numbers often I find its (cont.) best to come straight out and say look "Bear with me I've had a head injury so its going to take me a bit of time, I've got to get a pen and I'm going to take this number down,". If you go straight down and hit him between the eyes with that and normally they go O.K. fine.

Fac. And that works?

MI & M2 (together) Yeah

Fac. Just say yes or no if these other things are a difficulty, using public transport.

M1 T35I haven't used it yet.

M2 T27Yeah because my balance has gone so. A woman behind me with a mobile phone, the bus stopped and she flew and head butted into me bang, y'know its like that, people won't get up.....

M1 T36That's when me and M2, I haven't got no balance so I'll try public transport but...

Fac. Going to the shops, things like that. Would that a difficult thing to do?

M1 T37 I'd do it but only with Wifey. The idea of working from a list at the moment, its eh,

Fac. That's not a nice idea?

M1.T38 Well I know I've got to work from a list because, eh, the one time I went down there and eh I had to buy one thing, I come back with some special offer salmon which I thought was a marvellous offer, about three quid for a punt of salmon it was on offer. I thought "That's pretty good value that is, I'll get some of that". But I come back with about nine cartons of it. And she says "What the hell are you playing at? Are we going to be eating salmon for the next six weeks"?

"You can stick it in the freezer can't ye?

Fac. What kind of things would affect somebody's confidence in attempting those types of situations, what would go through your mind? and say to you "Don't try that,"

M2 T28Fall

Fac. A fall? And what would go through your mind?

- M2 T29Probably a brick! (laughs) Eh well its just the danger of falling and your unsure and unsteady, and you're disorientated with the traffic. I was robbed not so long ago.
- Fac. Right. Do you think that people with head injuries might feel they can't master these situations; because of the injury they might not be as confident and that might stop them?
- M2 T30Until I think you speak to Robin's class I think, I thought "Well that's it it, it's not, never going to alter obviously, y'know it can be whatever, to do different things because it doesn't happen overnight but I always thought that was it. You needed proof to get your confidence to go up.
- Fac. Did you ever have that nagging doubt M3, that "This is it, things aren't going to get any better?
- M3 T12Eh, somedays like, but then like at the same time I had a lot of people talking to me all the time.
- Fac. Telling you otherwise?
- M3 T13Yeah, telling me it would be O.K. like. So like I say like I think most people that have had a head injury like or any injury like, if you've got people around you that will talk with you most of the time you get a lot out of that like. Because I know people who haven't got any family or any people like that like, y'know with any people like that, they're never here! (rehab centre). You get a lot of eh help like.
- Fac. I'm glad you said that it could be the same for any injury because confidence can be knocked by lots of different things not just head injuries. I mean I would call that a belief that this is my lot and things won't get any better now. What belief do you think might affect you in that way, that might affect your confidence?
- M2 T31I think if you get negative things happening that might put you back when those things happen. It would impact probably more so when you have an injury like ours because you're sort of looking for hope aren't you. So when something good happens in life say like me, I've passed my assessment, its wonderful so I'm learning to drive now and that's something to strive for. But being sort of robbed for my wallet, it's a very negative thing and I didn't want to know. I wanted to go forward.
- Fac. Did that give you doubts about yourself?
- M2 T32Yes because I couldn't defend myself. Physically I'm not able to defend myself so that made me feel extremely vulnerable.
- Fac. And what would worry you most about that?

- M2 T33That society in this day and age y'know, the way it is there's just no morals out there with the youth of today and no principals, like an old lady I was an easy target.
- Fac. What do you think M1?
- M1 T40Yes, just like he says, but what you've got to say to yourself is that they don't know that you're head injured so it's not really....
- M2 T33No they don't know, they just know you've got an injury of some sort so is that relevant?
- M1 T41 Well as you say is that relevant? That they're prepared to do it to anybody that's more the wrong side, isn't it.
- Fac. I just wanted to ask you one last thing really before we wrap up. You might have problems with confidence, M1 described different situations where confidence is a difficulty. Similarly M2 described being a pedestrian as a difficulty with confidence that was overcome. Is that as big a problem after injury as perhaps financial difficulties with not working that stops you doing something?
- M2 T34Well that's going to be the downside, because suddenly, if your working all your life then like you've got this, it's a minefield with social services and DSS because they don't make it easy for you to get what you're entitled to.
- M1 T42Having said that, I'm glad they don't because for me the idea of handouts from social services was a big pill to swallow. I didn't like it at all and it took me a big gulp to swallow that. But having swallowed it in the first instance after my first handout, everybody was saying well you deserve. Once you've viewed it from that point of view (mobile phone goes off). Hello, it is indeed....
- M2 T35Yes as he said it's a hard pill to swallow straight away, it more bearable after the first handout. You've worked all your life and so you're entitled to it. But if you've got a brain injury and you've got to figure out all this stuff, it was headache stuff for me, you feel like banging you're head against the wall. I really wanted somebody to do this for me. I had a social worker who basically led me down the wrong bloody path, and I ended up going down a blind alley. You can't reason it out in the early days.
- M1 T43What I was going to say was I say having swallowed that pill as it were and you realise that you were happy you know, since I was sixteen you think to yourself well I'm entitled to what I'm entitled to. Then eh, you realise it's a bit of a minefield but once you've been through it, it makes you also realise that you're due what you're due on the next hurdle I think. So if you then get that then..I'm glad I've got my wife, that's all I can think because I couldn't do it on my own.
- Fac. I was just going to say that I think you've all informed me that the family are a vital part of the recovery process. Thanks very much for talking to me. (Brings session to its end).

MI T44If it helps the future, one thing I was going to say was that working with Headway, just our little, local group eh, going out to the public if you life, going out to make people aware of head injury victims, you know you've got your heart, your cancer, and you've got your stroke to, to, a degree, which I think people are more aware of than head injury, and yet, I haven't got the figures in my head now, but 120,000 people in Staffordshire...

Fac. The silent epidemic! That was his phrase.

M1 T45Yeah that's it are touched by head injury. It's amazing how difficult it is to make people aware.

## Appendix F

Copies of measures and demographic information sheet used in the main study.

Appraisal of Threat and Avoidance Interview

Demographic information sheet

Hospital Anxiety and Depression Scale

Quality of Life Index

Quality of Life Index: Item & Coping Strategy Breakdown

Coping Schedule

[Not available in the digital version of this thesis]

# Appendix Gi Data analysis for main research paper

ANOVAs used to analyse the rates of sub-domain responses

One-factor within-participant ANOVA for participant's proportion of TAs calculated from maximum possible TA scores for the Personal Safety, Dealing With People and Doing Things Sub-domains (N = 50).

## **General Linear Model**

#### Within-Subjects Factors

Measure: MEASURE 1

TA	Dependent Variable
1	PSTRANS
2	DWPTRAN
3	DTTRAN

#### Multivariate Testsb

Effect		Value	F	Hypothesis df	Error df	Sig.
TA	Pillai's Trace	.529	26.904 <sup>a</sup>	2.000	48.000	.000
	Wilks' Lambda	.471	26.904 <sup>a</sup>	2.000	48.000	.000
	Hotelling's Trace	1.121	26.904 <sup>a</sup>	2.000	48.000	.000
	Roy's Largest Root	1.121	26.904 <sup>a</sup>	2.000	48.000	.000

a. Exact statistic

h.

Design: Intercept

Within Subjects Design: TFW

## Mauchly's Test of Sphericity<sup>b</sup>

Measure: MEASURE\_1

Within Subjects Effect	Mauchly's W	Approx. Chi-Square	df	Sig.
TA	.991	.444	2	.801

Tests the null hypothesis that the error covariance matrix of the orthonormalized transformed dependent variables is proportional to an identity matrix.

## Mauchly's Test of Sphericity<sup>b</sup>

Measure: MEASURE 1

	Epsilon <sup>a</sup>				
Within Subjects Effect	Greenhouse- Geisser	Huynh-Feldt	Lower-bound		
TA	.991	1.000	.500		

Tests the null hypothesis that the error covariance matrix of the orthonormalized transformed dependent variables is proportional to an identity matrix.

a. May be used to adjust the degrees of freedom for the averaged tests of significance. Corrected tests are displayed in the Tests of Within-Subjects Effects table.

b.

