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Howes, Hannah

How to cite:

Howes, Hannah (2004) *The body and the self following acquired brain injury..* thesis, Swansea University.
http://cronfa.swan.ac.uk/Record/cronfa43019

THE BODY AND THE SELF FOLLOWING ACQUIRED BRAIN INJURY

HANNAH HOWES, B.S.c

Thesis submitted to the University of Wales for the degree of Doctor of Philosophy

July 2004

Department of Psychology

University of Wales, Swansea

LIST OF TABLES

SUMMARY

The effect of acquired brain injury (ABI) on the individual's perception of their body, and the effect of the injury on their self concept was studied. Existing literature has not addressed the significance of the body changes for the individual following ABI.

In women differences in body image and psychological health were found between the control and ABI group, these centred on a greater concern with health following injury. Two male clinical groups (a stroke and a traumatic brain injury group) were examined. The changes in body image and psychological distress were investigated using two carefully matched control groups. Males with ABI had lower self esteem and greater dissatisfaction with physical and sexual functioning. Using a longitudinal design, assessment was repeated at a one year interval for male and female clinical groups. The finding was that the pattern of psychological distress and poor body image is remarkably resistant to change.

The participant's experience of ABI was examined using qualitative methods. Female participants experience and was conceptualised as a grief like reaction, and a change in self. The male participants perception and was characterised by practical concerns with sexuality, relationship changes and social inclusion that seem amenable to inclusion in existing rehabilitation models.

Finally the experimental chapters were related to existing theoretical models. In particular the idea of the "body drop" that is a sudden change in the functioning of the body, triggers a reappraisal of the self was supported. The thesis argues that despite the existence of cognitive changes, it is often the physical changes that have resonance for the individual and thus have greater significance for the person with ABI.

DECLARATION

This work has not been previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed.......................   ....(candidate)

Date.............................Oct...2005.....................

STATEMENT 1

This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

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I hereby give consent for my thesis, if accepted, to be available for photocopying and for inter-library loan, and for the title and summary to be made available to outside organisations.

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Date.....................................Oct.....2005...........

ACKNOWLEDGEMENTS

I would like to take the opportunity to thank the people who helped (and hindered) with the completion of this work. To Prof. David Benton thank you for all your motivational talks, encouragement and (invariably in bad taste) jokes. To Dr. Stephen Edwards thanks for your microscopic eye for detail, brave attempts to improve my grammar and liberal use of football analogies. To my mentor Dr Lancelot Workman (and Frank) thank you for showing me that having more than one personality is no barrier to a career in Psychology. To Daisy Dimmock and all the staff at Headway thanks for your continued support, fabulous puddings and heart stopping games of Jenga.

To my parents, Captain Banana and Lady Maud thank your continued support, love and forbearance. To my partner in crime David Baker thank you for leaving the county, however it wasn't quite far enough as you discovered. Next time you might want to remember the fact that easy jet does not fly to Patagonia. To Netty thank you for your assistance in the world of vampire fighting and FBI activity, which we ran from our office on the 9th floor of the science tower (whilst writing up our research).

Most of all thanks to all the people with acquired brain injury that told me their stories. The bravery, determination, and good humour you have shown whilst having to overcome so many seemingly insurmountable obstacles continues to surprise me and has been an amazing lesson. This work is dedicated to you.

LITERATURE REVIEW

Any investigation of the brain has to take account of the vast complexity of this organ. The brain is responsible for sight, hearing, smell, touch and temperature. It defines individuality; it is the keeper of memories, the controller of skills and abilities, mediates emotions and facilitates communication with the environment. Consequently, damage to the brain is serious, with considerable costs to the individual and their family (Webb, Rose, Johnson & Atree, 1996). Even lesser degrees of brain injury frequently have a very long-term impact upon the life of the individual (Oddy, Coughlan, Tyerman & Jenkins, 1985) and a profound effect on feelings about self and identity.

To understand how brain injury might impact upon an individual's life and identity it is important to examine three distinct areas of existing research. It seems important to look at the **demographic factors**, to see who is at most risk from different categories of injury; which gender, age and social class is most affected? At the neuroanatomical level; how significant are the **different mechanisms of injury and patterns of damage**. At the behavioural level it is important to understand the **functional effects**; the multiple impairments, disabilities and handicaps that are the subtext of this health condition.

1.1 Demographic Factors

Acquired brain injury (ABI) can be caused through traumatic brain injury (TBI), cerebrovascular accident (stroke), and neurological disease. Strokes and TBI account for a significant proportion of neurological problems within the population. It is estimated that 1 million individuals attend hospital in the UK each year as a result of an ABI (Teasdale, 1995). Every year 150,000 people will have a minor ABI, 10,000 will have a mild ABI and 11,600 will have a severe ABI, of these only about 15% will return to work after 15 years (McMillan, Brooks, Brock, Greenwood, Dunn, Price, Dinsale, 1993).

Males are more likely to be affected by TBI at a rate of 2:1 (Teasdale, 1995). Those most at risk from TBI are aged between 15 and 29 years, and in this age group, males are five times more likely to sustain injuries (McMillan et al, 1993). One explanation for the greater incidence of young males with TBI is that they engage in more risk taking, and accident-prone behaviour. For TBI, road traffic accidents account for 40% to 50% of all incidents, and are most commonly associated with severe injuries. Domestic and industrial accidents account for 20 to 30%; sports and recreational injuries account for 10 to 15%; assaults account for 10% (McMillan et al, 1993).

At the other end of the spectrum older adults are also a high-risk group but falls rather than road traffic accidents are the major cause of injury (Mateer & Sohlberg, 2001). In comparison strokes affect males and females equally, and affect older adults more frequently than the young (Mateer & Sohlberg, 2001). There has been some data that suggests that low socio-economic status (SES) is associated with the risk of stroke

(Sacco, Benjamin, Broderick, Dyken, Easton, Feinberg, Goldstein, Gorelick, Howard, Kittner, Manolio, Whisnant & Wolf, 1997) and TBI (McKinley, Brooks, Bond, Martinage & Marshall, 1981).

1.2 Mechanisms of acquired brain injury and patterns of tissue damage

The most practical way of classifying brain damage aetiology is to consider focal and diffuse damage. Focal damage includes contusions, haematomas and abnormalities resulting from raised intracranial pressure. Diffuse brain damage includes diffuse axonal injury, brain swelling, hypoxic brain damage and diffuse vascular injury (Marsden & Fowler, 1998). In functional terms focal damage means that specific structures in the brain are affected, leading to specific functional deficits. Diffuse damage has more widespread effects affecting many structures and thus functions within the brain.

Stroke or cerebrovascular accident (CVA) is used to describe brain damage that occurs as a result of some disruption to the vascular supply of the brain. Stroke is one of three major neurological causes of death and disability, together with TBI and dementia (Mateer & Sohlberg, 2001). Strokes, of which there are many different types, usually result in localized or focal damage. Other causes of brain injury, such as toxic damage, cerebral infections and tumour may have diffuse or focal effects.

Diffuse axonal injury is the single most important lesion in TBI (Adams, Doyle, Ford et al, 1989). This type of injury is thought to be responsible for the extent of the impairment of consciousness in the acute stage and to account for much of the disability experienced by survivors in the later stages after all types of injury (McCellan, Adams, Graham, Kerr & Teasdale, 1990). Diffuse axonal injury is thought to be caused by an extremely rapid deceleration of the skull, e.g. with road traffic accidents, an assault or a fall. Acceleration-deceleration forces often affect anterior frontal and temporal brain systems (Mateer & Sohlberg, 2001). The brain's plasticity may cause it to recoil and incur *contra coup* damage, striking the opposite side of the skull. Such impact may lead to a shearing of white matter within the brain, damaging corticoid-cortical, cortico-subcortical neuronal pathways, arising from rotational forces as the brain attempts to skew within the skull. Diffuse axonal injury leads to widespread disruption of nerve pathways (cortical and sub cortical) and of small blood vessels. It is believed that this type of injury has the greatest significance for recovery (Teasdale, 1995) as it is thought to cause widespread diffuse damage.

Ischaemic brain injury is by far the most common secondary insult in traumatic brain injury (Graham, Adams & Doyle, 1978). Ischaemic damage is caused by reduced blood flow that disrupts an adequate oxygen supply to neuronal cells. Ischaemic damage is also the primary damage associated with stroke, cardiac arrest, and accidents such as drowning, electrocution, and toxic poisoning.

The bleeding, bruising and swelling of the tissues minutes and hours after initial injury causes a third type of injury. Emission of bodily fluids may cause the brain to swell, which can cause serious complications as the brain is in a fixed space and can cause crushing against the skull. Any increase in intracranial volume can lead to an increase in intracranial pressure, which must be carefully monitored following ABI.

1.3 Functional effects of brain damage on the person

1.3.1 *Assessment of severity*

The traditional approach is to assess the severity of the brain damage, which is commonly classified according to the Glasgow Coma Score (Jennett, Snoack, Bond & Brooks, 1981) (see Table 1.). The most widely used definition for severe ABI is currently a patient score of 3-8. Originally this was defined as no eye opening, no comprehensible verbal response, and not obeying commands. Moderate ABI was defined as a patient with a score of 9-12. This group may be more difficult to identify than either lesser or more severe injuries. The most clinically difficult definition is mild or minor ABI, those with a score of 13-15.

Attention is also given to the length of posttraumatic amnesia (PTA) following injury, the longer the length of PTA, the more severe the injury, and this is also used to classify injuries as mild, moderate or severe.

PTA includes the period of coma and extends until the memory for events becomes reliable, consistent, and accurate (Mateer & Sohlberg, 2001).

Table 1. Glasgow Coma scale (GCS)

Eye opening	
Opens eyes on own	4
Opens eyes on request	3
Opens eyes in request to painful stimuli	2
Does not open eyes	1
Best motor response	
Follows request to move	6
Pushes painful stimuli away	5
Withdraws from painful stimuli	4
Has abnormal (decoriate) flexion	3
Has abnormal (decoriate) extension	2
Makes no motor response	1
Verbal; response	
Converses and is orientated	5
Confused speech or disorientated	4
Uses words but doesn't make sense	3
Makes only sounds or incomprehensible words	2
Makes no noise	1

Table from Jennett, Snoack, Bond & Brooks (1981).

The likelihood of residual impairment increases with the degree of severity but even mild brain injury can cause impairment and disabilities. The likelihood of full recovery is small at the very severe level. Even in the moderate and mild range, recovery may result in a good outcome only over an extended period of time and following rehabilitation input.

The cognitive and psychosocial consequences of ABI are related to anatomical and neuropsychological damage and also the individuals pre-morbid functioning and abilities. The sites of brain damage relate to observed cognitive and behavioural impairments. The time frame of recovery should be conceptualised in months and years. The consequent disabilities and handicaps are often life long but dynamic, changing with time for better or for worse.

The World Health Organisation definitions (WHO, 1980) of impairment, disability and handicap provide a useful tool with which to investigate the subtle effects of brain damage. Although this perspective has been criticised by some (Oliver, 1990) for using a medical model of disablement, in the context of brain injury it is a framework that has been used to understand the functional effects on the individual.

Impairment is defined as any loss or abnormality of psychological, physiological or anatomical structure or function. This is at the level of the affected organ, so an ABI causes ABI. Disability is defined as any restriction or lack of ability, resulting from impairment, to perform an everyday activity in the manner or within the range considered normal for a person of the same age, culture, and education. This is at the person level, so how does the damage at the organ level (brain damage) affect the person.

Handicap is defined as a disadvantage for a given individual, resulting from impairment or a disability that limits or prevents the fulfilment of a role that is considered normal, depending on age, sex, and social or cultural factors for the individual. This is at the social level, so how does brain damage affect the way a person carries out their work, personal relationships and leisure time. The brain-injured individual will present with a complex pattern of multiple impairment, disability and handicap. The three most common conceptual categories are cognitive impairment, physical impairment and psychosocial problems, these categories allow us to examine in detail the significance of such deficits on recovery and understand the potential affects on the individual's concept of self.

1.4 Cognitive impairments

The person with brain damage has by definition reduced cognitive capability with which to perceive and interact with the world. Some of the most important clinical deficits include deficits of memory, attention, language and disorders of the frontal lobes, particularly dysexecutive syndrome. All of these capabilities (or lack of them) are highly significant for the individual and their understanding of their changed identity.

1.4.1 *Memory deficits*

Memory has great significance for the brain damaged individual, as this is what defines the person in time and facilitates the development of new skills. Amnesia (or memory loss) can be caused by damage to structures in the medial temporal lobes (especially the hippocampus and amygdala), the midline diencephalon, or the basal forebrain.