Design: Intercept

Within Subjects Design: TFW

## **Tests of Within-Subjects Effects**

Measure: MEASURE\_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig.
TA	Sphericity Assumed	21293.240	2	10646.620	29.662	.000
	Greenhouse-Geisser	21293.240	1.982	10744.596	29.662	.000
	Huynh-Feldt	21293,240	2.000	10646.620	29.662	.000
	Lower-bound	21293.240	1.000	21293.240	29.662	.000
Error(TA)	Sphericity Assumed	35174.778	98	358.926		Ì
	Greenhouse-Geisser	35174.778	97.106	362.229		
	Huynh-Feldt	35174.778	98.000	358.926		
	Lower-bound	35174.778	49.000	717.853		

#### **Tests of Within-Subjects Contrasts**

Measure: MEASURE\_1

Source	TFW	Type III Sum of Squares	df	Mean Square	F	Sig.
TA	Linear	19053.858	1	19053.858	48.473	.000
	Quadratic	2239.381	1	2239.381	6.895	.011
Error(TA)	Linear	19260.874	49	393.079		
	Quadratic	15913.904	49	324.774		

## **Bonferroni Multiple Comparisons: T-Tests**

#### **Paired Samples Statistics**

		Mean	N	Std. Deviation	Std. Error Mean
Pair 1	PSTRANS	41.2500	50	29.3694	4.1535
	<b>DWPTRAN</b>	46.8571	50	25.0200	3.5384

## Paired Samples Test Personal Safety & Dealing with People

		Paired Differences					
		95% Confidence Interval of the Difference					
		Mean	Std. Deviation	Std. Error Mean	Lower	Upper	
Pair 1	PSTRANS - DWPTRAN	-5.6071	26.0024	3.6773	-12.9969	1.7826	

## Paired Samples Test Personal Safety & Dealing with People

1	t	df	Sig. (2-tailed)
Pair 1 PSTRANS - DWPTRAN	-1.525	49	.134

## **Paired Samples Statistics**

		Mean	N	Std. Deviation	Std. Error Mean
Pair 1	PSTRANS	41.2500	50	29.3694	4.1535
]	DTTRAN	68.8571	50	34.5965	4.8927
Pair 2	DWPTRAN	46.8571	50	25.0200	3.5384
	DTTRAN	68.8571	50	34.5965	4.8927

## Paired Samples Test Personal Safety & Doing Things / Dealing with People and Doing Things

		Paired Differences					
		95% Confidence Interval of the Difference				· ·	
		Mean	Std. Deviation	Std. Error Mean	Lower	Upper	
Pair 1	PSTRANS - DTTRAN	-27.6071	28.0385	3.9652	-35.5756	-19.6387	
Pair 2	DWPTRAN - DTTRAN	-22.0000	26.2921	3.7183	-29.4721	-14.5279	

## Paired Samples Test Personal Safety & Doing Things / Dealing with People and Doing Things

		t	df	Sig. (2-tailed)
Pair 1	PSTRANS - DTTRAN	-6.962	49	.000
Pair 2	DWPTRAN - DTTRAN	-5.917	49	.000

One-factor within-participant ANOVA for participant's proportion of reported Avoidance calculated from maximum possible Avoidance scores for the Personal Safety, Dealing With People and Doing Things Sub-domains (N = 50).

### **General Linear Model**

### Within-Subjects Factors

Measure: MEASURE\_1

AMOID	Dependent
AVOID	Variable
1	PSAVTRAN
2	DWPAVTRA
3	DTAVTRAN

## Multivariate Testsb

Effect		Value	F	Hypothesis df	Error df	Sig.
AVOID	Pillai's Trace	.145	4.067 <sup>a</sup>	2.000	48.000	.023
	Wilks' Lambda	.855	4.067 <sup>a</sup>	2.000	48.000	.023
	Hotelling's Trace	.169	4.067ª	2.000	48.000	.023
<u> </u>	Roy's Largest Root	.169	4.067ª	2.000	48.000	.023

a. Exact statistic

b.

Design: Intercept

Within Subjects Design: AVOID

## Mauchly's Test of Sphericity<sup>b</sup>

Measure: MEASURE 1

Within Subjects Effect	Mauchly's W	Approx. Chi-Square	df	Sig.
AVOID	.933	3.340	2	.188

Tests the null hypothesis that the error covariance matrix of the orthonormalized transformed dependent variables is proportional to an identity matrix.

## Mauchly's Test of Sphericity<sup>b</sup>

Measure: MEASURE 1

	Epsilon <sup>a</sup>			
Within Subjects Effect	Greenhouse- Geisser	Huynh-Feldt	Lower-bound	
AVOID	.937	.973	.500	

Tests the null hypothesis that the error covariance matrix of the orthonormalized transformed dependent variables is proportional to an identity matrix.

a. May be used to adjust the degrees of freedom for the averaged tests of significance. Corrected tests are displayed in the Tests of Within-Subjects Effects table.

h

Design: Intercept

Within Subjects Design: AVOID

#### **Tests of Within-Subjects Effects**

Measure: MEASURE\_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig.
AVOID	Sphericity Assumed	3039.687	2	1519.844	5.143	.008
	Greenhouse-Geisser	3039.687	1.874	1622.008	5.143	.009
	Huynh-Feldt	3039.687	1.946	1562.117	5.143	.008
	Lower-bound	3039.687	1.000	3039.687	5.143	.028
Error(AVOID)	Sphericity Assumed	28960.265	98	295.513		
	Greenhouse-Geisser	28960.265	91.827	315.377		
	Huynh-Feldt	28960.265	95.348	303.732		
	Lower-bound	28960.265	49.000	591.026		}

#### **Tests of Within-Subjects Contrasts**

Measure: MEASURE\_1

Source	AVOID	Type III Sum of Squares	df	Mean Square	F	Sig.
AVOID	Linear	2590.083	1	2590.083	7.126	.010
	Quadratic	449.604	1	449.604	1.976	.166
Error(AVOID)	Linear	17810.108	49	363.472		
	Quadratic	11150.157	49	227.554		

Bonferonni method unplanned multiple comparisons: Paired Sample T-tests

## **Paired Samples Statistics**

		Mean	N	Std. Deviation	Std. Error Mean
Pair 1	PSAVTRAN	17.2500	50	24.4702	3.4606
İ	DWPAVTRA	18.6667	50	23.9518	3.3873
Pair 2	PSAVTRAN	17.2500	50	24.4702	3.4606
	DTAVTRAN	27.4286	50	37.6131	5.3193
Pair 3	DWPAVTRA	18.6667	50	23.9518	3.3873
	DTAVTRAN	27.4286	50	37.6131	5.3193

## **Paired Samples Correlations**

		N	Correlation	Sig.
Pair 1	PSAVTRAN & DWPAVTRA	50	.606	.000
Pair 2	PSAVTRAN & DTAVTRAN	50	.699	.000
Pair 3	DWPAVTRA & DTAVTRAN	50	.779	.000

## **Paired Samples Test**

		Paired Differences			
		Mean	Std. Deviation	Std. Error Mean	
Pair 1	PSAVTRAN - DWPAVTRA	-1.4167	21.4892	3.0390	
Pair 2	PSAVTRAN - DTAVTRAN	-10.1786	26.9619	3.8130	
Pair 3	DWPAVTRA - DTAVTRAN	-8.7619	24.1733	3.4186	

## **Paired Samples Test**

		Paired Differences 95% Confidence Interval of the Difference				
		Lower	Upper	t	df	Sig. (2-tailed)
Pair 1	PSAVTRAN - DWPAVTRA	-7.5238	4.6905	466	49	.643
Pair 2	PSAVTRAN - DTAVTRAN	-17.8411	-2.5161	-2.669	49	.010
Pair 3	DWPAVTRA - DTAVTRAN	-15.6319	-1.8919	-2.563	49	.013

One-factor within-participant ANOVA for participant's proportion of avoidance calculated from TA scores for the Personal Safety, Dealing With People and Doing Things Sub-domains (N=50).

## **General Linear Model**

## Within-Subjects Factors

Measure: MEASURE\_1

YESAVO	Dependent Variable
1	PSYESAV
2	DWPYEAV
3	DTYESAV

## Multivariate Tests<sup>b</sup>

Effect		Value	F	Hypothesis df	Error df	Sig.
YESAVO	Pillai's Trace	.030	.742 <sup>a</sup>	2.000	48.000	.481
	Wilks' Lambda	.970	.742 <sup>a</sup>	2.000	48.000	.481
	Hotelling's Trace	.031	.742a	2.000	48.000	.481
	Roy's Largest Root	.031	.742a	2.000	48.000	.481

a. Exact statistic

b.