All these structures lie close to the midline of the brain, which may explain why damage is often bilateral. Although there is controversy about which structures within these regions need to be damaged to produce amnesia, the regions are quite strongly connected, so that amnesia resulting from lesions to each of the three main brain regions may be functionally indistinguishable (Mayes, 1991).

It seems possible that many amnesiacs have damage to two main processing systems. The first main system is retrograde amnesia; this refers to the type of memory loss in which the survivor cannot remember personal information and events from the time period immediately preceding the accident and the accident itself. This can stretch backwards for hours, days, months and sometimes years (Mayes, 1991). This type of amnesia had great significance for the individual as they may not remember crucial events, they may fail to recognise their partner or fail to acknowledge children or grandchildren.

The second main type of deficit involves the everyday memory processing system that lays down new memories. Prospective memory is perhaps the most practical aspect of everyday memory (Winograd, 1988). It is the ability to remember to carry out intentions. This type of memory problem is potentially very disruptive, and can affect all aspects of life post injury.

This is because the patient is unable to learn new skills or remember new information such as appointments, rehabilitation staff and when to take medication.

1.4.2 *Attention deficits*

Attention is another area of cognition that has the potential to hugely disrupt life post injury, after all it allows us to attend selectively to information and to operate in a sophisticated and goal directed manner. Attention refers to the voluntary control over more automatic brain systems, so as to be able to select and manipulate sensory information and store information briefly, or for prolonged periods of time (Posner & Peterson, 1990). Attention deficits can result from damage to various brain regions. Considerable interest has been directed at attention in the visual modality such as unilateral neglect, extinction, and simultanagnosisa. One type of damage, unilateral parietal damage, often leads to the neglect syndrome, wherein a patient fails to acknowledge that objects or events exist in the hemispace opposite their lesion, usually the left side. Neglect can also apply to aspects of motor behaviour (Styles 2002), when the right motor cortex is affected. Such patients forget to move limbs on the left side. If they walk they drag the neglected leg behind them, sometimes to the extent that it is practically possible, they even forget to put clothes on half their body (Carter, 1998).

A review of patient data reveals that different brain locations, pathways, and circuits underlie these different deficits. In general the cortical areas are involved with higher-level attentional mechanisms. The frontal cortex serves aspects of executive control, monitoring of attention and the planning of goal directed behaviour. The parietal cortex is involved in orienting and selection of tasks and behaviour (Styles, 2002). Sub cortical areas such as the superior colliculus and thalamus are involved in arousal, shifting and modulating attention. However we know from neuroscience that these areas do not work in isolation (Styles, 2002).

1.4.3 *Language deficits*

Language, that uniquely human ability, is also vulnerable to the affects of cerebral damage. In 95% of adults the brain regions specialised for language are located in the left hemisphere (Carter, 1998). Damage to the left hemisphere can lead to language disorders called aphasia, which refer to the collective deficits in language comprehension and production. The main areas of the brain involved with language are Broca's area (located in the rear of frontal lobe) that is specialised for speech articulation and Wernicke's areas (located in the temporal lobe) that is specialised for language comprehension. Therefore there are two main types of aphasia; expressive or receptive aphasia, which reflect a difficulty in expressing thoughts, or understanding speech. The most common aphasic disturbance is anomia, characterised by impairments in visual naming and word association processes (Sohlberg & Mateer, 1989).

For many individuals, aphasic problems persist, and patients are confronted with lasting problems in understanding or producing spoken and written language. Primary and secondary aphasic impairments are distinct, the former are due to problems with the language processing mechanisms themselves. Aphasic problems can also be a result of memory problems, attention disorders, or perceptual impairments, and these are called secondary aphasia. Aphasia has been found to be associated with coma, more severe motor deficits and more severe cognitive disorders in a TBI sample (Gil, Cohen, Groswasser, 1996).

1.4.4 *Frontal lobe deficits*

Any damage to the frontal lobes is potentially serious. The associated changes in functioning and behaviour may not be apparent to the patient, whilst being very disruptive to the patient's family. The frontal lobes are very large structures and constitute approximately 30% of the total cortical surface (Goldman-Rakic, 1984). The location of the frontal lobes in the skull renders them susceptible to damage in the event of a closed ABI. In particular, these functions are commonly disrupted following injury to anterior frontal and temporal brain systems- areas that are often affected by TBI resulting from acceleration-deceleration forces (Mateer & Sohlberg, 2001).

Frontal lobes can be conceptualised as the executive in charge of the integration of skills. The cognitive deficits can be subtle, with intellect preserved but organizational skills may be profoundly impaired. In a sense the frontal lobe deficit translates to a loss of flexibility, and frontal lobe patients can be rigid and concrete in their thinking. The frontal lobes also have strong connections with limbic structures (e.g. the hippocampus and amygdala), which are involved in learning, memory, and emotional processing (Bechara, Damasio & Damasio, 2000).

Damage to emotional processing can cause disinhibition, inappropriate or shallow responses, and these deficits can result in anti –social behaviour (Prigatano, 1992). Damasio (1997) introduced the concept of somatic markers when making decisions. Emotional associations help us to act in a socially appropriate way. The frontal lobe patient may be aware of the death of a close relative and understand the finality of it, but he is divested of the emotional pain that accompanies the loss. In the clinical literature frontal lobe dysfunction is termed dysexecutive syndrome.

1.5 Physical impairments

Whilst cognitive damage is the primary functional effect of cerebral damage, physical deficits such as sensory processing, hemiplegia and apraxia are common. These have significance for the individual and how they interact with the world: examples include blindness, semi-paralysis and movement disorders. A further feature of such physical disabilities is that they tend to mark the individual out to others as visibly disabled, and the individuals have to negotiate the associated stigma that this may bring.

1.5.1 *Sensory processing or perception*

Perception is our ability to synthesize the information gained through the senses and to put that information into a form that is psychologically meaningful. Our sense organs - eyes, ears, nose, tongue and somatosensory receptors in the skin allow us to do this.

Each organ does essentially the same job: it translates a particular type of stimulus into electrical impulses (Carter, 1998); the brain then recognises these impulses and attaches meaning to them. An example of such a deficit would be optic nerve damage that leads to visual field deficits; the results of such damage include unilateral blindness, tunnel vision and homonymous hemianopsia.

Proprioception is the sense of body awareness telling us the position of our limbs, our posture and equilibrium. It involves the integration of several sensory inputs: touch and pressure sensations from skin, muscles and tendons, visual and motor information from the brain and data about our balance from the inner ear. Proprioception uses so many different brain areas that it is very rare for it to be lost altogether (Carter, 1998).

Examples of how propriception functionally affects the individual include the perception of self, in some cases patients may claim a paralysed body part is unattached, belongs to someone else, or is functioning without impairment.

For example patients may only dress unparalyzed limbs or allow their arms and hands to drag along their wheelchair spokes. In considering the relationship of the body in the environment, impairment can affect practical skills e.g. bumping into walls, tripping over obstacles. Confusion between left and right in following directions or dressing is a common clinical feature (Burt, 1970).

1.5.2 *Hemiplegia*

Lesions of the motor cortex usually result in hemiplegia, the loss of voluntary movements in the contralateral side of the body. Hemiplegia most frequently results from a haemorrhage in the middle cerebral artery. This functionally affects the individual with a paralysis on one side of the body. Hemiplegia is more commonly associated with strokes than TBI. If a stroke produces hemiplegia, reflexes are absent immediately after the insult, they then return and can even become hyper-responsive.

1.5.3 *Apraxia*

Many cortical lesions result in coordination deficits that cannot be attributed to hemiplegia, motor weakness, sensory loss, or motivation (Keretz & Hooper, 1982).

Apraxia is the name given to a deficit in planning and carrying out movement and results in a difficulty with goal directed gestures. These gestures may consist of arbitrary behavioural acts such as following a sequence of arm gestures.
It must be emphasised that the affected body part is not paralysed or weak but clumsy.

As deficits of sensory processing, hemiplegia and apraxia are all common sequelae of ABI, such obvious physical deficits can contribute to the feeling that the body is no longer working as it was before the injury. Such feelings are potentially disruptive to the survivor's sense of self. The visibility of such deficits to others is also significant and marks the individual with ABI as "disabled" with all the stigma that this brings.

1.6 *Psycho-social sequelae*

Everyone who has sustained an ABI can expect to experience psychosocial changes as well as the cognitive and physical sequelae. Researchers consistently suggest that psychosocial problems associated with TBI (Morton & Wehman, 1995) and stroke (Oddy, Coughlan, Tyerman & Jenkins, 1984) are a major challenge faced during rehabilitation. Some of the most obvious and significant areas of identity change following ABI include awareness, affect, self-esteem, body image, social isolation, sexual behaviour, relationship status and employment.

1.6.1 *Awareness*

There are three levels of awareness that may be impaired following ABI; a total impairment of awareness such as that following coma, impairments of specific deficits or an impairment of the perception of self (Wilson, 2003). Oddy et al (1985) suggested that such problems are likely to be as long term they found that following TBI patients may not adequately perceive their behavioural limitations even several years post injury.

Prigatano, Altman and O'Brian, (1990) found that patients with TBI may have good awareness of some behavioural limitations, while relatively impaired awareness of other limitations. They found that the areas of greatest disagreement tend to cluster around judgments of social and emotional competence. They may behave in a childish, confused, bewildered manner, or choose inappropriate work (Prigatano & Schacter, 1991). This may be partly or entirely due to the disruption of executive function, associated with the frontal lobes of the brain. Damage to this area as outlined previously, affects the ability to be self aware, have insight into the effects of personal actions, show sensitivity or feel empathy.

Apparent impairment in awareness may also be due to a psychological reaction, known as denial syndrome, and it is thought that pre-morbid personality factors may play a role. Moore, Stambrook and Peters (1989) thought that "denial" may be an effective coping style for patients facing long term stressors as a result of their illness.

1.6.2 *Depression*

Whilst some think that depression following TBI is a result of damage to noradrenergic and serotinergic pathways in the left hemisphere (Robinson, Kubos, Starr, Erao & Price 1983), there is no independent research that supports Robinson's theory that the monoaminergic systems should be strongly lateralised to the left side of the brain (Gainotti, 1993).

In the literature more attention has been given to reactive depression that is a common reaction to the experience of loss, and as documented, following brain injury there are multiple losses with which to contend. It has also been suggested that it follows a recognition that the old "pre-injury self" is absent or diminished (O'Hara, 1988).

Following a stroke estimates of depression vary, Oddy et al (1985) estimated that 63% of their stroke sample reported depression. Fiebel and Springer (1982) found the incidence of nurses' ratings of depression was 26% in their sample of 91 stroke patients, 6 months after stroke, and was correlated with a failure to resume social activities. Depression is also a significant problem following traumatic brain injury, and again estimates vary. Tyerman and Humphrey (1984) interviewed 25 patients in a self report study and found that 64% were depressed following acquired brain injury. Kreutzer and Zasler (1989) found that 71% reported an increase in depression.

Garske and Thomas (1992) found that 55% in their sample of 47 adults with severe ABI would be classified as depressed in their self-report study.

The different incidence of depression following stroke and traumatic brain injury may be accounted for by different measures of depression (Hospital Anxiety and Depression Scale, Zigmond & Snaith 1982 vs. Beck Depression Inventory, Beck & Steer 1984), different time points post injury (6 months vs. 2 years), and the use of patient and significant other ratings (subjective vs. objective). Nevertheless despite disputes as to exact incidence, it seems clear that depression is a common sequela of TBI and stroke.

1.6.3 *Anxiety*

Anxiety is a common sequela following acquired brain injury and may be a result of trying to make sense of what has happened, a fear about what the future holds, and that life may never return to "normal". Anxiety may arise as a result of realistic perceptions of reduction in functional ability, an increase in the feeling of failure and/or a general fear and concern about what the future might hold (Mateer & Sohlberg, 2001).

Tyerman and Humphrey (1984) found that 44% reported anxiety following ABI. In Linn, Allen and Willer's (1994) study of 60 TBI patients they found that 50% had high scores of anxiety. The relative similarity of these figures suggests that a little less than half of patients with TBI are likely to experience anxiety following injury. Recent studies found anxiety disorders in 10-20% of stroke patients post insult (Yuping, Xiqing, Zhao, 2001, Schettke, Loew, Wetzig, Brandes, Schueter and Wiedl, 2001).

1.6.4 *Self Esteem*

Coopersmith (1967) stated that self-esteem refers to the evaluation that individuals make and customarily maintain with regard to themselves. It expresses an attitude of approval or disapproval, and indicates the extent to which "they believe themselves to be capable, significant, successful, and worthy".

In other words, self-esteem is a personal judgment of worthiness that is expressed in the attitudes individuals have towards themselves. To maintain positive self-image it is necessary to seek out and accept positive information about oneself while avoiding or rejecting negative information (Robson, 1988).

There is a paucity of evidence that examines the direct outcome of an individual's self-esteem following ABI (McGuire & Greenwood, 1990). However it seems important to point out that in the case of individuals with brain injury, they may have experienced a real decline in function, and their perception of the decline in function, and their perception of the decline in their capabilities may well be accurate. This perception can be very damaging to self image (Mateer & Sohlberg, 2001).

It might further be inferred that self esteem following ABI would be especially vulnerable given that Heinemann and Shontz (1982) state that self esteem is influenced by the propensity of individual to emphasize competencies over limitations, abilities over disabilities, and feelings of worth and dignity over feelings of hopeless and resignation.

It must be remembered, however, that it is the individual's perception of success, rather than their peer's appraisal of their competence and success, that determines how well individuals regard themselves. In order to achieve positive self-evaluation individuals need to reach a level of perfection in valued areas that either meet or exceed their aspirations in an attempt to over come their perceived deficiencies (Marsh, 1986).

The recognition that definitions of success occur within a personal frame of reference does not mean that it is not possible to make some general statements regarding the conditions usually associated with favourable self-appraisals. For example, favourable attitudes and acceptance by persons significant to the individuals are likely to have enhancing effects on their self-judgment and feelings of self worth (Cramer, 1988). The consequences of high self esteem seem to be to lessen the tendency to social isolation and to pay greater attention to personal values than group mores (Robson, 1998). In the clinical literature low self esteem is correlated with anxiety and depression (Robson, 1998).

1.6.5 Body Image

While individuals have to adjust to an alteration in their body due to illness and disability, they also have to adjust to a new body image. Roid and Fiffs (1994) stated that body image is the view of your own body, state of health, physical appearance, skills or sexuality. Body image is taken to refer to "the picture we have in our minds of the size shape and form of our bodies, and to our feelings concerning these characteristics and our consistent body parts" (Slade, 1994). Therefore body image has both a perceptual, attitudinal and cognitive component (Grogan, 1999).

Body image can be measured using self report questionnaires designed to capture aspects of people's attitudes and perception of their bodies. Historically silhouette based matching test's (SMT'S) have been used to assess body image perceptions because of their ease in use and affordability. Typically SMT's employ between 5 and 12 silhouettes that serve to represent various anthropomorphic shapes based on waist-to-hips ratios. However these SMT scales have been more closely associated with measures of psychological phenomena than with consistent size changes. This is particularly relevant when considering that there has not been a consistent height reflected in the figures, thus creating unequal comparison between figural stimuli. As a result there is no interval standard upon which the silhouettes are based at best these tools produce an ordinal scale that must be analysed non-parametrically.

Two common measures used in body image research come from the Eating Disorder Inventory-2 (Garner, 1991). The first of these is the Body Dissatisfaction scale, which measures satisfaction with specific body sites such as waist, hip and thighs. The other is the Drive for Thinness scale that measures restricting tendencies, desire to loose weight, and fear of weight gain. Both subscales have received extensive use and psychometric evaluation in adult and adolescent samples (Garner, 1991).

As an alternative to paper and pencil test's many body image studies use Body Mass Index (BMI)) as an objective measure of population norms. Body fat can be calculated using the formula; weight in kg/ height in metres2, this provides a guideline based on weight and height to estimate those underweight, overweight and obese. BMI for age and sex cut off's can be used which are underweight = BMI < 5th percentile, overweight = BMI < 85th percentile, and obese = BMI <95th percentile (Himmes & Dietz, 1994).

Research has found that there is a physical attractiveness stereotype: "what is beautiful is good." Physically attractive people are perceived to be more socially desirable, more successful and happier (Franzoi & Herzog, 1982). Men tend to place more importance on bodily functions directly related to sex, whereas women emphasize physical stamina and condition (Franzoi & Herzog, 1987). Grant and Fodor (1986) found that physical attractiveness was highly correlated with self-esteem in women, but in men physical effectiveness was more highly correlated.

For both sexes the salient characteristic for judging male attractiveness is upper body appearance, whereas for judging female attractiveness it centred on weight issues. Greenfield, Quinlan, Harding, Glass and Bing (1987) found that 81% of women often felt fat; nearly 50% described themselves as being overweight.
Women consistently report greater dissatisfaction with appearance than men (Stowers & Dunn, 1996). Silberstein et al (1988) reported that 75% of females in their study chose an ideal figure thinner than themselves. Research has reported that male body image concerns are equally split between those who wish to lose weight and those who wish to gain weight (Drewnoski & Lee 1987, Silberstein et al 1988).

Mahoney (1974) reported that body image was more closely related to self concept for males than for females, whereas Lerner, Karabrenick and Stuart (1973) found the opposite to be true. Franzoi and Shields (1984) and Secord and Jourard, (1953) have demonstrated that people's thoughts about their bodies relate to their attitudes towards themselves. They found a significant positive correlation between body cathexis (ratings of body parts) and self cathexis (ratings of aspects of self).

Under normal circumstances the body is the focus of an individual's identity, but with illness and disability there is an increase in somatic preoccupation, focusing awareness on physical sensations and changes (Franzoi & Herzog, 1987). Dewis (1989) was careful to point out that it should not be assumed that those with an altered body have an abnormal body image.

There is scant research directly examining the impact of brain injury on body image. However there is a literature on body image following disease or injury. Some researchers have found that disease and injury resulted in a poor body image whilst others have found no differences between the physically disabled and other chronic conditions. Stensman (1989) looked at 10 acquired (spinal cord) and 12 congenitally (cerebral palsy) physically disabled individuals. The results found that there were essentially no differences between the groups and they did not differ from an able bodied reference group. This suggests that there are no differences in body image between acquired and congenital conditions, and no differences between the able bodied and disabled in terms of body image.

Wachs and Zaks (1960) administered the draw-a person test to two clinical groups. In the spinal injury group were 30 traumatically injured meals with an average length of hospitalisation of 5.4 years. The control group consisted of 30 male inpatients with "incurable" chronic diseases with an average length of hospitalisation of 2.5 months.

The groups were comparable on average age and education. There were 60 drawings of the human form by these participants, which were analysed for abnormalities. Among the 30 most pathological drawings, there were an equal number by the spinal injury groups and the control group. An analysis of 24 variables within these drawings revealed few differences between the groups. The results of this study would suggest that there are no differences in body image, as measured by the draw a person test, between the physically disabled and other chronic conditions.

However recent studies have suggested that physical disability can have a negative effect on body and self-image. Jahanshahi and Marsden (1990) compared 85 idiopathic spasmodic torticollis patients with an equally chronic group of 49 cervical spondylosis sufferers in terms of body concept, depression and disability. The torticollis patients were significantly more depressed and disabled and had a more negative body concept. Depression had different determinants in the two groups. Extent of disfigurement was a major predictor of depression in torticollis. Neuroticism accounted for the greatest proportion of the variance in depression in cervical spondylosisis. The results of this study suggested that equally chronic but more disabled torticollis sufferers are significantly more depressed and have a more negative body concept.

Furthermore in-depth studies of specific disabled populations have lent support to the idea that some conditions result in poor body image and psychosocial functioning. Wier, Pentland and Crosswaite (1995) looked at 20 patients with idiopathic lower motor neurone paralysis (Bell's palsy).

These patients were assessed with a battery of questionnaires to measure self-image, mood and functional disability. They found that quarter of the subjects showed a disturbance of self-image, and seven individuals highlighted facial appearance as the most distressing sequence of the condition. Anxiety and depression were associated with impairment of social and daily living activities. Anxiety and depression correlated with depressed self-image in those with severe facial palsy. The most striking finding was that social disability was the most prominent functional consequence of the disorder.

This study suggested that disability can result in a disturbance of self image, and that anxiety and depression are related to self image. Furthermore that affect was linked to social functioning, which was a prominent feature of this disorder.

Dewis (1989) looked at body changes in spinal cord injured adolescents. The age group was 15-20, which has parallels with the comparatively young age of those who have survived a traumatic brain injury. She found that the crucial issue with this group was the meaning of body changes: normalization, which related to impaired excretory control, loss of musculature and physique, deterioration in physical appearance and hygiene, the intrusion of rehabilitation appliances and the maintenance of physical appearance and function. Subjects worked hard to keep pain and disability hidden and to control evidence of discomfort and fatigue. She found that negative feelings about physique focused on loss of muscle bulk/abdominal musculature, which leads to a "quad belly", meaning a plumper, less firm stomach. Dewis found that previous pride in a muscular body was linked to former lifestyle.

In this group, grooming and hygiene were important, and appearance of the hair was especially significant. A lack of privacy was also an important variable that resulted in poor body image.

In a retrospective study Kreppel and Crowe (2000) found that body image was affected negatively following a first stroke. Before stroke only physical self-esteem and body image were correlated, after stroke all measures of self-esteem correlated with evaluations of body image. They suggested that the effect of body image had become generalised, contributing to poor self worth and possibly culminating in depressive cognitions. Piotrowski (1982) found that poor body image was correlated with clinical evidence of psychopathology. She found that following a stroke, females with poor body image were more anxious about their condition.

Taken together evidence from multiple populations (torticollus, spinal cord injury, Bell's palsy, stroke) suggested that illness and disability could lead to poor body image (Jahanshi & Marsden 1990, Dewis 1989, Wier et al 1995, Kreppel & Crowe 2000). Furthermore the results of these studies suggested a link between poor body image and psychosocial functioning (affect, self-esteem, social functioning), (Jahanshi & Marsden 1990, Piotrowski 1982, Wier et al 1995, Kreppel & Crowe 2000). It is likely that the person with acquired brain damage has to adjust to an altered body image, and the injury may have a negative impact on self image and psycho-emotional functioning.

1.6.6 *Social Isolation*

In his longitudinal research Oddy et al (1980, 1985) found that social isolation was a consistent and long-term problem in their TBI sample. In 1978 Oddy et al interviewed 49 individuals' 6 months post injury and found that they had a decrease in close friendships. Oddy et al (1980) interviewed 44 individuals 12 months post injury and they reported a decrease in social visits.

Oddy et al went back to this cohort 7-years post injury and found that loneliness was major problem with 50% having limited friendships, and 60% having no partner (Oddy et al 1985).

Klonoff et al (1984) looked at the quality of life of 78 traumatically brain injured individuals at 2 and 4 years post injury, and found social functioning to be a consistent problem. Fiebel and Springer in their sample of stroke patients (1984) linked nurses' ratings of depression to failure to resume social activities. They claimed that this association between depression and social functioning showed that psychosocial disability occurred following stroke, although the mechanism was not clear.

1.6.7 Sexual Behaviour

Sexuality can be defined as the collection of characteristics that identify and communicate the sexual nature of an individual (Best, 1993). The literature suggests that changes in sexuality are a common sequelae post injury.

From extensive clinical experience Lezak (1978) reported patients had either a completely absent sex drive or increased sexual interest. Relating this to the pattern of injury, Simpson, Blaszcyznski and Hodgikinson (1999) theorised that sexual disinhibition is linked to injury of the frontal lobes, whereas hypersexuality is more closely associated with bilateral temporal lobe lesions.

Kreutzer and Zasler (1989) looked at sexual behaviour in males following TBI; 57% reported a decrease in sex drive, 14% reported an increase in sex drive, and, 28% reported that sex drive was the same. 57% reported their ability to maintain an erection decreased; 52% found no change in their ability to orgasm and 62% reported a diminished frequency of intercourse. They concluded in their study that brain injury alters sexual functioning as well as desire and that these changes were mostly for the worse. Furthermore from the evidence presented in the Kreutzer and Zasler (1989) study it appears that survivors have awareness of these changes in sexuality.

Following stroke individuals may also be left feeling isolated and rejected with markedly reduced sexual opportunities (Kreppel & Crowe 2000). The few studies conducted with premorbidly sexually active sufferers under 60 years of age, have consistently found that stroke has a marked detrimental effect on the frequency and duration of sexual intercourse (Wade, Hewer, Skilbeck & David, 1985). This decline does not appear to be related to the site of the lesion, the severity of motor paralysis or other arterial diseases, but is thought to be associated with the loss of sensation of touch (Wade et al, 1985).

Carleton (1995) stated that drugs administered post injury may decrease sex drive and impair the ability to perform sexually. These drugs include hypertensives, anticoagulants, diuretics, vaso-dilators, anti-depressants, tranquillisers and sleeping pills.

The attitude of spouses/carers toward their stroke affected partners also has an important influence on intimacy, with declines in sexual activity being more likely to be associated with unrealistic or overprotective attitudes, or a perception that the sufferer is more childlike (Kinsella & Duffy, 1980). Lezak (1988) also pointed to the lost empathetic sensitivity needed to make sex mutually satisfying. It would appear difficult to predict those who might encounter problems as couples react to sexual problems differently, based on a combination of their pre-morbid personalities and the overall dynamics of the relationship (Miller, 1993).