Design: Intercept

Within Subjects Design: YESAVO

## Mauchly's Test of Sphericity<sup>b</sup>

Measure: MEASURE\_1

	Manahlada W	Approx. Chi-Square	ae.	e:-
Within Subjects Effect	Mauchly's W	Cni-Square	QI .	Sig.
YESAVO	.950	2.440	2	.295

Tests the null hypothesis that the error covariance matrix of the orthonormalized transformed dependent variables is proportional to an identity matrix.

## Mauchly's Test of Sphericity<sup>b</sup>

Measure: MEASURE\_1

		Epsilon <sup>a</sup>	
Within Subjects Effect	Greenhouse- Geisser	Huynh-Feldt	Lower-bound
YESAVO	.953	.990	500

Tests the null hypothesis that the error covariance matrix of the orthonormalized transformed dependent variables is proportional to an identity matrix.

a. May be used to adjust the degrees of freedom for the averaged tests of significance. Corrected tests are displayed in the Tests of Within-Subjects Effects table.

b.

Design: Intercept

Within Subjects Design: YESAVO

## Tests of Within-Subjects Effects

Measure: MEASURE\_1

Source		Type III Sum of Squares	df	Mean Square
YESAVO	Sphericity Assumed	841.410	2	420.705
	Greenhouse-Geisser	841.410	1.906	441.556
	Huynh-Feldt	841.410	1.981	424.814
	Lower-bound	841.410	1.000	841.410
Error(YESAVO)	Sphericity Assumed	52328.333	98	533,963
	Greenhouse-Geisser	52328.333	93.372	560,426
	Huynh-Feldt	52328.333	97.052	539.177
	Lower-bound	52328.333	49.000	1067.925

## Tests of Within-Subjects Effects

Measure: MEASURE\_1

Source		F	Sig.
YESAVO	Sphericity Assumed	.788	.458
	Greenhouse-Geisser	.788	.452
	Huynh-Feldt	.788	.457
	Lower-bound	.788	.379
Error(YESAVO)	Sphericity Assumed		
	Greenhouse-Geisser		
	Huynh-Feldt		
	Lower-bound		

## **Tests of Within-Subjects Contrasts**

Measure: MEASURE\_1

Source	YESAVO	Type III Sum of Squares	df	Mean Square	F	Sig.
YESAVO	Linear	816.327	1	816.327	1.329	.255
	Quadratic	25.084	1	25.084	.055	.815
Error(YESAVO)	Linear	30106.576	49	614.420		
	Quadratic	22221.757	49	453.505		

## **Descriptives**

## **Descriptive Statistics**

	N	Minimum	Maximum	Mean	Std. Deviation
PSYESAV	50	.00	100.00	27.3143	35.4911
DTYESAV	50	.00	100.00	33.0286	41.9108
DWPYEAV	50	.00	100.00	31.0389	35.3924
Valid N (listwise)	50				

# Appendix Gii Data analysis for main research paper

Correlations between ATAI scales and demographic variables

## Correlations between Demographic Variables of Age at Injury, Time Since Injury, Age at Assessment, Years in Education and ATAI scales

#### Correlations

	· · · · · · · · · · · · · · · · · · ·	-	<del> </del>		7		<del> </del>		<u> </u>			Time since		
		QLI	AVOID	TA	DT.AVOID	DT.TA	DWPAVOID	DWP.TA	PS.AVOID	PS.TA	AGEATINJ	Inj	AGE	YEARSEDU
Quality of Life	Pearson Correlation													
ŀ														
	n a 1.:													
Overall Avoidance	Pearson Correlation	557**							ļ					
7 (VOIGILIO				ı										
Overal TA	Pearson Correlation	546**	.684**											
							ļ							
														İ
Doing things	Pearson Correlation	407**	.894**	.588**								İ		i
Avoidance														
Doing Things	Pearson Correlation	- 445**	.537**	.833**	.497**						l 			]
TA Tallings	rearson correlation	-,443	.557	.033										
Dealing with	Pearson Correlation	560**	.950**	.618**	.779**	.476**								
People Avoidance														
	D Comulation	476**	.603**	.927**	.508**	.654**	.579**							
Dealing with People TA	Pearson Correlation	470**	.603**	.921	.508	.024	.577							
, copie iii														
Personal	Pearson Correlation	466**	.787**	.626**	.699**	.462**	.606**	.508**						
Safety														
Avoidance			l j		C 40+*	.627**	.467**	.553**	.702**					
Personal Safety Total	Pearson Correlation	551**	.592**	.772**	.542**	.62/**	.467**	,,,,,,,	.702				1	
Salety Total														
Age at Injury	Pearson Correlation	311*	.232	.194	.129	.048	.195	.138	.264	.301*				
, rigo at myony				i										
							256	222	050	-,060	225			
Time since	Pearson Correlation	.189	198	-,225	090	157	-,256	232	.050	-,000	225			
Injury										i			e .	
A	Pearson Correlation	163	.085	.032	.060	058	012	025	.275	.237	.773**	.445**		
Age at Assessment	1 carson correlation	-, 105												
												054	1000	
Years in Edu	Pearson Correlation	.103	078	010	- 004	022	- 077	023	120	.068	- 159	.056	- 109	

<sup>\*\*</sup> Correlation is significant at the 0.01 level (2-tailed)

<sup>\*</sup> Correlation is significant at the 0.05 level (2-tailed).

## Appendix Giii

Data analysis for main research paper

Multiple regression tables

## Threat Appraisal Sub-domain Multiple Regression: Dependent - QOLI

#### Variables Entered/Removed<sup>b</sup>

Model	Variables Entered	Variables Removed	Method
1	DT.TOT, PS.TOT, DWP.TOT	•	Enter

a. All requested variables entered.

b. Dependent Variable: QLITOT

#### **Model Summary**

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.589 <sup>a</sup>	.347	.304	4.0267

a. Predictors: (Constant), DT.TOT, PS.TOT, DWP.TOT

## **ANOVA**<sup>b</sup>

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	395.629	3	131.876	8.133	.000a
	Residual	745.858	46	16.214		
	Total	1141.487	49			

a. Predictors: (Constant), DT.TOT, PS.TOT, DWP.TOT

b. Dependent Variable: QLITOT

#### Coefficients<sup>a</sup>

	:	Unstand Coeffi	lardized cients	Standardize d Coefficients		
Model		В	Std. Error	Beta	t	Sig.
1	(Constant)	25.746	1.351		19.062	.000
]	PS.TOT	812	.324	395	-2.507	.016
1	DWP.TOT	206	.149	224	-1.380	.174
	DT.TOT	101	.346	050	291	.773

a. Dependent Variable: QLITOT

## Threat-appraisal Sub-domain Multiple Regression Dependent Variable-Anxiety

## Variables Entered/Removed<sup>b</sup>

Model	Variables Entered	Variables Removed	Method
1	DT.TOT, PS.TOT,		Enter
l	DWP.TOT		

a. All requested variables entered.

b. Dependent Variable: ANX.TOT

#### **Model Summary**

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.561a	.314	.268	4.2912

a. Predictors: (Constant), DT.TOT, PS.TOT, DWP.TOT

#### **ANOVA**<sup>b</sup>

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	371.697	3	123.899	6.728	.001 <sup>a</sup>
1	Residual	810.220	44	18.414		
l	Total	1181.917	47			

a. Predictors: (Constant), DT.TOT, PS.TOT, DWP.TOT

b. Dependent Variable: ANX.TOT

#### Coefficients<sup>a</sup>

		Unstandardized Coefficients		Standardize d Coefficients		
Model		В	Std. Error	Beta	t	Sig.
1	(Constant)	4.416	1.473		2.998	.004
	PS.TOT	1.040	.345	.494	3.013	.004
	DWP.TOT	.190	.159	.200	1.194	.239
	DT.TOT	207	.372	100	555	.582

a. Dependent Variable: ANX.TOT

## Threat-appraisal Sub-domain Regression: Dependent Variable-Depress

## Variables Entered/Removed<sup>b</sup>

Model	Variables Entered	Variables Removed	Method
1	DT.TOT, PS.TOT, DWP.TOT	•	Enter

a. All requested variables entered.