Despite clinical reports that brain injury can lead to absent or increased sex drive (Lezak 1978), recent studies with stroke and TBI survivors suggest that for most, brain injury alters sexual functioning and desire in a negative direction (Wade et al 1985, Kreutzer et al 1989). Furthermore interpersonal factors such as lost empathetic awareness and changes in partner's attitude compound the detrimental effect of brain injury on the sexual functioning of the survivor. Miller (1993) identified Post Traumatic Sexual Indifference Syndrome (PTSIS) as a frequently seen reaction to TBI, stating that sexual problems can become a symptom around which other interpersonal problems can crystallize.

The evidence from clinical reports and controlled studies indicate that following ABI sexual behaviour will change and that these changes are mostly for the worse. Such changes will necessarily affect the individual and their partner.

For many people with disabilities the ability to integrate sexuality with their disability has a profound impact on the person's adaptation to the disabling condition (Best, 1993). The evidence would suggest that the effect of sexual dysfunction on the survivor's already fragile sense of self cannot be underestimated.

1.6.8 *Relationship characteristics*

Reports from both the individual with ABI and the partner/carer indicate that the quality of intimate relationships may change following ABI. Kreutzer and Zasler (1989) reported that in male TBI survivors 38% reported decreased communication, 50% reported that communication remained the same and 12% reported an increase in communication with their significant other. Clinical reports suggest that the spouse may become the target of the patient's fears, anger and frustration. The roles may change and the spouse may feel like they have another child, who is dependent on them, and feel trapped physically and financially (Lezak, 1988). It appears that for the ABI person and their partner it is likely that the quality of their relationship will have changed following injury.

Clinical reports also suggest that the relationship between the brain damaged child and parent will alter, with the care giving role of the parent extended, terminating only with death (Lezak 1988). The relationship of the brain injured parent and their child will also be affected. The child may not receive the same level of attention from one or both parents and there may be shame and/or guilt at having a "different family" (Lezak 1988).

1.6.9 *Employment*

Dikmen, Machmer and Temkin, (1993) found that many moderately to severely ABI people remained unable to work, support them selves financially, live independently, or participate in pre-injury activities at least up to 2 years post injury. Oddy et al (1985) pointed to the problems of being unemployed as being the lack of any time structure or a network of friends; the lack of goals to attain or the opportunity to show competence; an absence of identity and/ or status. Oddy et al (1985) found that in his 7 year follow up of those who had sustained a TBI, those who were working had been able to rebuild their social lives and sometimes marry. This has been supported by other studies that stress a strong and consistent positive association between employment and social integration, leisure activities, enhanced self esteem, and perceived quality of life (Grosswasser, Melamed, Agranov & Keren, 1999).

Furst, Alfano and Abbott (2000) in their very long term longitudinal study found that in their cohort of 10 TBI patients, 12-15 years post injury only 1 participant had returned to full time gainful employment, even though this was considered a reasonable goal for many on discharge from rehabilitation.

They suggested that there are limitations to employment goals of cognitive rehabilitation with severe traumatic brain injury. In contrast recent studies using comprehensive and integrated rehabilitation programmes have proven to be effective in returning patients to stable employment. A follow up study of 334 severe TBI patients indicated that 55.7% were gainfully employed 8-13 years post discharge (Grosswasser et al, 1999).

It seems therefore that in the short term employment is elusive for many up to 2 years post injury (Dikem et al, 1993), the long term prospects may include gainful employment but only after an extended period of comprehensive rehabilitation (Grosswasser et al, 1999). The significance of employment seems to be the enhanced social integration and maintenance of a degree of pre-injury life and status (Oddy et al, 1985). Unemployment post injury has been found to be associated with a wide range of negative outcomes in long term studies for those with ABI (Oddy et al, 1985, Dikem et al, 1993).

1.7 *Summary.*

When considering the impact of ABI on self image it is important to realise the diverse impact upon identity, affecting many aspects of an individual's life. The individual has to face cognitive changes that may affect the way they interact with the world. Memory deficits may cause an individual to effectively "lose" huge chunks of their previous life. Deficits of attention, working memory and dysexecutive syndrome all contribute to a chaotic everyday existence.

The individual also has to adapt to physical changes, the body no longer works as it did before, and may appear clumsy and "aged" before its time. In normal circumstances the body is the focus of identity but with illness and disability can become a preoccupation. The survivor also has to cope with many psycho-emotional changes, such as employment status, relationship status, and feelings about the body and the self. It seems psychopathology in the form of anxiety, depression and low self esteem is also a common feature. The broad spectrum of impairment and disability can be expected to present problems of adjustment, especially given the existence of the memory of the intact self.

RESEARCH AIMS AND METHODOLOGY

2.1 *The Powerful Position of Cognitive Rehabilitation*

Rehabilitation of acquired brain injury has often been in practice, cognitive rehabilitation. Hence neuropsychological textbooks have names such as "Cognitive approaches in neurological rehabilitation' (Seron & Delouche, 1989). There is no doubt that, as listed in the literature review, cognitive deficits are important sequelae of ABI. Memory (Mayes, 1991, Winograd, 1992), attention (Posner & Peterson, 1990, Styles, 2002), language (Carter, 1998, Sohlberg & Mateer, 1989) and frontal lobe disorders (Prigatano, 1992, Bechara, Damasio & Damasio, 2000) are all significant for the everyday functioning of the individual.

This understandable concern with cognitive deficits following ABI has driven research and consequently rehabilitation techniques. Cognitive neuropsychology is based on the modularity assumption, the fractionability assumption and the transparency assumption (Caramazza, 1984). The principle of modularity states that any cognitive system is composed of several modules, interrelated but functionally independent. According to the second assumption, the brain lesion destroys one or more modules leaving the others unharmed. Finally the transparency assumption states that the pathological behaviour is the result of the functioning of the system with the exclusion of the impaired modules.

These three assumptions have lead rehabilitation professionals to approach patients with a set of tests to measure deficits, scans to locate damage, with the stated aim of locating the loci of the impairment. Rehabilitation based on such analysis would often focus on one aspect of cognition (Seron & Delouche, 1989). Such approaches have lead to highly specialised models that fail to take account of the impact on other behaviours (Seron & Delouche, 1989). A failure to take a holistic approach has lead to the neglect of physical and psychosocial changes that may be important for the individual. Whilst cognitive changes are now well understood by rehabilitation professionals (cognitive rehabilitation now has it's own international conference), these physical and psychosocial changes have not received substantial attention in the literature (McKinlay et al, 1981).

2.2 *The Neglect of the Physical in Rehabilitation of those with ABI*

In particular it is apparent that the impact of the changed physical self has not received the attention it deserved. Other medical conditions that impact physical functioning, have an established tradition of examining the impact of the changed physical self, on the survivors well being.

As outlined in the literature review, this is especially concerning as recent studies suggest that physical disability can have a negative effect on self image and this had been linked to psychiatric distress (Jahanshi & Marsden, 1990, Pentland & Crossewaite, 1995, Dewis, 1990, Kreppel & Crowe, 2000). Psychologists have been looking at an important variable for self-concept called body image, but this has not so far been utilized in ABI research, despite the well documented physical changes the individual with ABI can expect to experience.

Research questions that need to be considered include the significance of body image and psychological distress post ABI. It was important to establish the body image concerns of those with ABI: are they the same as individuals of the same age and sex without injury? Does body image differ between those with ABI and those without injury?

To answer these questions a methodological approach with various advantages would be to use self report questionnaires and clinical data, in a systematic way, to illuminate the differences between ABI and controls and establish relationships between variables. As the aim of this research is to establish the nature of body image and psychological well-being in those with ABI, it is necessary to isolate satisfaction with certain body parts, and to measure levels of anxiety, depression and self esteem. It is such quantitative approaches that enable us to measure the frequency of a phenomenon (Morgan, 1998). Quantitative data have the enormous advantage of allowing statistical evaluations with the ability to present confidence limits for means and the probability of differences occurring by chance. Quantitative methods allow changes in conceptions concerning the body to be monitored over time and differences to be statistically examined. This approach looks at the group level and is able to illuminate how certain variables interact together. The strength of this approach is that we can make statements about a group of individuals who have been injured and see how they differ from a control group and representatives of other groups. Using a larger sample you can begin to generalize and make statements that hold true for that group. This research is considered more reliable because the data are collected in a standardized manner. Through the use of generally accepted measures results can be replicated and compared with previous and subsequent studies.

Through the use of generally accepted measures results can be replicated and compared with previous and subsequent studies.

If we are going to investigate body image and psychological health in men and women with ABI it is also important to take account of the patient's experience. Whilst quantitative research techniques have an important role in moving research forward, in this case establishing group features, it was also important to place any findings in a real world setting. It seems important to establish what the meaning was for the individual. In many health situations phenomenological work has a growing reputation for taking account of meaning in many health situations (Smith 1996, Osborne and Smith, 2000, Swift and Wilson, 2001).

As suggested earlier by Seron & Delouche (1989) much of previous rehabilitation research has been theoretically weak, it has been narrow in its focus, producing modular, isolated models of rehabilitation. To move forward with rehabilitation following ABI, it seems important that various research traditions support and inform each other. Therefore psychiatric measures of clinical levels of anxiety, depression and low self esteem were related to the personal experience of distress. It hoped that such an integrated approach would help to isolate the important variables for physical and psychological adaptation following ABI. This type of theoretical approach should ensure that the variables being studied are connected to their social structure rather than being abstract or decontextualised (Searle, 1994). It is also hoped that this type of research will contribute to existing models of body image and identity, and have practical applications for future ABI rehabilitation.

The research was therefore concerned with the measurement of body image and psychological health following ABI. The personal accounts of those with real experience were central to understanding the meaning for the participant. The aim is to establish the body image concerns of those with ABI and relate this to psychological health. Measurement can help to tell us that certain groups are at greater risk, however qualitative work is able to put it in context. Questions such as what brings a person to such a point of distress? What are the triggers? Is it permanent or a transient state? What alleviates? How do individuals cope? These are all important questions that clinical interviews analyzed using qualitative techniques could help us elucidate. However when deciding to use qualitative techniques, to complement quantitative techniques, careful consideration is needed of the plethora of different methodologies currently in use. Popular methods include grounded theory, discourse analysis and interpretative phenomenological analysis. Comparison of these different methodologies and their use in published research is required before any methodological approach is adopted.

Rationale for using IPA rather than grounded theory or discourse analysis.

Grounded theory was first described by Glaser and Strauss (1967). Unlike quantitative research where time is spent reviewing the literature and planning details of all stages of the research process, there is a need to start gathering data in order to formulate ongoing plans and, perhaps, to discover the nature of the research questions (Heath & Cowley, 2004). Grounded theory research aims to develop substantive or formal theory (Robrecht, 1995).

Grounded theory's roots lie in symbolic interactionism, which in itself stems from the pragmatist ideas of James, Dewey, Cooley and Mead (Hammersley, 1989). The term "symbolic interactionism" was invented by Blumer (1937) and his development of the interactionist approach together with naturalistic inquiry is a key influence on grounded theory. Hammersley's (1989) detailed analysis show's that Blumer's concept of inquiry involved comparison of cases to develop the features of each case, the production of emergent meaning and ongoing refinement of the characteristics of the relationship. Parallels with grounded theory, where concepts are related and developed around a core, via a process of ongoing comparisons, are clear.

The main features of grounded theory include theoretical sampling, the constant comparative method, coding and categorising and theory generation, which occur simultaneously (Glaser & Strauss, 1967,Glaser, 1978). Strauss and Corbin (1990) focused on developing the analytic techniques and providing guidance to novice researchers. This emphasis has been the focus of some criticism with Keddy, Simms and Stern (1996), believing it produced a rigidity never intended for grounded theory.

Glaser (1978) thought that prior understandings should be based on the general problem area and reading very widely to alert or sensitise one to a wide range of possibilities. More focused reading occurs only when emergent theory is sufficiently developed to allow the literature to be used as additional data (Hickey, 1997). However not all theorists agree with this stance, for example, Robrecht (1995) found it problematic the concept of themes "emerging" from the data . In addition this type of research is typically suited to larger data sets to enable "saturation" to occur. Another feature is the focus on producing general theory applicable to general trends. This type of research is not concerned with the individual's account.

There exists some confusion as to what discourse analysis is (Cheek, 2004), although there is agreement with its concern with language. Some theorists place discourse as linguistically located and therefore begin to analyze the text for the way it has been constructed in terms of syntax and semantics;

> "The term discourse refers in this context actually to occurring instances of communication, such as a novel, a newspaper article, a classroom article or a conversation between friends. These instances form linguistic units, which generally exceed the limits of a single sentence. The discursive analysis of these units may help to highlight by means of various methods, the structural features and relations which characterise these linguistic constructions" (Thompson, 1988).

Other theorists take a more socially aware and explicitly political stance, and argue that language cannot be considered to be transparent or value free. In this way the language that we take to be most "natural", that is the spoken word or talk, does not "have" universal meaning but is assigned particular meanings by both speakers and listeners according to the situation where language is used (Cheek, 2004).

> A group of ideas or patterned way of thinking which can be identified in textual and verbal communications and located in wider social structures" (Lupton, 1992).

For the French philosopher Michel Foucault, discourse refers to ways of thinking and speaking about aspects of reality (Cheek, 2004). Discourses are taken to be the scaffolds of discursive frameworks, which order reality in a certain way, they determine who can speak, when and with what authority; and conversely who cannot (Ball, 1990. This theoretical position is interested in the prominent position of some discourses over others (for example scientific, medical). Cheek and Rudge (1993) believe that such discourses achieve “truth” status, where truth ‘is an effect of the rules of a discourse’.

One distinguishing characteristic of discourse analysis over other qualitative techniques is the disregard of meaning. In discourse analysis as discussed here, text is the data, and the approach is therefore not about exploring “the” content or meaning of the text. Rather it is about explaining how certain things came to be said or done, and what has enabled and/or constrained what can be said or done, and what can be spoken or written in a particular context (Cheek, 2004). In the most extreme cases there may be no relationship between the world outside (the factual record) and the world inside (beliefs, attitudes) (Potter & Wetherell, 1987).

This research methodology has provided some insightful details of social phenomena such as blamings, accusations and mitigations (Drew, 1978, Jayyusi, 1984, Lee, 1984, Watson, 1978, 1983, Watson and Weinberg 1982, Wowk, 1984). Studying police interrogation and murder confessions has been a rich source of data for such theorists as they bring issues of culpability and motive to the forefront of the discourse. For example when suspects construct descriptions of their crimes they do “motive work” (Mills, 1940). That is they construct a version of the crime and what led them to commit it in such a way that the act is mitigated or even justified (Scott and Lyman, 1968).

Similarly, Hopper (2003) found that motives are not inner dispositions that cause actions, but rather rhetorical constructs that define action with respect to particular social constructs. Hopper (2003) examined divorce discourses and offered evidence that two vocabularies of motive emerged after the events that the vocabulary purportedly explained. Using this linguistic analysis he showed that the motives people use to explain their divorces can only be understood as rhetorical devices that imposed a sense of order onto situations that were otherwise fraught with ambiguous and contradictory events, emotions and inclinations towards behaviour (Hopper, 2003).

A phenomenological perspective believes that there is some relationship between what the person says and the beliefs he or she holds. IPA is concerned with an individual's personal perception or account of an object or event as opposed to an attempt to produce an objective statement of the object or event itself. This type of qualitative research examines a smaller sample of respondents who have a greater similarity of characteristics such as age, gender and health situation.

Previous research examples include those waiting genetic testing (Smith, Michie, Allanson & Elwy, 1996), women in their first pregnancy (Smith, 1999), and patient's experience of haemodialysis (Smith, 1996). This method uses semi-structured interviews to explore in greater detail how the individual responds to a particular topic. The purpose of using IPA is to provide a richer account of how the person is thinking about and dealing with a complex and ongoing health situation.

Rationale for using Mixed Methods Research and reference to the literature debating mixed methods designs

When investigating human behaviour it is most fruitful to use a variety of methods (Patton, 1990). The purpose of using mixed methods research is to extend understanding from one method to another. Such research also gives you the opportunity to converge or confirm findings from different data sources (Katsulis, 2003). One popular contemporary method is to use concurrent strategies. The purpose is to confirm, cross-validate or corroborate findings. An example of confirmation, cross validation and corroboration might be the questionnaire data that quantifies psychological measures of distress (anxiety, depression, self esteem) and yields representative and broadly generalizable information about the proportion of individuals with ABI who are affected by these mood states. This is then compared to the interview data that might bring up the same themes of personal distress from an individuals perspective.

A further strength of this approach is to gain a broader perspective than would be achieved using single method alone. For example by using narrative interviews you get many more clues as to the meaning of the distress for the individual.
A further strength of combining both methodologies is that they can be done simultaneously. Often participants value the chance to give their account of the experience in a way that participating through response to a questionnaire is often not valued. By using both methods you utilize the advantages of both methods that is getting the breadth and depth of qualitative research, with the generalizability and replicability of quantitative research.

A limitation of this approach is that most academics are aligned more closely to one tradition. Mixed methodology research can be seen as messy and showing a lack of commitment to either empirical or interpretative ideology. Quantitative purists believe that social observations should be treated as entities in much the same way that physical scientists treat physical phenomena (Johnson & Onwuegbuzie, 2004). Further they contend that the observer is separate from the entities that are subject to observations (Johnson & Onwuegbuzie, 2004). Quantitative purists maintain that social science inquiry should be objective. That is, time and context free generalizations (Nagel, 1986) are desirable and possible, and real causes of social scientific outcomes can be determined reliably and validly.

Qualitative purists reject what they call positivism. This refers to a philosophical point of view influenced by Francis Bacon and the British Empiricists (Reber, 1995). For the positivists all knowledge is contained within the boundaries of science and only those questions answerable from the application of the scientific method can be approached (Reber, 1995). Qualitative purists argue for the superiority of constructivism, idealism, relativism, humanism, hermeneutics, and sometimes post modernism (Guba & Lincoln, 1989, Smith, 1983, 1984). These purists contend that multiple constructed realities abound, that time and context free generalization are neither desirable nor possible, that research is value bound, that it is impossible to differentiate fully causes and effects, that logic flows from specific to general, and that the knower and the known cannot be separated because the subjective knower is the only source of reality (Guba, 1990). It is usually assumed amongst purists that these paradigms represent a whole set of philosophical ideas and that each is tied tightly bound to specific ways of doing research.

Both sets of purists view their paradigm as ideal for research, and implicitly if not explicitly, advocate the incompatibility thesis (Howe, 1988), which posits that qualitative and quantitative research paradigms, including their associated methods cannot and should not be mixed (Johnson & Onwuegbuzie, 2004).

Guba stated, "accommodation between paradigms is impossible. We are led to vastly diverse, disparate and totally antithetical ends (Guba, 1990). Some contend that the two dominant research paradigms have resulted in two distinct research cultures "one professing the superiority of 'deep, rich, observational data' and the other the virtues of 'hard, generalisable data" (Sieber, 1973).

From this viewpoint to accept the complementary nature of different approaches is misleading as these methodologies are derived from fundamentally different epistemological and worldview oppositions, and are therefore incommensurable (Niglas, 2004).

However it has been argued that there are major differences in philosophical and methodological preferences within the camp of qualitative researchers, as well as within the ranks of quantitative researchers, and research practice is much more complicated that that proposed by the paradigmatic view (Niglas, 2004). Therefore two or three exclusive epistemological paradigms that purists seem to have to offer do not exhaust the "potential, or even actual, range of methodological views to be found amongst social researchers" (Hammersley, 1992).

Feminist researchers might take issue with the inclusion of the quantitative methodology as it is thought that methodology is gendered (Oakley 1997,1998), with quantitative methods being traditionally associated with words such as positivism, scientific, objectivity, statistics and masculinity (Westmarland, 2001). In contrast, qualitative methods have generally been associated with interpretism, subjectivity, non-scientific and femminity (Westmarland, 2001). These associations have led some feminist researchers to criticize (Reinharz, 1979, Graham, 1983, Pugh, 1990) or even reject (Graham and Rawlings, 1980) the quantitative approach, arguing that it is in direct conflict with the aims of feminist researchers (Graham 1983, Miles, 1983).

Some feminist researchers have criticized quantitative positivistic methods for ignoring and excluding women (Oakley, 1974) and "adding" women to male knowledge (Westmarland, 2001). However recent mixed methodology research has been designed by women to take account of women's issues for example investigating domestic violence during pregnancy. Salmon, Baird, Price, & Murphy (2004) used mixed methodology designs and the results suggest that in their case the combined approach strengthened knowledge claims. The focus of this research was evaluating a midwifery intervention. The quantitative analysis of changes between pre, post and follow up questionnaires, showed an increase in knowledge, efficacy beliefs and positive attitudes towards enquiry. These changes were subject to some decay over time, but remained above pre-test levels at the 6 month follow up. In depth interviews were conducted with thirty-eight midwives during the programme introduction.

Midwives were interviewed at three and six months post introduction. Data indicated that the programme was viewed positively. The most practical difficulty associated with asking the question was the attendance of the male partner at consultations. Other perceived barriers to enquiry included: lone working and the potential threat of violence; shortages of staff, in particular those associated to retention and recruitment of midwifery staff. Extending the programme and offering regular updates was seen as important.

Haque (1997) conducted a study in which mixed methodology helped to explain any lack of convergence. This study explored acculturation, religiosity, gender role ideology, generational differences, explanations of mental health symptoms, coping mechanisms and help seeking behaviour of a sample of Muslim women in America. A mixed methodology was implemented by using both quantitative instruments and qualitative exploration. Quantitative instruments consisted of demographic information, an Islamic Religiosity Scale (IRS), the American International Relations Scale (AIRS) and the Attitudes Toward Seeking Professional Psychological Help scale (ATSPPH). Qualitative exploration was implemented via semi-structured interviews and a focus group. Forty-two Muslim women completed the quantitative measures. From this sample of forty-two, eighteen Muslim women participated in the qualitative component of the study, which included the semi-structured interview, and seven participated in the group discussion.

Four 2x2x2 ANOVAs and a multiple regression procedure were used to analyse the quantitative data. Qualitative analysis took place by reviewing the scripts and coding to come up with themes. Although quantitative results showed no significant difference between immigrant and first generation Muslim women in their attitudes toward seeking professional help, qualitative results showed that both immigrant and first generation Muslim women revealed a stigma continuum which could be accounted for as a result of one's Racial/Cultural development. Moreover, quantitative results revealed no significant difference between high religious women and low religious women in attitudes towards seeking professional psychological help. Nevertheless, qualitative analysis revealed that religious identity development was a process that helped in explaining aspects of religiosity for both immigrant and first generation Muslim women. Furthermore, Muslim women reported frustration over being judged by an external standard and a community image (Haque, 1997).

It is apparent that using mixed methodology in human research can corroborate or explain any lack of convergence in the results. It is also apparent that mixed designs offer a way of triangulating evidence not available in any other way. Using more than one method to study the same phenomenon can strengthen the validity of results. In short, when dealing with the complexity of issues surrounding acquired brain injury, approaches that get at objective and subjective variables are most likely to fairly address and answer the research questions.

FEMALE BODY IMAGE AND PSYHOLOGICAL HEALTH FOLLOWING ABI[1]

3.1 INTRODUCTION

As outlined previously in chapters 1 and 2, cognitive research has lead to sophisticated models that aim to rehabilitate those with ABI; in contrast the concept of the changed physical self-following ABI has been given little attention.

Physical appearance is viewed as important for women (Jackson, Sullivan and Rostker, 1988), perhaps because of the social importance placed on the female body (Janelli, 1993). The ideal body image represents youth, beauty, vigour, intactness and health. There is likely to be decreased self-esteem, insecurity and anxiety among those who deviate from this ideal (Salter, 1997).

Ideals about body image influence how we judge others and how we judge ourselves. Secord and Jourard (1953) found a high positive correlation between body cathexis (ratings of body parts) and self cathexis (ratings of aspects of self). Depression has also been found to correlate with body dissatisfaction (Marsella, Shizuru, Brennan & Kameoka, 1981, Noles, Cash and Winstead, 1985).

Female body dissatisfaction is concerned with 3 dimensions: sexual attractiveness, weight concern and physical condition (Franzoi & Shields, 1984).
Furthermore Silbertsein, Striegel-Moore, Timko and Rodin (1988) found that for women sexual attractiveness and physical condition were related to self esteem. The

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[1] A version of this chapter has been published in the journal Brain Injury.

effects of physical disability on female body image following ABI have not received much attention in the literature. Research has looked at female body image following other health conditions. Gross, Ireys and Kinsman (2000) looked at women with spina bifida and rheumatology related illness. They looked at all 8 subscales of the Eating Disorders Inventory (Garner, Olmstead & Polivy, 1981) and found that 20% scored above the eating disorder cut off point (indicating eating disorder symptomology) on at least 1 subscale. They found that 6 respondents (8.4%) scored above the cut off point for drive for thinness. They found that 36% (n= 24) fell above the eating disorder cut off point on the body dissatisfaction subscale.