b. Dependent Variable: DEP.TOTA

## **Model Summary**

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.488a	.238	.186	3.5309

a. Predictors: (Constant), DT.TOT, PS.TOT, DWP.TOT

#### **ANOVA**<sup>b</sup>

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	171.352	3	57.117	4.581	.007ª
	Residual	548.565	44	12.467		
l	Total	719.917	47			

a. Predictors: (Constant), DT.TOT, PS.TOT, DWP.TOT

b. Dependent Variable: DEP.TOTA

#### Coefficients<sup>a</sup>

		Unstand Coeffi		Standardize d Coefficients		
Model		В	Std. Error	Beta	t	Sig.
1	(Constant)	2.015	1.212		1.663	.103
	PS.TOT	.342	.284	.208	1.204	.235
1	DWP.TOT	.201	.131	.271	1.530	.133
	DT.TOT	.141	.306	.087	.461	.647

a. Dependent Variable: DEP.TOTA

## Avoidance Sub-domain Regression: Dependent Variable QOLI

## Variables Entered/Removedb

Model	Variables Entered	Variables Removed	Method
1	SA.D, DWPAVOI		_
	D, PS.AVOID, DT.AVOID		Enter

a. All requested variables entered.

b. Dependent Variable: QLITOT

## **Model Summary**

			Adjusted R	Std. Error of
Model	R	R Square	Square	the Estimate
1	.613a	.375	.318	3.9700

a. Predictors: (Constant), SA.D, DWPAVOID, PS.AVOID, DT.AVOID

## ANOVA<sup>b</sup>

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	416.486	4	104.121	6.606	.000ª
	Residual	693.496	44	15.761		ł
	Total	1109.982	48			<u> </u>

a. Predictors: (Constant), SA.D, DWPAVOID, PS.AVOID, DT.AVOID

b. Dependent Variable: QLITOT

#### Coefficients<sup>a</sup>

			dardized icients	Standardize d Coefficients		
Model		В	Std. Error	Beta	t	Sig.
I	(Constant)	22.794	.800		28.495	.000
ļ	PS.AVOID	-1.011	.504	414	-2.005	.051
	DWPAVOID	546	.182	575	-2.998	.004
	DT.AVOID	.504	.403	.277	1.251	.218
	SA.D_	.123	.245	.101	.501	.619

a. Dependent Variable: QLITOT

## **Avoidance Sub-domain Regression: Dependent Variable Anxiety**

## Variables Entered/Removed<sup>b</sup>

Model	Variables Entered	Variables Removed	Method
1	SA.D, DWPAVOI D, PS.AVOID, DT.AVOID		Enter

a. All requested variables entered.

## **Model Summary**

			Adjusted R	Std. Error of
Model	R	R Square	Square	the Estimate
1	.644 <sup>a</sup>	.415	.359	4.0542

a. Predictors: (Constant), SA.D, DWPAVOID, PS.AVOID, DT.AVOID

## **ANOVA**<sup>b</sup>

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	489.875	4	122.469	7.451	.000ª
	Residual	690.338	42	16.437		
	Total	1180.213	46			

a. Predictors: (Constant), SA.D, DWPAVOID, PS.AVOID, DT.AVOID

b. Dependent Variable: ANX.TOT

b. Dependent Variable: ANX.TOT

#### Coefficients<sup>a</sup>

		Unstandardized Coefficients		Standardize d Coefficients		
Model		В	Std. Error	Beta	t	Sig.
1	(Constant)	5.889	.836		7.044	.000
l	PS.AVOID	.589	.534	.228	1.104	.276
1	DWPAVOID	.458	.186	.455	2.458	.018
	DT.AVOID	129	.433	066	¬.298	.767
	SA.D	.124	.281	.099	.441	.661

a. Dependent Variable: ANX.TOT

## Avoidance Sub-domain Regression: Dependent Variable Depression

## Variables Entered/Removed<sup>b</sup>

Model	Variables Entered	Variables Removed	Method
I	SA.D, DWPAVOI D, PS.AVOID, <sub>a</sub> DT.AVOID		Enter

a. All requested variables entered.

## **Model Summary**

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.528 <sup>a</sup>	.279	.211	3.5146

a. Predictors: (Constant), SA.D, DWPAVOID, PS.AVOID, DT.AVOID

## **ANOVA**<sup>b</sup>

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	201.060	4	50.265	4.069	.007ª
	Residual	518.812	42	12.353		
	Total	719.872	46		:	

a. Predictors: (Constant), SA.D, DWPAVOID, PS.AVOID, DT.AVOID

b. Dependent Variable: DEP.TOTA

b. Dependent Variable: DEP.TOTA

## Coefficients<sup>a</sup>

	Unstandardized Coefficients			Standardize d Coefficients		
Model		В	Std. Error	Beta	t	Sig.
1	(Constant)	3.997	.725		5.514	.000
	PS.AVOID	.532	.463	.264	1.149	.257
]	DWPAVOID	.328	.162	.417	2.030	.049
	DT.AVOID	588	.375	383	-1.569	.124
	SA.D	.229	.244	.234	.940	.353

a. Dependent Variable: DEP.TOTA

## **Appendix Giv**

Data analysis for main research paper

Table of predictors

Path analysis: 5-step regression procedure

<u>Table 11</u>. Hierarchical regression analysis exploring the relative predictive relationships between avoidance, TFWs, anxiety, depression and quality of life.

Dependent variable	Model	Predictor	Adj. <u>R</u> <sup>2</sup>	<u>beta</u>
Quality of Life (QOLI)	1.	Depression	0.35	-0.60**
	2.	Avoidance	0.43	-0.34*
Depression (HADS)	1.	Anxiety	0.30	0.56**
Avoidance (ATAI) 1.	1.	TFW	0.44	0.67**
	2.	Anxiety	0.54	0.39**
Anxiety (HADS)	1.	Avoidance	0.37	0.62**
	2.	Depression	0.46	0.35*
TFW (ATAI)	1.	Avoidance	0.38	0.62**

<sup>\*</sup> p < 0.01; \*\* p < 0.001 Adjusted  $R^2$  shown for each model. Beta values are displayed for each pathway.

Path Analysis: Regression - Step One

Dependent Variable: Quality of life

## Variables Entered/Removeda

Model	Variables Entered	Variables Removed	Method
1	DEP.TOTA		Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).
2	AVOIDTOT		Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).

a. Dependent Variable: QLITOT

#### Model Summary<sup>c</sup>

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.599ª	.358	.345	3.8958
2	.67 I <sup>b</sup>	.450	.425	3.6472

a. Predictors: (Constant), DEP.TOTA

b. Predictors: (Constant), DEP.TOTA, AVOIDTOT

c. Dependent Variable: QLITOT

## **ANOVA<sup>c</sup>**

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	390.095	1	390.095	25.703	.000ª
	Residual	698.136	46	15.177		
	Total	1088.232	47			
2	Regression	489.626	2	244.813	18.404	.000 <sup>b</sup>
	Residual	598.605	45	13.302		
	Total	1088.232	47			

a. Predictors: (Constant), DEP.TOTA

b. Predictors: (Constant), DEP.TOTA, AVOIDTOT

c. Dependent Variable: QLITOT

### Coefficients<sup>a</sup>

			lardized cients	Standardize d Coefficients		
Model		В	Std. Error	Beta	t	Sig.
I	(Constant)	24.818	1.012		24.534	.000
	DEP.TOTA	736	.145	599	-5.070	.000
	AVOIDTOT					
2	(Constant)	25.161	.955		26.338	.000
1	DEP.TOTA	555	.151	452	-3.672	.001
	AVOIDTOT	178	.065	336	-2.735	.009

a. Dependent Variable: QLITOT

### Excluded Variables<sup>c</sup>

					Partial	Collinearity Statistics
Model		Beta In	t	Sig.	Correlation	Tolerance
1	TA	315 <sup>a</sup>	-2.474	.017	346	.775
ł	AVOIDTOT	336ª	-2.735	.009	378	.808
	ANX.TOT	336ª	-2.492	.016	348	.689
2	TA	172 <sup>b</sup>	-1.113	.272	165	.507
	AVOIDTOT					
	ANX.TOT	203 <sup>b</sup>	-1.321	.193	195	.510

a. Predictors in the Model: (Constant), DEP.TOTA

b. Predictors in the Model: (Constant), DEP.TOTA, AVOIDTOT

c. Dependent Variable: QLITOT

### Residuals Statistics<sup>a</sup>

	Minimum	Maximum	Mean	Std. Deviation	N
Predicted Value	12.8282	24.9823	20.5548	3.2276	48
Residual	-8.2338	5.5822	1.887E-15	3.5688	48
Std. Predicted Value	-2.394	1.372	.000	1.000	48
Std. Residual	-2.258	1.531	.000	.978	48

a. Dependent Variable: QLITOT

Path Analysis: Regression Step Two

**Dependent Variable: Depression** 

### Variables Entered/Removeda

Model	Variables Entered	Variables Removed	Method
Model	Efficied	Kemoveu	Method
1	ANX.TOT		Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >=
		L.	.100).