Gross et al (2000) concluded that young women with chronic illnesses and disabilities are vulnerable to poor psychological adjustment, including symptoms of eating disorders; these findings are generally consistent with other studies. Gross et al (2000) point out that the body image dissatisfaction results from their sample may reflect "real" body dissatisfaction resulting from a major chronic condition rather than a distortion *per se*. In the Gross et al (2000) study only 24% of those respondents with moderate or extreme physical impairment had symptoms of body dissatisfaction, indicating that physical impairment itself did not completely determine body dissatisfaction.

Gross et al's (2000) study supported earlier ideas that there was no proportional relationship between the severity of a physical deficit and the psychological distress generated (Lacey and Birtchnell, 1986). In contrast to Gross et al (2000), Watson (1999) found that women with disabilities had similar concerns to women without disabilities, but had additional concerns because of discrimination. Watson (2000) stated that the majority expressed negative feelings about aspects of the body, but had an overall positive self-image.

There is limited research on the effects of acquired brain injury on body image, in particular following TBI. Kreppel and Crowe (2000) in their retrospective study found body image was significantly negatively affected and was associated with a reduction in self esteem both in males and females following first stroke. Piotrowski (1982) found that in female stroke survivors, poor body image was associated with feeling more anxious about their illness.

Female body image following acquired brain injury has not been investigated in isolation. The present study adopts the position of Tyerman and Humphrey (1984) that while accurate self appraisal may be limited by cognitive impairment it is the subjective impairment that dictates psychological adjustment. The present study employed a between subjects design to examine the perceived effect of acquired brain injury on body image and psycho-emotional functioning, in an attempt to come to a deeper understanding of how acquired brain injury affects female body image.

The specific hypotheses were (1) that there would be differences in body dissatisfaction between the ABI and female comparison (FC) group in this study. (2) That there would be differences in eating disorder symptomology between the ABI and FC groups. (3) That there would be psycho-emotional differences between the ABI and FC as measured by self esteem, anxiety and depression. (4) That the way in which body image impacts psycho-emotional health would be different for ABI and FC groups.

3.2 METHOD

3.2.1 *Participants*

The study was initiated after gaining approval from the local research ethics committee. Twenty-six women were recruited for the study; thirteen had had an ABI, and thirteen were non-ABI controls. ABI participants were recruited from the local general hospital Headway group. A clinical neuropsychologist referred ABI patients from an outpatient clinic. Criteria for selection included documented evidence of traumatic brain injury or stroke, time lag since injury at least 6 months, age between 18-65 years, and absence of severe comprehension problems. Control participants were recruited from members of the public to form a female comparison group. The exclusion criteria for the FC group included any physical, psychiatric or neurological disorder, and drug or alcohol dependency.

Variable	Group	Mean	SD
Age (Years/ months)	ABI	40.46	13.09
	Controls	39.08	14.29
BMI	ABI	25.91	9.53
	Controls	21.89	2.77
Time since injury (Years)	ABI	5.52	5.39

Table 2. Means/ standard deviations, of age, BMI, and time since injury.

In the ABI sample eight women were identified as having had a traumatic brain injury (TBI) and five women were identified as having had a stroke by their clinical psychologist on the basis of their clinical records. The mean age of the women in the ABI group was 40 years (SD = 13.09). Each person in the clinical group was matched for age, education levels, pre-injury socio-economic status, and body mass index (BMI), to form the (FC) group.

3.2.2 *Materials*

The assessment measures comprised of 1) disability measures, 2) psychosocial distress measures and 3) body image measures. The actual measures are listed below:

1. The Mini Mental State Examination (Folstein, Folstein & McHugh 1975).
2. The Brain Injury Community Rehabilitation Outcome Scales (Powell, Beckers, Greenwood, 1998).
3. Rosenberg Self Esteem Scale (Rosenberg, 1979).
4. The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983).
5. The Body Dissatisfaction Index (modified version of Franzoi & Shields Body Esteem Scale, 1984).
6. The Eating Disorders Inventory (Garner, Olmstead and Polivy, 1981)

All the relevant sections are described in detail below, and appear in the appendices.

3.2.3 *Ethical Information*

An information sheet was provided with detailed information about the study. It also informed participants about the confidential nature of the study and assured participants that taking part would not affect their healthcare in any way. A consent form was provided that asked participants to tick boxes to confirm that they had read and understood what was being asked of them. Participants were asked to sign and date the form. A letter for general practioners was made available to all patients so that they could inform their doctor if they so wished.

3.2.4 *Personal Information*

Participants were asked to give details of their age, gender, educational level, occupation of chief income earner in household pre-injury, occupation of chief income earner in household post injury.

Participants were also asked to give their weight (in stones and pounds) and height (in feet and inches). In the statistical database all weights were converted to kilograms and all heights into metres so that each individual's body mass could be calculated. The body mass index (BMI) is the most widely used and reliable epidemiological indicator of body fat (Logue, 1991).

The ABI participants were asked what event had caused their injury, for example; their head being hit, a stroke, an illness, a tumour, an overdose, or other event. The ABI participant's responses together with the information provided by the clinical psychologist were used to ascertain and classify the aetiology of their injury.

Furthermore the clinical psychologist provided information as to whether the participant had visible scars, was a wheelchair user, had a hemiplegia or weakness, and whether they had motor spasticity. Socio-economic status was classified according to the Market Research Society guidelines (2003).

3.2.5 *The Mini Mental State Examination (Folstein, Folstein & McHugh 1975)*

This is a simplified scored form of cognitive mental status examination. The Mini Mental State Examination (MMSE) includes 11 questions and takes 5-10 minutes to administer. The measure concentrates only on cognitive aspects of mental function. The MMSE tests 6 domains; orientation, registration, attention, recall, language and perception. The patient receives a single score with a possible maximum of 30.

The MMSE is the most widely used and studied screening measure of cognitive impairment (Hodges, 1994). It has the advantages of brevity, ease of administration, and high inter rater reliability (Hodges, 1994). The MMSE permits comparisons to be drawn between intellectual changes and other aspects of mental function. The advantages of using the MMSE in clinical work are that it is; quantified, reliable, valid and short.

3.2.6 *Brain Injury Community Rehabilitation Outcome Scales (Powell, Beckers & Greenwood, 1998).*

The BICRO-39 is an outcome measure designed to assess functioning in the community following acquired brain injury. It is relatively short in comparison to other measures such as the 136-item sickness impact profile (Bergner, Bobbitt, Carter & Gilson, 1981) and is specifically for use following acquired brain injury. The items included evaluations of quality of life in such areas as mobility, personal care, and productive employment.

There are 8 subscales that are scored 5 (don't do at all), 4 (constant help), 3 (a lot of help), 2 (some help), 1 (prompts only), 0 (no help). The factors; personal care, mobility, self-organisation, socialising and psychological well being have 6 questions each, producing a maximum score (indicating serious impairment) of 30, and a minimum score of 0 (indicating no impairment).

Productive employment has 5 questions producing a maximum score of 20 (indicating no productive employment), and a minimum score of 0 (indicating productive employment). Contact with partners/ own children, and contact with parents/ siblings each have two questions producing a maximum score of 10 (indicating no contact) and a minimum score of 0 (indicating frequent contact).

The BICRO-39 has high content validity and good test-retest reliability (Powell et al, 1998). The generally high correlations between the BICRO-39 and other scales assessing aspects of disability and handicap provided preliminary confirmation of its construct validity. The basic requirements of most of the scales were met in terms of utility both in individual clinical assessment and in-group research, as described by Johnston, Keith and Hinderer (1992).

3.2.7 *Rosenberg Self Esteem Scale (Rosenberg 1979)*

Self esteem was measured using the Rosenberg Self Esteem Scale (Rosenberg, 1979) that has been widely used with both healthy (Franzoi & Shields, 1994) and brain-injured adults (Kreppel & Crowe, 2000). It has acceptable reliability and concurrent and construct validity (Franzoi & Shields, 1994).

This is a ten-item questionnaire and is based on contrived items, yielding a seven-point scale, which produces a single score 0-7, a high score indicates high self-esteem. Test-retest reliability had been found to be r = 0.85 (Silber & Tippett 1965, cited in Rosenberg 1979).

3.2.8 *The Hospital Anxiety and Depression Scale (Zigmond & Snaith 1983)*

The Hospital Anxiety and Depression Scale (HADS) is a brief 14 item, self report measure of anxiety and depression developed by Zigmond and Snaith (1983). It was developed for use in general medical outpatient clinics but is now widely used in clinical practice and research (Herrmann, 1997).

The HADS has two subscales: anxiety and depression, and each subscale has 7 items. At present interpretation of the HADS is based primarily on the use of cut-off scores, although there is no single, generally accepted cut-off score for the HADS (Herrmann, 1997). The tests authors recommend that for the anxiety and depression scores alike, raw scores of between 8-10 identify mild cases, 11-15 moderate cases, and 16 and above, severe cases (Snaith & Zigmond, 1994).

3.2.9 *The Eating Disorders Inventory (Garner, Olmstead, & Polivy 1983)*

This questionnaire was designed specifically to investigate the body image concerns presented by females. It demonstrates good all round validity and reliability and can be applied to distinguish unhealthy body attitudes in clinical and non-clinical populations (Garner et al, 1983). Two of the EDI subscales were used: Drive for

Thinness [DFT] and Body Dissatisfaction [BD]. Both the subscales operate on a six-point scale, ranging from always agree to never agree. The data were recorded according to the author's guidelines (Garner et al, 1983).

The DFT scale (7 items) measured the desire to lose weight and be thin. The BD scale (9 items) measures dissatisfaction with different parts of the body relating to weight and correlates strongly with body image disturbances.

3.2.10 *Body Dissatisfaction Index (Franzoi & Shields 1984)*

Body dissatisfaction was measured using a modified version of the Franzoi & Shields, Body Esteem scale, which is based on the Secord and Jourard (1955) Body Cathexis Scale. The measure was devised to assay attitudes towards the body by simply asking people whether they had positive or negative feelings about different body parts; it has been used previously to study body image following a first stroke in young adults (Kreppel & Crowe, 2000). This modified form features 32 body parts; appetite, waist, thighs, body build, buttocks, hips, legs, figure, stomach, weight, body scent, nose, lips, ears, chin, breasts, appearance of eyes, cheeks/ cheekbones, sex drive, sex organs, sex activities, body hair, face, physical stamina, reflexes, muscular strength, energy level, biceps, physical condition, agility, health, physical condition. Participants were then asked to rate on a 5 point scale whether they had positive or negative feelings towards each constituent part, where 1 is strong negative feelings, 3 is have no feelings either way and 5 is strong negative feelings.

Split-half reliability co-efficient for the BCS measure was reported to be 0.83 for males (Secord & Jourard, 1955) and test re-test reliability has been reported as 0.87 by Tucker (1982).

3.2.11 *Procedure*

The questionnaires themselves were ordered according to a cyclic Latin square design. All instructions were given verbally and repeated in written format on the questionnaires. The experimenter conducted the Mini Mental State Examination, and the experimenter was present throughout completion of the questionnaires in order to help with any comprehension difficulties. Once completed questionnaires were collected in by the experimenter. All participants were given a numerical code making them identifiable only to the researcher. At the end of the study participants were debriefed and once the results were analysed a feedback information sheet was provided. All data were analysed using the Statistical Package for Social Sciences (S.P.S.S).

3.3 RESULTS

An independent t-test revealed that there were no significant differences between the age, BMI, educational level and original SES (taken as the baseline for the clinical group) of the controls and clinical groups. On these socio-demographic variables, as judged by these measures they were a matched sample (Table 3 and Table 4).

Variable	Classification	ABI Frequency (percentage)	Controls Frequency (percentage)
Educational level	Secondary school/ GCSE -	30.8%	30.8%
	Further education/ A-Levels +	46.2%	30.8%
	Higher education	23.1%	38.5%
Original SES	[B] Professional	15.4%	0. 0%
	[C1] White Collar	46.2%	69.2%
	[C2] Skilled Manual Worker	7.7%	15.4%
	[D] Semi Skilled Manual Worker	30.8%	7.7%
	[E] Unemployed	0.0%	7.7%

Table 3. Educational level and original socio-economic group (baseline) of clinical and control group.

Independent t-tests revealed that there were no significant differences between the present SES of the ABI group and the SES of the FC group (Table 3).

Variable	ABI	Frequency (percentage)
Present SES	[B] Professional	7.7%
	[C1] White Collar	46.2%
	[C2] Skilled Manual Worker	15.4%
	[D] Semi Skilled manual worker	23.1%
	[E] Unemployed	7.7%

Table 4. Present socio-economic group of clinical group.

Although there was a trend towards downward economic mobility this was not statistically significant.

3.3.1 *ABI specific characteristics*

Overt physical characteristics were recorded to give an idea of variables that might affect body image. 15.4% of the women with ABI had visible scars, 15.4% hemiplegia, and 7.7% of the women with ABI had motor spasticity.