a. Dependent Variable: DEP.TOTA

### **Model Summary**

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.557 <sup>a</sup>	.311	.296	3.2847

a. Predictors: (Constant), ANX.TOT

### ANOVA<sup>b</sup>

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	223.604	1	223.604	20.724	$.000^{a}$
1	Residual	496.312	46	10.789		
	Total	719.917	47			

a. Predictors: (Constant), ANX.TOTb. Dependent Variable: DEP.TOTA

### Coefficients<sup>a</sup>

			dardized ficients	Standardize d Coefficients		
Model		В	Std. Error	Beta	t	Sig.
1	(Constant)	2.004	.958		2.093	.042
	ANX.TOT	.435	.096	.557	4.552	.000

a. Dependent Variable: DEP.TOTA

### Excluded Variablesb

					Partial	Collinearity Statistics
Model		Beta In	t	Sig.	Correlation	Tolerance
1	TA	.263a	1.921	.061	.275	.755
	AVOIDTOT	.146 <sup>a</sup>	.932	.356	.138	.609

a. Predictors in the Model: (Constant), ANX.TOT

b. Dependent Variable: DEP.TOTA

### $Excluded\ Variables^b$

						Collinearity
1				}	Partial	Statistics
Model		Beta In	t	Sig.	Correlation	Tolerance
1	ANX.TOT	.387 <sup>a</sup>	3.422	.001	.454	.755

a. Predictors in the Model: (Constant), TAb. Dependent Variable: AVOIDTOT

### Residuals Statistics<sup>a</sup>

	Minimum	Maximum	Mean	Std. Deviation	N
Predicted Value	-6.2363	20.8555	7.7917	6.8224	48
Residual	-12.1647	11.2525	-6.4763E-17	5.9721	48
Std. Predicted Value	-2.056	1.915	.000	1.000	48
Std. Residual	-1.993	1.844	.000	.978	48

a. Dependent Variable: AVOIDTOT

Path Analysis: Regression Step Three

Dependent Variable: Avoidance

### Variables Entered/Removeda

Model	Variables Entered	Variables Removed	Method
1	TA		Stepwise (Criteria:  Probability-of-F-to-enter <= .050,  Probability-of-F-to-remove >= .100).
2	ANX.TOT		Stepwise (Criteria:  Probability-of-F-to-enter <= .050,  Probability-of-F-to-remove >= .100).

a. Dependent Variable: AVOIDTOT

### Model Summary<sup>c</sup>

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.673 <sup>a</sup>	.453	.441	6.7766
2	.752 <sup>b</sup>	.566	.547	6.1033

a. Predictors: (Constant), TA

b. Predictors: (Constant), TA, ANX.TOTc. Dependent Variable: AVOIDTOT

### **ANOVA<sup>c</sup>**

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	1751.465	1	1751.465	38.139	.000ª
	Residual	2112.452	46	45.923		
	Total	3863.917	47			
2	Regression	2187.642	2	1093.821	29.364	.000b
	Residual	1676.275	45	37.251		
	Total	3863.917	47		_	

a. Predictors: (Constant), TA

b. Predictors: (Constant), TA, ANX.TOTc. Dependent Variable: AVOIDTOT

### Coefficients<sup>a</sup>

			Unstandardized Coefficients			
Model		В	Std. Error	Beta	t	Sig.
1	(Constant)	-4.588	2.230		-2.057	.045
	TA	.643	.104	.673	6.176	.000
	ANX.TOT					
2	(Constant)	-7.157	2.145		-3.337	.002
	TA	.460	.108	.482	4.264	.000
	ANX.TOT	.699	.204	.387	3.422	.001

a. Dependent Variable: AVOIDTOT

### Excluded Variables<sup>b</sup>

					Collinearity
				Partial	Statistics
Model	Beta In	t	Sig.	Correlation	Tolerance
1 ANX.TOT	.387 <sup>a</sup>	3,422	.001	.454	.755

a. Predictors in the Model: (Constant), TA

b. Dependent Variable: AVOIDTOT

### Residuals Statistics<sup>a</sup>

	Minimum	Maximum	Mean	Std. Deviation	N
Predicted Value	-6.2363	20.8555	7.7917	6.8224	48
Residual	-12.1647	11.2525	-6.4763E-17	5.9721	48
Std. Predicted Value	-2.056	1.915	.000	1.000	48
Std. Residual	-1.993	1.844	.000	.978	48

a. Dependent Variable: AVOIDTOT

Path Analysis: Regression - Step Four Dependent: Anxiety

### Variables Entered/Removeda

Model	Variables Entered	Variables Removed	Method
1	AVOIDTOT		Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).
2	DEP.TOTA		Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).

a. Dependent Variable: ANX.TOT

### **Model Summary**

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.625 <sup>a</sup>	.391	.378	3.9561
2	.700 <sup>b</sup>	.490	.468	3.6584

a. Predictors: (Constant), AVOIDTOT

b. Predictors: (Constant), AVOIDTOT, DEP.TOTA

### **ANOVA<sup>c</sup>**

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	461.997	1	461.997	29.520	$.000^{a}$
	Residual	719.919	46	15.650		
	Total	1181.917	47	1		
2	Regression	579.656	2	289.828	21.656	.000b
	Residual	602.260	45	13.384		
	Total	1181.917	47			

a. Predictors: (Constant), AVOIDTOT

b. Predictors: (Constant), AVOIDTOT, DEP.TOTA

c. Dependent Variable: ANX.TOT

### Coefficients<sup>a</sup>

		0	Unstandardized Coefficients			
Model		В	Std. Error	Beta	t	Sig.
1	(Constant)	6.014	.756		7.952	.000
	AVOIDTOT DEP.TOTA	.346	.064	.625	5.433	.000
2	(Constant)	4.072	.958		4.249	.000
1	AVOIDTOT	.261	.065	.472	3.985	.000
	DEP.TOTA	.450	.152	.351	2.965	.005

a. Dependent Variable: ANX.TOT

### Excluded Variables<sup>c</sup>

Model		Beta In	t	Sig.	Partial Correlation	Collinearity Statistics Tolerance
1	TA	.136ª	.868	.390	.128	.547
	DEP.TOTA	.351a	2.965	.005	.404	.808
2	TA	.022 <sup>b</sup>	.143	.887	.022	.507
}	DEP.TOTA					

a. Predictors in the Model: (Constant), AVOIDTOT

b. Predictors in the Model: (Constant), AVOIDTOT, DEP.TOTA

c. Dependent Variable: ANX.TOT

Path Analysis: Regression Step 5

**Dependent Variable: Threat-Appraisals** 

### Variables Entered/Removeda

Model	Variables Entered	Variables Removed	Method
1	AVOIDTOT		Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remo ve >= .100).

a. Dependent Variable: TA

### **Model Summary**

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.673a	.453	.441	7.0946

a. Predictors: (Constant), AVOIDTOT

### **ANOVA**<sup>b</sup>

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	1919.672	1	1919.672	38.139	.000ª
	Residual	2315.328	46	50.333		
	Total	4235.000	47			

a. Predictors: (Constant), AVOIDTOT

b. Dependent Variable: TA

### Coefficients<sup>a</sup>

		Unstandardized Coefficients		Standardize d Coefficients		
Model		В	Std. Error	Beta	t	Sig.
1	(Constant)	13.758	1.356		10.144	.000
	AVOIDTOT	.705	.114	.673	6.176	.000

a. Dependent Variable: TA

### Excluded Variables<sup>b</sup>

Model		Beta In	t	Sig.	Partial Correlation	Collinearity Statistics Tolerance
1	DEP.TOTA	.222a	1.885	.066	.271	.808
j	ANX.TOT	.122 <sup>a</sup>	.868	.390	.128	.609

a. Predictors in the Model: (Constant), AVOIDTOT

b. Dependent Variable: TA

### Appendix Gv

Data analysis for main research paper

T-tests and correlations between early and late groups of time since injury Calculation for test of significance between correlations

# Correlations between TAs, Quality of Life, Depression, Anxiety and Avoidance for 10 Participants Within Late Group

### **Correlations**

		QLITOT	ANX.TOT	DEP.TOTA	AVOIDTOT	TA
QLITOT	Pearson Correlation					
	Sig. (2-tailed)					
	N					
ANX.TOT	Pearson Correlation	507				
	Sig. (2-tailed)	.163				
	N	9				
DEP.TOTA	Pearson Correlation	402	.719*			
	Sig. (2-tailed)	.284	.029			
	N	9	9			
AVOIDTOT	Pearson Correlation	766**	.608	640		
· I	Sig. (2-tailed)		1	.648		
	- '	.010	.082	.059		
	N	10	9	9		
TA	Pearson Correlation	71 <b>7*</b>	.690*	.492	.586	
	Sig. (2-tailed)	.020	.040	.179	.075	
	N	10	9	9	10	

<sup>\*\*.</sup> Correlation is significant at the 0.01 level (2-tailed).