3.3.2 *Body Image differences between ABI and Comparison Females*

Independent t-tests were used to test for differences between FC and the ABI on the body dissatisfaction index. The women with ABI were more dissatisfied with their waist (M = 2.38, SD =0.87) than FC (M = 3.31, SD =1.25), (t (24) = - 2.19, p <. 05). The ABI women were more dissatisfied with their health (M= 2.15, SD =1.21) than FC (M= 3.54, SD =1.13), (t (24) = - 3.01, p <. 05).

There was a trend towards more women with ABI scoring above the cut off point for the EDI on body dissatisfaction and drive for thinness (Table 4). Using the raw scores independent t-tests revealed that there were no significant differences between the ABI and FC groups on the drive for thinness and body dissatisfaction subscales of the EDI.

Group	Above cut off BD (n/ freq)	Below cut off BD (n/ freq)	Above cut off DRT (n/ freq)	Below cut off DRT (n/ freq)
Women with Head Injuries	6 (46.6%)	8 (53.4%)	1 (7.7%)	12 (92.31%)
Controls	3 (23.1.%)	10 (76.9%)	0	13 (100%)

Table 5. Number and frequency of women scoring above and below the cut-off point for the EDI. Note. Scoring above the cut-off point on the EDI would indicate body image disturbance.

3.3.3 *Disability and Body Image*

Correlational analyses were conducted to assess the nature of relationships between body image and disability. To see if body image differences between the ABI and FC groups are related to disability it is necessary to see whether satisfaction with waist or health correlates with physical characteristics, cognitive function, and community functioning. As physical characteristics and MMSE cut off scores were dichotomous variables, point biserial correlations were used, and as the community functioning scores were of interval nature a parametric Pearson's product moment correlation was used.

3.3.4 *Physical characteristics*

Satisfaction with waist and health did not correlate with any of the physical characteristics, visible scars, hemiplegia or motor spasticity. However age correlated with satisfaction with health ($r_{pb} = -.58$, $p < .05$,) those ABI who were older were less satisfied with their health.

3.3.5 *Cognitive Function*

There was a significant negative correlation between MMSE scores and satisfaction with health ($r_{pb} = -.73$, $p < .05$). Those women with ABI that had greater cognitive functioning were less satisfied with their health.

3.3.6 *Community Functioning-Bicro-39*

There was a significant negative correlation between social functioning and satisfaction with health ($r = -.81$, $P = .001$). Those women with ABI who had greater social problems were less satisfied with their health.

There was a significant negative correlation between employment and satisfaction with health ($r = -.63$, $P < .05$). Those women with ABI who had greater employment difficulties were less satisfied with their health.

3.3.7 *Eating disorders inventory*

There was a significant negative correlation between satisfaction with waist, drive for thinness ($r = -.70$, $p < .05$) and body dissatisfaction ($r = -.74$, $p < .01$). In the sample of women with ABI, those with a greater drive for thinness and body dissatisfaction were less satisfied with their waist. Neither subscale of the EDI used correlated with health.

3.3.8 *Affect*

The results show that 61.55% of the ABI sample had mild to severe scores of anxiety at a clinical level. In comparison 38.47% of the FC group scored in the mild to severe bracket for clinical levels of anxiety as recommended by the test authors (Zigmond & Snaith, 1983). The results show that 61.53% of the ABI group had mild-severe levels of clinical depression in comparison with 0% of FC (Table 6 and 7).

Variable	ABI (n/freq)	Controls (n/freq)
Mild Anxiety	3 (23.08%)	1 (7.70%)
Moderate Anxiety	4 (30.77%)	2 (23.07%)
Severe Anxiety	1 (7.70%)	1 (7.70%)

Table 6. Scores above the cut off point on the anxiety subscale of the HADS.

Variable	ABI (n/freq)	Controls (n)
Mild Depression	4 (30.77%)	0
Moderate Depression	2 (15.38%)	0
Severe Depression	2 (15.38%)	0

Table 7. Scores above the cut off point on the depression subscale of the HADS

In the statistical analyses the raw scores from the HADS for anxiety and depression were used. The ABI group had a mean anxiety score of 9.31 (SD = 4.79), and a mean score for depression of 8.38 (SD = 5.27). The FC sample had a mean anxiety score of 8.00 (SD = 4.12), and 3.15 (SD = 2.15) for depression. Independent t-tests were used to test for differences between FC and the ABI groups on the HADS scale. There was a significant difference between the ABI and FC depression scores (t (26) = 3.31, p<. 01). There was no significant difference between the ABI and FC anxiety scores.

3.3.9 *Self Esteem*

Independent t-tests were used to test for differences in self esteem as measured by Rosenberg's self esteem scale. There was a significant difference between the ABI and the FC self esteem scores, (t (26) = -3.47, p<. 01). The ABI self esteem scores (M = 2.69, SD = 2.10) were significantly lower than the FC group (M = 5.08, SD =1.32).

3.3.10 *The Effect of Cognitive and Physical Disability on Self Esteem following ABI*

To investigate the relationship between cognitive and physical disability Pearson's correlations were carried out. There was a significant negative correlation between cognitive function and self esteem (r = -.63, p<. 05). In this group of women with ABI higher cognitive functioning was associated with lower self esteem. There was a significant negative correlation between mobility and self esteem (r = -.64, P<. 05). Greater mobility difficulties were associated with lower self esteem. There was a significant negative correlation between social functioning and self esteem (r = -.65, P<. 05). High scoring for a lack of social contact was associated with low self esteem in this group of women with ABI.

3.3.11 *Body Image and Self Esteem following ABI*

To investigate if there were any direct links, self esteem was correlated with satisfaction with health and weight (the body parts that the ABI sample were significantly less satisfied with on the body cathexis scale). There was a significant positive correlation between satisfaction with health and self esteem (r =. 61, p<. 05). Those women with ABI who were more dissatisfied with their health had a lower self esteem. There was also a significant positive correlation between satisfaction with physical condition and self esteem (r = .75, p<. 01). Those women with ABI who were more dissatisfied with their physical condition had a lower self esteem.

3.3.12 *Depression*

Depression correlated with MMSE (r =. 64, P<. 05), those women with ABI who were functioning at a higher cognitive level were more depressed. Social functioning correlated with depression (r =-.69, P<. 01). Those women with ABI who had greater social problems were more depressed.

Psychological well-being (r =. 73, P<. 05) and anxiety (r = .65, P<. 01) correlated with depression. Poorer psychological well-being and greater levels of anxiety seem to correlate with depression. Self esteem and depression showed a significant positive correlation (r = -.58, P<. 05).

Depression correlated with satisfaction with appetite (r =-.68, P<. 01), physical stamina (r = -.63, P<. 05), biceps (r =-.59, P<. 05), physical condition (r =-.68, P<. 05) and health (r = -.77, P<. 05). Those women with ABI who had greater scores of depression were less satisfied with their appetite, physical stamina, biceps, physical condition and health.

3.3.13 *Relationships of body dissatisfaction in the female comparison group*

Having established the significant correlations in the women with ABI, it is important to establish if any relationships that are significant for the ABI group are absent in the FC as this could help to explain the significant differences in body dissatisfaction scores. Dissatisfaction with waist or health did not correlate with either subscale of the EDI.

3.3.14 *Correlations of Self Esteem and Depression in the female comparison group*

Having established the significant correlations in the ABI, it is important to establish if any relationships that are significant for the ABI group are absent in FC, as this could help to explain the significant differences in self esteem and depression.

Correlations between self esteem and depression were carried out. There was a significant positive correlation between drive for thinness and self esteem, (r = -.58, p<. 05). High drive for thinness was associated with low self esteem. Self esteem was also associated with satisfaction with the face (r = .62, P<. 05) and reflexes (r = .64, P<. 05). Those who had greater self esteem had greater satisfaction with their face and reflexes. There was a significant positive correlation between self esteem and depression (r = -.65, P<. 05). Those that had low self esteem had greater depression. There was a significant positive correlation between depression and satisfaction with appearance of the eyes (r = -.72, P<. 05). Those that had greater scores of depression had less satisfaction with the appearance of their eyes.

3.3.15 *Profile of how Disability Affects Body Satisfaction and Self Esteem following ABI*

Satisfaction with health seems to be affected by cognitive function, social functioning and employment in women who have sustained ABI.

Cognitive functioning, mobility and social functioning seem to affect self esteem following ABI.

3.3.16 *Comparison of the Profile of Significant Correlations between the women with ABI and female control group*

There was a relationship between age and satisfaction with health in the ABI group that was absent in the FC. There was a relationship between drive for thinness, body dissatisfaction and satisfaction with waist in the ABI group that was absent in the FC. However, there was a relationship between drive for thinness and self esteem in the FC that was absent in the ABI. In the FC self esteem was correlated with satisfaction with reflexes and face. In the ABI group self esteem was correlated with satisfaction with health. There was a relationship between physical condition and health in the ABI group that was absent in the FC. Depression and self esteem were correlated for both groups in the analyses. In the FC depression was correlated with satisfaction with appearance of eyes. In the ABI group depression was correlated with satisfaction with physical stamina, biceps, appetite, physical condition and health.

It seems there are clear differences between the ABI and FC women in this sample on a number of measures of body image and psychological health. The women with ABI were less satisfied with their health and waist. Furthermore the women with ABI had lower self esteem and higher depression scores than the FC. Self esteem and satisfaction with health were correlated in this ABI group.

3.4 DISCUSSION

It seems there are clear differences between the ABI and FC women in this sample on a number of measures of body image and psychological health. Considering body image, women with ABI were less satisfied with their health and waist.

Considering psychological health, the women with ABI had lower self esteem and higher depression scores than the FC. Furthermore self esteem and satisfaction with health were correlated in this ABI group.

The greater dissatisfaction with waist follows a pattern of normal female body dissatisfaction but in a more enhanced or extreme version, hence the difference in scores with the FC. The greater dissatisfaction is interesting in the ABI group because of its correlation with both the subscales of the Eating Disorder Inventory used (Garner et al, 1981). However with correlational data (and especially multiple correlational data) it is important to remember the effect of multiple comparisons and so should be treated with caution.

In the present sample of women with ABI 7.7% scored above the cut off point for drive for thinness (indicating body image disturbance, Gross et al, 2000) and 47% scored above the cut off point for body dissatisfaction. Whilst the present study is a small and heterogeneous sample, the figures are not dissimilar to Gross et al's (2000) study of women with spina bifida and rheumatology related illnesses. In this sample 8.4 % of women scored above the cut off point for drive for thinness, and 36% of women scored above the cut off point for body dissatisfaction. Taking these findings together it would suggest that women with disabilities such as ABI and spina bifida are at some risk from body image disturbance.

Furthermore in the present study body dissatisfaction was elevated in the women with ABI compared to matched controls, although this failed to reach statistical significance. This trend cannot be dismissed as it is possible that with a larger sample size this trend may reach significance. To draw any conclusions further data are welcomed.

In the present sample the FC did not show this profile of greater waist satisfaction and the relationship with the EDI subscales. However the FC women did show a relationship between high drive for thinness and low self esteem, suggesting that in a group of healthy women those with low self esteem are more likely to become vulnerable to and possibly adopt the thin norms, resulting in the high drive for thinness.

Interpreting this work with caution it seems that women with ABI show a similar pattern to non-ABI women, in that there will be a small group of women who are likely to present with eating disorder symptomology. With a larger sample perhaps this trend towards greater body image disturbance as measured but the EDI in women with ABI would be significantly greater than FC.

The greater dissatisfaction with health in the ABI group is interesting because it may be their subjective perception of reality post injury. The women in the ABI are not as healthy or physically able as the non-ABI, a further control group using another chronic condition might help to elucidate if this pattern is unique to brain injury or a feature of all chronic conditions.

In the ABI group crude disability measures of motor spasticity and hemiplegia and visibility of scars, disability did not correlate with satisfaction with either dimension of body dissatisfaction (health or waist). Whilst caution is warranted as a result of the small sample size, these results are congruent with other work that has found no relationship between severity of physical condition and body dissatisfaction (Gross et al, 1981). Taking the results together these findings lend support for the idea that the severity of the deficit is not connected to the psychological distress generated (Lacey & Birtchnell, 1986).

In the ABI group there was a correlation between satisfaction with health and cognitive function. The women with greater cognitive function were less satisfied with their health. This finding would lend support to Wilson (2000) who believed that following ABI injury it might be counterproductive to try to push levels of awareness too far. It would certainly seem that those with lesser cognitive faculty are in one sense "protected" from the full impact of the injury.

In the ABI group dissatisfaction with health was of central importance, and showed a relationship with social and employment problems after brain injury. On a practical level if you are not feeling well you are less likely to work or engage in social activity. This finding would lend support to the idea that you have to take a holistic view that can accommodate many variables post injury.