### Correlations for 10 participants within early group

### **Correlations**

		QLITOT	ANX.TOT	DEP.TOTA	TA	AVOIDTOT
QLITOT	Pearson Correlation					
	Sig. (2-tailed)					1
]	N					
ANX.TOT	Pearson Correlation	667*				
	Sig. (2-tailed)	.035				
•	N	10				
DEP.TOTA	Pearson Correlation	615	.534			
	Sig. (2-tailed)	.058	.112			
	N	10	10			
TA	Pearson Correlation	560	.660*	102		İ
	Sig. (2-tailed)	.093	.038	.779		
!	N	10	10	10		
AVOIDTOT	Pearson Correlation	412	.626	165	.792**	
	Sig. (2-tailed)	.237	.053	.648	.006	1
	N	10	10	10	10	

<sup>\*.</sup> Correlation is significant at the 0.05 level (2-tailed).

<sup>\*.</sup> Correlation is significant at the 0.05 level (2-tailed).

<sup>\*\*.</sup> Correlation is significant at the 0.01 level (2-tailed).

### Early and Late Group Comparisons: T-tests

### **Group Statistics**

	HIGLOWGP	N	Mean	Std. Deviation	Std. Error Mean
AVOIDTOT	Early	10	6.6000	8.5401	2.7006
	Late	10	5.6000	7.1368	2.2568
ANX.TOT	Early	10	7.5000	4.5277	1.4318
	Late	9	6.4444	3.5395	1.1798
DEP.TOTA	Early	10	5.1000	2.6437	.8360
	Late	9	6.1111	5.5777	1.8592
QLITOT	Early	10	20.2157	3.9142	1.2378
	Late	10	21.0199	5.5602	1.7583

### **Independent Samples Test**

		Levene's Test for Equality of Variances	
		F	Sig.
AVOIDTOT	Equal variances assumed Equal variances not assumed	.580	.456
ANX.TOT	Equal variances assumed Equal variances not assumed	1.704	.209
DEP.TOTA	Equal variances assumed Equal variances not assumed	2.958	.104
QLITOT	Equal variances assumed Equal variances not assumed	3.316	.085

### **Independent Samples Test**

		t-test for Equality of Means				
AVOIDTOT	Fauctori	t	df	Sig. (2-tailed)	Mean Difference	
AVOIDIOI	Equal variances assumed	.284	18	.780	1.0000	
	Equal variances not assumed	.284	17.450	.780	1.0000	
ANX.TOT	Equal variances assumed	.561	17	.582	1.0556	
	Equal variances not assumed	.569	16.706	.577	1.0556	
DEP.TOTA	Equal variances assumed	514	17	.614	1.0111	
	Equal variances not assumed	496	11.157	.630	-1.0111 -1.0111	
QLITOT	Equal variances assumed	374	18	.713	8043	
	Equal variances not assumed	374	16.162	.713	8043	

Test of significance between two Pearson's r correlations (Edwards, 1984).

$$\Gamma_{1} = -.766 : z_{1} = 1.008$$

$$\Gamma_{2} = -.412 : 2_{2} = 0.436.$$

$$\sigma_{2_{1}-2_{2}} = \sqrt{\sigma_{2_{1}}^{2}} + \sigma_{2_{2}}^{2}$$

$$= \sqrt{\frac{1}{n_{1}-3}} + \frac{1}{n_{2}-3}$$

$$O_{z_{1}-2_{2}} = \sqrt{\frac{1}{10-3}} + \frac{1}{10-3} = 0.535$$

$$2obt = \frac{2_{1}-2_{2}}{\sigma_{2_{1}-2_{2}}}$$

$$2obt = \frac{1.003-0.436}{0.535}$$

$$2obt = 1.07, \rho = (approx) 0.28 ns.$$

Edwards, A.L. (1984). An introduction to linear regression and correlation. 2nd Ed. New York: W.H. Freeman and Company.

# Appendix Gvi

Answers provided for ATAI open questions

### ATAI Open Ended Question Responses

Phase One.

I was wondering: has there been anything in particular that you've been put off doing since you've had your injury?

I don't like others to see my disability at the sports centre

I used to have difficulties with buses.

Going back to work & getting back into sports

Working

Don't do artwork anymore, I haven't got the nerves.

no

Walking

no

Reading

no

I get put off being independent at times, doing DIY etc

Socialising. I don't have the confidence that I had before.

I've had difficulty coping in work situations

Playing football, going back to work.

Social gatherings. I'm not quite so confident.

Going out and socialising

I've been medically advised not to fly in a plane or to drive a car.

I've been put of having to deal with my finances.

No

No

No

No Sex

Social situations have been difficult

Having a paid job.

Flower arranging. Can't drive at the moment. I've been apprehensive about cooking

Driving. Doing stuff in the garden.

I've been put of going back to work.

Chatting up women. Going to social places I used to visit. Socialising

No

Talking to women.

Trying to juggle more than one thing at once.

Doing things around the house. Paperwork (forms etc). Hoovering

Having a job and the attitudes of employers.

Nothing

Swimming; because of my appearance at the pool. How I look puts me off. I can't exercise like I used to so I don't look as good.

Chatting up females.

I'm unsure of whether to go to Camp America with sister.

Going out and socialising.

**Nothing** 

No

No

Going out to talk to girls in pubs.

My self-image when swimming, but have now got over that. Physical difficulties stop me from cooking or ironing.

My hearing is absolute shit. It affects me all the time but I feel like people don't want to know. If someone says something too quickly I lose it. My girlfriend has absolutely no patience.

The only thing is I want to do that I don't is clubbing, but I'm worried about what people will think

Don't like it when kids take the piss out of me.

### Personal Safety

Is there anything else that might make you feel unsafe?

no

no

Having to go up heights, for instance, climbing up ladders

no

Epilepsy worries me about going out. My uncle had a stroke when he was out.

no

People in my neighbourhood are sometimes threatening but I don't have a problem.

nο

I feel unsafe if I'm on my own in the evenings

no

no

Cycling and swimming

nο

Walking on ice.

no

no

no

no

no

I don't go out if I've got a headache. I can't be responsible for my own doings.

no

no

People generally make me feel unsafe.

no

Skinheads: I'll never trust anybody ever again.

no

No I'm fairly careful. I take care on the roads and I wear seatbelts.

A lack of a sense of smell makes me wary about the possibility of not smelling fires.

No

no

My tiredness makes me feel unsafe.

My eyesight difficulties make me feel unsafe.

Riding a bike and roller skating.

no

Driving abroad because it relates to what happened.

no

The limitations brought on by epilepsy, e.g. heights, narrow walkways, and computers.

Nothing

Obsessions make me check doors and myself. I don't want to go out in case I haven't locked the doors.

Nothing

no

Crowds make me feel unsafe.

**Nothing** 

No

No

A lot of stuff in the paper makes me feel dubious about going out. No Dying, having had this injury makes me feel more vulnerable. No I don't really feel unsafe. When I walk I shake if there's a car beside me. Dealing with People Is there anything that you can think of that might put you off dealing with people? no If people are nasty, I don't want to be with them. My 'shakes' make me feel stupid like when I try to roll up cigarettes. no no no no Sometimes, peoples' shock at seeing me in a wheelchair frustrates me. I don't take care of myself as much, my appearance has suffered. no no The main thing for me is the threat of violence. no no no People taking the piss. I can't take jokes anymore. Not trusting people, due to the thought of what happened to me. no no no no no no no People asking questions and having to go through the whole thing again. People not knowing about the problems associated with epilepsy and brain injury. They assume you're a nutter who needs a straight jacket. People who swear, I have strong feelings about this and get very annoyed. No No The impatience of people is difficult to deal with. They may not tell me things because they might be scared of my reaction. I don't like being academically criticised. People don't know how to explain things to me, they tend to over and under-simplify information.

No

No

I'm more stuck in one place and so less mobile: I can't go on pub crawls anymore.

Nothing

People asking too many questions about the injury.

No, I like being with other people.

People pushing me aside because of who I am, like when queuing or in the pub.

### **Doing Things**

Is there anything else you can think of that might put you off doing things?

no

no

no

no

no

no

no

skydiving

no

no

no

Money difficulties.

### No

Being physically immobile. Another thing is that my nephew can beat me at chess – I taught him to play. I can't concentrate like I used to. He's just a kid.

Tiredness for me is the big thing. I need to sleep in the day to do my homework at night its frustrating.

I feel I've gone a long way forward so I don't really think about it.

Just what people might think.

People looking at me puts me off going swimming.

## Appendix H

Public domain briefing

# Thesis Title Coping and adjustment following acquired brain injury: A public domain briefing paper

### **Andrew Brennan**

School of Psychology, University of Birmingham June, 2002

### 1. BACKGROUND

### 1.1 Summary

This thesis was researched by Andrew Brennan, Clinical Psychologist in Training at the University of Birmingham, in collaboration with clinical research tutors Dr. Theresa Powell and Dr. Gerry Riley. It fulfilled part of the requirements for the degree of Doctorate in Clinical Psychology (Clin.Psy.D) training programme.

The thesis comprises a literature review paper that examined the existing literature relating to models of coping as aetiological factors of adjustment following acquired brain injury. This was followed by an empirical paper which took as its focus the issue of avoidance of situations that are considered difficult by people with traumatic brain injuries<sup>1</sup>, and which they may feel less confident about since their injury. The review paper examined two main bodies of literature, Goldstein's 'catastrophic reaction' model (Goldstein, 1939; 1952) and applications of Lazarus and Folkman's (1984) stress-appraisal and coping theory to adjustment following acquired brain injury. It is suggested that there is an emerging model of 'avoidance coping' in stress-appraisal and coping investigations that is analogous to the catastrophic reaction model. What is more, avoidance coping, although common after acquired brain injury, seems to predict adjustment difficulties. Overall, the utility of this coping hypothesis is suggested to be, at present, underdeveloped in the literature due to a lack of identified reasons as to why somebody may cope by avoidance, whereas others do not.

The main study examined the relationships between threat-appraisals, avoidance and adjustment factors of anxiety, depression and quality of life within a cross sectional survey design. By employing psychological measures, including a structured interview devised specifically to measure participants' appraisals of threat and avoidance after brain injury (ATAI), fifty people with traumatic brain injuries were interviewed. The inclusion of a quality of life measure was an attempt to build on the established findings of a relationship between anxiety, depression and avoidance coping. Some criticisms may be levelled here given that avoidance may be construed as a psychological feature of both anxiety and depression. Quality of life, on the other hand, would perhaps constitute a more distinct psychological concept from avoidance coping, anxiety and depression.

<sup>&</sup>lt;sup>1</sup> Acquired brain injuries are those relating to generic injuries to the brain, and may include strokes, anoxic injuries and infections, as well as impacts to the head. The literature review refers to this more generic category, whereas the empirical paper exclusively investigates people with traumatic brain injuries. Traumatic brain injuries result from impacts to the head, though the present empirical study specifically focuses upon those who had 'non-penetrating' traumatic brain injuries.

Statistical analyses revealed that, as hypothesised, appraisal of threat and associated avoidance were related to overall levels of adjustment following traumatic brain injury. In general, avoidance of perceived threats after brain injury bore the strongest relationship to all the adjustment factors. A category that assessed one's apprehensions about 'doing things' after their injury suggested that these were the most frequently reported difficulties and reasons for avoidance. However, concerns about one's 'personal safety' and particularly social avoidance after injury were most strongly related to adjustment difficulties as measured by anxiety, depression and quality of life. However, as threat-appraisals were not 100% predictive of avoidance, future studies might aim to better understand the process by which threat-appraisal leads to avoidance, and the factors that may be influential in this process. In addition, although avoidance appears to be predictive of difficulties after injury, further research needs to identify coping strategies and personal resources that might relate to the individual's well being following acquired brain injury.

Ethical approval for the study was received from Worcester, West Birmingham and South Birmingham NHS ethics committees in 2001. The author would particularly like to thank all within the HEADWAY organisation, and clinical psychologists, Mr Robin Paigmans and Mr Dave Quinn for their considerable help.

### 1.2 Introduction

It has been suggested that avoidance is a relatively frequent coping response following acquired brain injury. The stress-appraisal and coping research has established a link between the frequency of avoidance coping strategies that an individual reports and emotional difficulties as measured by indices of anxiety or depression. Traditionally, however, adjustment following traumatic brain injury has been considered within the context of the severity or location of neurological damage that the individual has Inconsistencies in the research literature indicate that these neurological profiles have been inadequate for explaining individual differences in adjustment. Some attempts have been made to redress this imbalance and psychological models have instead been employed in an attempt to explain a person's emotional coping responses to acquired brain injury. These, for example, have featured Goldstein's 'catastrophic reaction' model (Goldstein, 1939;1952), van Zomeren, Brouwer and Deelman's (1984) 'coping hypothesis' and applications of Lazarus and Folkman's (1984) stress-appraisal and coping theory. Here it is typically suggested that anxiety is invoked when an individual is presented with a situation post injury that they perceive they can no longer manage, and that this may result in negative consequences for their self esteem and confidence, and therefore their withdrawal from everyday situations. However, to date these theories have been unable to further our understanding of individual differences in post injury adjustment, or to illuminate those who are more vulnerable to anxiety difficulties. It is here where the stress-appraisal and coping literature has provided some explanation of individual differences through those who employ more avoidance strategies when under stress. Nevertheless, there are as yet few empirical studies to explain why an individual might be more susceptible to employing avoidance strategies or what it is they find stressful. Furthermore, it has been suggested that avoidance may, in the short term, be an adaptive response to the changes brought on by injury, but maladaptive in the longer term. Quantitative studies have not so far examined this possibility.

In addition, the literature review raised particular issues regarding the comparisons and contrasts between Goldstein's (1939) theory, which was formulated in relation to the adjustment of World War I veterans with acquired brain injuries, and applications of the stress-appraisal and coping theory, originated through study of non-clinical populations. Goldstein's theory is rich in its philosophy and engenders a unique insight into the circumstances faced by people with brain injuries. It has been much heralded by the recently ascending literature on psychotherapy for people with acquired brain injuries. The stress-appraisal and coping literature, on the other hand, is less holistic in its portrayal of the individual, yet has a potentially wide scope for identifying, and empirically supporting, the influential factors in adjustment following acquired brain injury.

As stated, reviewing the stress-appraisal and coping literature relating to acquired brain injury (Brennan, 2002) revealed that a number of studies have established a link between avoidance and adjustment difficulties. This line of enquiry has, however, generally failed to capture the nature of the specific difficulties experienced by people with acquired brain injuries, as have those employing the catastrophic reaction model. Yet, this is despite a central feature of such models to discuss the individual's reaction in context of their 'appraisal' of situations that may lead to their coping by avoidance; the evidence base for this model remains thin. The present study aimed to address this caveat with the questions; why do some people avoid activities and what situations do they avoid? Do assessments of threat-appraisal and avoidance, specific to people with brain injury, substantiate the predictive relationship to adjustment as found in the stress-appraisal and coping literature?

In brief, the stress-appraisal and coping paradigm (Lazarus and Folkman, 1984) proposes that, when an individual is confronted with a stressor, they appraise whether or not it is a threat to them (primary appraisal), and, secondly, if they have the resources to cope with it (secondary appraisal). This model therefore has the scope to illuminate the reasons why people may cope by avoidance. Avoidance coping is enacted in an attempt to protect the individual from emotional overwhelm. The present study used Lazarus and Folkman's framework to explore the 'threat-appraisals' of people with traumatic brain injuries that may lead to avoidance, and how these relate to emotional adjustment. Specifically, threat-appraisals are defined as the anticipated threat of harm, loss or damage. This, for example, may relate to the belief that one is more vulnerable to attack and physical injury, or to the event of a memory failure and consequent loss of confidence in one's ability.

### 2. STUDY AIMS

The study was exploratory and its main aims were:

- i. To identify what people with acquired brain injury appraise as threatening
- To examine the extent to which people cope by avoiding participation in activities because of these appraisals
- To investigate the relationship between appraisal, avoidance, emotional adjustment (anxiety and depression) and quality of life.

### 3. METHOD

### 3.1 Design

The study employed a cross sectional survey design. It also involved a brief qualitative study comprising interviews with people who had sustained an acquired brain injury or who were either professional or familial carers. Four focus groups were combined with individual interviews and autobiographical accounts in the literature for this part of the research.

### 3.2 Participants

Fifty people took part in the main study (41 males and 9 females) and were recruited from either community day services or NHS rehabilitation programmes. Each person was interviewed at least 9 months post injury by the author. Interviews lasted approximately between one and one and a half hours.

### 3.3 Interview and Questionnaire measures

Each person completed the following research measures:

- i. Appraisal of Threat and Avoidance Interview (ATAI)
- ii. Quality of Life Index (QOLI)
- iii. Hospital Anxiety and Depression Scale (HADS)
- iv. Coping Schedule

The ATAI was devised by the author for the present study and was based upon the themes elicited from the brief qualitative study. Threat appraisals and avoidance were assessed by, first, presenting a statement that derived from the first part of the study. If this statement was endorsed then the participant was asked if it meant that they would then avoid the related situation. For example:

1 a)	Is this true? Sometimes I wor while I'm out.	ту I might g	get attacked and inju	red
If	Yes:	es 🗌	No Used to	o be
<i>b</i> )	Have you avoide	ed going out	t because of this?	
	Ye	es 🔲	No 🗌	

### 3.4 Procedure

Potential participants were approached by staff known to them within services for people with acquired brain injuries and brief details of the study were explained. All participants gave their written consent and were informed of their right to withdraw from the study at any time. The author administered all measures.

### 4. KEY FINDINGS

### 4.1 Qualitative Phase

Results for the preliminary qualitative phase generated five categories of difficulties that people with acquired brain injuries described as threatening since their injury. These are listed below:

- Issues of personal safety (e.g., I sometimes worry I might get attacked and injured while I'm out)
- Dealing with people (e.g., I sometimes feel like I don't fit in)
- Awkward situations (e.g., I sometimes feel uncomfortable watching T.V. in case a programme reminds me of the injury)
- Issues about doing things (e.g., It sometimes bothers me that I can't do things like I used to)
- An inventory of specific activities (e.g., Confidence difficulties when going shopping, or out to the pub)

These categories of situations were employed in the development of the appraisal of threat and avoidance interview (ATAI). Good internal reliabilities were found for the subdomains of the interview ( $\alpha > 0.7$ ) with the exception of 'Awkward Situations', which was consequently eliminated from statistical analysis of the sub-domains.

### 4.2 Main Study Findings

Results were analysed using correlation and multivariate statistical analyses.

The most frequently reported threat-appraisals and associated avoidance were reported for the ATAI sub-domain 'Doing Things'. The highest proportion of avoidance in this category related to frustrations about being unable to accomplish tasks that were possible pre-injury. The 'Particular Activities' that people perceived they did less of because of reduced confidence since their injury were 'doing paid work' and 'being in crowds'. For issues relating to 'Dealing with People' the most frequently reported avoidance due to threat-appraisals related to concerns about negative social comparisons by others.

All the categories of the ATAI were related to anxiety and depression and quality of life measures. Therefore, the greater the frequency of reported threat-appraisal the poorer the levels of adjustment. Also, the greater the frequency of reported avoidance, the poorer the levels of adjustment. Overall, avoidance was the strongest predictor of adjustment difficulties and a path analysis technique suggested that avoidance mediated the relationship between threat-appraisals and adjustment factors. This analysis also reflected the relationships that might be expected between anxiety and avoidance from the established theories of Mowrer (1939) and Rachman (1984), and also the relationship between anxiety and depression as established by learned helplessness theory (Abrahmson, Seligman & Teasdale, 1978).

It was found, however, that threat-appraisal does not necessarily lead to avoidance. On average there was a 40% rate of concordance, that is 40% of reported threat appraisals were associated with the consequent avoidance of a situation. Lazarus and Folkman's

model and the involvement of a secondary appraisal process suggest one hypothesis that may explain this finding. Their model proposes that a secondary appraisal process occurs which involves the evaluation of one's own capacity to deal with the threat in question. It was proposed that this secondary appraisal process might determine whether an appraisal of threat results in avoidance or not. This therefore requires further examination.

An additional preliminary analysis explored the ten individuals with the earliest times since injury (mean = 1.79 years) in comparison with the ten individuals with the latest times since injury (mean = 22.26 years). It was hypothesised that avoidance would relate to negative indices of adjustment in the later stages, but not in earlier stages since injury. This was found for quality of life but not for anxiety and depression. Furthermore, the difference between the early and late groups for quality of life and avoidance correlations was not significant. Thus, although there was some evidence for the hypothesised relationship between avoidance and time since injury, the evidence from this aspect of the study is, on the whole, equivocal.

### 5. CONCLUSIONS AND FUTURE DIRECTIONS

This research has enabled a better understanding of the situations that people with traumatic brain injuries find difficult due to the changes brought on by injury. It has investigated the relationship between a perceived threat and related avoidance and has thus illuminated the need to better understand this process. It has also provided evidence that both threat-appraisals and avoidance relate to poorer adjustment. Specifically, however, it has investigated avoidance coping within a context of some of the subjective difficulties expressed by people with traumatic brain injuries.

In sum, 'Doing Things' after a brain injury represented the greatest rates of threat appraisals and avoidance, but avoidance of social situations, followed by personal safety threat-appraisals and avoidance, bore the greatest predictive relationship to the adjustment factors of anxiety, depression and quality of life. Overall, avoidance appeared to mediate the relationship between threat-appraisals and adjustment. Clinically, this may suggest that interventions should target people with brain injuries' confidence within social situations and situations where they feel unsafe. In particular, interventions may target patterns of avoidance and anxiety in these situations that appear to predict negative indices of depression and quality of life.

The present study was limited by the psychometric properties of the ATAI, which, in the main, would require further analyses to establish its external and construct validity. The sub-domains of the Appraisal of Threat and Avoidance Interview, for example, were not statistically validated as separate constructs due to the modest sample size. Further limitations were also due to the cross sectional nature of the design. The use of self-report measures can be limited, as individuals may not provide accurate reports of their behaviour. Ideally these would be supplemented with additional information from other sources, for example carers' behavioural reports or case study methods. Alternative coping strategies were not measured in the context of the appraisals measured and the use of avoidance coping did not necessarily imply a lack of approach strategies. Thus, the study did not represent an exhaustive analysis of coping following acquired brain injury.

As the study was primarily correlational in its analyses, it is therefore exploratory; a causal role of threat-appraisal and avoidance cannot be therefore be confirmed. Ideally, a longitudinal analysis would be required, particularly to investigate further the concept of avoidance as a possible protective factor in the earlier stages of adjustment to injury.

The present study has identified factors related to negative indices of adjustment, avoidance coping and threat-appraisals, but has not, conversely, adequately explained what is related to better adjustment. Future studies might therefore aim to understand the factors that that result in greater well being following acquired brain injury, and how the coping strategies for those individuals compare to those who have poorer adjustment. For example, an individual's optimism in striving for goals following brain injury has been discussed in both the review and empirical papers as a possible future line of enquiry. A greater understanding of the links between threat-appraisal and avoidance would also be beneficial, as it appears that not all those who perceive threat go on to avoid. Perceived social support and an individual's self efficacy have been cited elsewhere as important factors that may influence the relationship between coping and adjustment and would thus merit further investigation in the sphere of acquired brain injury.

### 6. REFERENCES

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### For further information

Brennan, A.J. (2002). Volume I Research Papers: Coping and adjustment following acquired brain injury. Research Thesis, University of Birmingham: Birmingham

Review Paper Models of coping and theories of individual adjustment following

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Empirical Paper Self-reported threat-appraisal and avoidance following traumatic

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anxiety, depression and quality of life.