Health also correlated with age in the ABI sample but not in the FC group, even though they were matched on age. Age was related to satisfaction with health in the ABI sample but not in the FC sample, even though they were matched on age. This is interesting because it suggests that it is not age *per se* that is affecting the evaluations of satisfaction with health. McKee (1998) talked about the way older people perceive falls as being a crucial variable in recovery. He was concerned with the way in which some older people saw the fall as the start of an inevitable continual decline into old age, whilst others saw the event as an isolated incident unconnected to ageing and decline. The second group were found to have better recovery in a controlled between subjects design study.

Following brain injury, such as stroke, which is associated with older adults, some people may evaluate this as an accepted part of the process of getting older, and thus the prognosis of continual decline. However young people may be more likely to evaluate it as an isolated incident and thus there is a correlation between age and satisfaction with health in the brain injured group. The present study shows tentative support for the idea that the way in which people perceive their illness, has an affect on adjustment (McKee, 1998), such as satisfaction with health post injury.

There was no significant difference in anxiety sores between the ABI and the FC. This supports earlier work by Crawford, Henry, Crombie and Taylor (2001) in a large-scale population design; they found elevated anxiety scores in a significant number of the population using the same measure, the HADS. Anxiety was connected to low self esteem in the ABI group, which supports Robson (1988). However this finding was not replicated in the FC group. This suggests that the anxiety in the FC group is at a manageable level and does not affect self evaluations, however the anxiety in the ABI group, although not significantly different is not at a manageable level and is affecting self evaluations. Perhaps having a ABI means that you are less well equipped cognitively, or otherwise, to tolerate anxiety, whereas the FC injured appear to be able to do so. Furthermore poor psychological well-being was linked to lower self esteem in the ABI group, further supporting the suggestion that psychological distress is less well tolerated and more significant for self evaluations in the ABI group.

There was a significant difference in depression between the ABI group and the FC, women with ABI had significantly greater scores of depression. Depression was correlated with cognitive function in the ABI sample. Again this would lend support for Wilson (2000) who found that greater levels of post injury awareness can have negative associations, the greater depression might be a reflection of the greater understanding of their situation.

In the ABI group depression was also correlated with social functioning, anxiety and psychological well-being. Again caution is warranted in the interpretation of multiple correlational analyses, it would lend some tentative support for the idea that psychopathology is likely to occur together (Robson, 1988) and also for a holistic clinical approach, that can take account of the many variables that are significant for women post ABI and their interactions.

Depression was correlated with dissatisfaction with several body parts (appetite, physical stamina, biceps, physical condition, health) relating to physical functioning in women with ABI. This finding supports earlier work by Franzoi and Shields (1984) who found that physical condition was important for psychological health in women. That the women with ABI had significantly greater scores of depression and that in this group depression correlated with several body parts also supported earlier work by Marsella et al (1981) who found that dissatisfaction with 17 body parts was associated with depression in a (mixed gender) student sample.

In the FC comparison group depression scores only correlated with appearance of eyes. This provides some support for Franzoi and Shields (1984) who emphasized how important facial attractiveness is for women (in non-clinical situations).

Self esteem was significantly lower in the ABI group than the female comparison group. Self esteem was correlated with cognitive function; those that were functioning at a higher cognitive level have lower self esteem. The finding again supported Wilson (2000) who thought that greater awareness can have negative consequences for the survivor, such as a greater insight to their circumstance.

Self esteem was correlated with mobility in the ABI sample, those that had greater mobility difficulties had lower self esteem. The importance of community functioning to all round well-being post injury is once again highlighted, as well as the need for a holistic approach that can accommodate a multitude of variables.

Self esteem also correlated with dissatisfaction with physical functioning in women with ABI. In contrast FC self esteem correlated with reflexes and facial satisfaction. The facial satisfaction component supports earlier work by Franzoi and Shields (1984) and Silberstien et al (1988) who emphasized how important facial attractiveness was for women. These concerns are absent in the ABI, and it seems to suggest that after ABI a new “physical health concern” dominates female body image.

That dissatisfaction with health correlates with self esteem could suggest that the women with ABI in this sample had internalised their condition, perhaps having a brain injury had made them feel less good about themselves. The correlation between satisfaction with health and low self esteem fits in with the idea of the "body drop" (McKee,1988). This concept was originally used in relation to older people and falls. The idea is that this traumatic event (fall/acquired brain injury) brings about a change in physical functioning, which impacts identity. In such events our bodies let us down and all sorts of negative associations accompany our personal evaluations of the event (decline, disability, loss, death, frailty). How others relate to us may also change following brain injury. There are common misconceptions that the public hold about brain injury (Swift & Wilson, 2001). Following brain injury people may mistake balance and co-ordination problems for being drunk, or a brain injury as a psychiatric illness, as being "mad". McKee and Gott (2002) have looked at the idea of shame following the body drop.

Shame might be applicable after a body drop from acquired brain injury, especially if people think you are drunk or mistake you for being mentally ill. Gilbert and Miles (2002) have talked about the fact it is not so much the distance from the ideal self but the closeness to the undesired self that is significant. Falls and acquired brain injury bring you closer to the undesired self and further away from your desired self. Gilbert et al (2002) talks about the problems of having to live in the world "as an undesired self". It might be suggested that this is applicable following brain injury, and thus satisfaction with health is of central importance. It is suggested that the brain injury has made these women dissatisfied with their health, the injury also has made the women closer to their undesired selves, and further away from their desired self.

As well as the primacy of the concern with health following ABI, there is some concern with thinness that would be comparable with normal female body image concern. Having an ABI does not completely obliterate this concern, but health becomes more important and this is what self esteem becomes tied up. Concerns about facial attractiveness seem less relevant or important to this ABI group.

Self esteem and depression were correlated in both groups, despite the ABI group having significantly lower self esteem and greater depression scores than the FC. This correlation supports Robson (1988) who points out that self esteem and depression are connected in clinical samples, but this study suggests that this also holds true for non-clinical samples.

The present study suggests that prior to brain injury, women have the normal weight and sexual attractiveness/ facial appearance concerns. Following ABI a new physical /health functioning concern dominates the body image schema and relates to post injury self esteem and depression. Some EDI symptomology is evident in both groups of women, although the ABI show a trend towards greater body dissatisfaction. Facial attractiveness/ appearance is no longer relevant in this group. The suggestion is that following brain injury the body image schema in women changes profoundly, with appearance no longer being so important, indeed facial attractiveness is no longer relevant. Health now dominates the schema and body dissatisfaction appears elevated in this group.

Body image concerns are tied up with social functioning, employment difficulties, and mobility as measured with the Bicro-39. The results suggest that following brain injury health dissatisfaction becomes internalised and affects how these women feel about themselves, possibly leading to depression. ABI dramatically changes the way these women feel about themselves and their bodies.

The present findings do not support the work of Watson (1999) who found that women with disabilities express some negative feelings about the body but overall have a positive self image. In this sample, women with ABI retained the female waist dissatisfaction/thin concern (although in a more extreme form).
They became less concerned with facial/sexual attractiveness and became much more concerned with physical health. The women with ABI did not show an overall positive self image, these women had significantly lower self esteem and greater depression. However, these different findings (Watson, 1999) may be a function of acquired versus congenital disabilities. It is possible that ABI is potentially more damaging to self because the individual has a healthy and intact self, and loses this identity. Watson (1999) thought that age of onset of disability would be especially relevant for feelings about the body, the findings of this acquired condition appear to support this idea.

There are a number of limitations not least the sample size and the heterogeneous (in brain injury terms) sample. The sample size although modest has parallels with other body image research done with clinical groups (Stensman 1989, Dewis 1989). Furthermore the present study presents the concerns of women following ABI, when previous research in this area has mixed the concerns of both genders (Kreppel & Crowe, 2000), despite evidence that males and females have body image concerns that differ in nature, magnitude and direction (Logue 1998, Grogan, 1999). The present study also used a carefully matched control group (that includes variables such as BMI) when other research in this area has used retrospective designs (Kreppel

& Crowe, 2000). All data are self reported apart from the cognitive measure, and condition related characteristics. However, the present study takes the position of Tyerman and Humphrey (1984) that, although awareness might be impaired following ABI, it is the subjective experience that is the reality for the patients and it is precisely this perspective that has been lacking in the clinical research. The patients were taken from an outpatient group and so the concerns might be more serious or salient than those who are no longer receiving clinical interventions.

Nevertheless female body image is not well-understood post brain injury and whilst other clinical conditions have established work in this area it is not known how significant a variable body image might be following ABI. This is of some concern when the research suggests that even women without chronic health conditions are more at risk from disorders of body image than men (Logue, 1998). The results suggest that ABI significantly changes body image in women and for the worse. The present study supports and extends earlier work by Kreppel and Crowe (2000) that feelings about the self are negatively affected following brain injury, and that this is associated with significantly greater scores of depression.

3.4.1 *Rehabilitation implications*

The finding that women with brain injuries have poor body image, and that the poor body image was primarily concerned with health, was the main finding of the present study.

The results also support the notion that any intervention should be based on the assumption that the body image dissatisfaction may be based on 'real' dissatisfaction with a major chronic condition rather than a perceptual distortion (Gross et al, 2000). Body image dissatisfaction following brain injury in women should be considered along with that the concept of the "body drop", the idea that the body no longer functions as it did before, and that this can be a very frightening perception. To identify these fears and implement ways of reducing or eliminating them through appropriate action can do much to aid adjustment. Because much of the body image dissatisfaction centred on physical functioning and health, exercise and strength building activities such as walking, swimming and light weight lifting are likely to be of benefit to woman with ABI. In addition to the physical benefits of increased physical strength, agility and co-ordination that might facilitate positive appraisals of the body following brain injury, such activities can increase kinaesthetic awareness after injury and insult.

The greater depression and lower self esteem observed in the women with brain injuries suggests that any interventions would need to take a holistic approach that deals with many complex variables. The women might require assistance from the clinician to reappraise their situation and gain a fresh meaning of their circumstance (Stroebe, Hannson, Stroebe & Schur, 2001). Self-empowerment is advocated by Mateer and Sohlberg (2001) as a self-mastery and self-efficacy approach, which can be applied to a broad range of therapeutic issues.

Social skills' training has been suggested as a method for assisting realistic, positive self-evaluation and assertive transactions with others in the community (Ylviasaker, 1998). Mateer and Sohlberg (2001) further suggested that increasing the individual's sense of responsibility, both for self and others, for example volunteering, can help increase social cohesiveness and build self esteem. Facilitating adjustment following ABI will necessarily involve dealing with these issues and addressing them in future interventions should be a matter of priority.

MALE BODY IMAGE AND PSYCHOLOGICAL HEALTH FOLLOWING ABI[2]

4.1 INTRODUCTION

Whilst as outlined in chapter 1 and 2, cognitive research has driven rehabilitation techniques, there are other factors of significance when evaluating prospects of recovery. Researchers have consistently suggested that psychosocial problems associated with traumatic brain injury (Morton & Wehmen, 1995) and stroke (Oddy et al, 1985) are major challenges that face rehabilitation. Furthermore the physical changes receive consistently less attention than cognitive change post ABI.

The loss of self concept is perhaps one of the most profound and disturbing consequences of ABI. An important part of self-concept is the subjective view of your own body, state of health, physical appearance, skills or sexuality (Roid & Fiffs, 1994), which has been termed body image in the literature. In a few cases body image changes following brain injury are due to perceptual disturbance, however, it has been suggested that even those without such neurological disturbance, have to adjust to an alteration in body image due to any residual illness or disability (Drench, 1994, Gillies, 1984). Kent and Keohane (2001) have talked about the social consequences of an altered appearance such as the fear of negative evaluation. Major health and social problems have consistently been associated with the negative changes in self image.

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[2] A version of this chapter has been accepted for publication and is currently in press at Brain Injury.

In the non ABI there are differences in body image according to gender in terms of the nature and magnitude of concerns about weight, appearance and functioning (Logue, 1991). Whilst female weight concerns centre on weight loss (Greenfield, Quinlan, Harding, Glass & Bing, 1987), males are equally split between those who wish to lose weight and those who wish to gain weight (Drewnoski & Yee, 1987, Silberstein, Striegel-Moore, Timko & Rodin, 1988). Men tend to place more importance on bodily functions directly related to sex, whereas women emphasize physical stamina and condition (Franzoi & Herzog, 1987). Grant & Fodor (1986) found that physical attractiveness was highly correlated with self-esteem in women, but in men physical effectiveness was more highly correlated. Mahoney (1974) reported that body image was more closely related to self concept for males than for females, whereas Lerner, Karabenick & Stuart (1973) found the opposite to be true.

Kreppel & Crowe (2000) in a retrospective study, found body image was significantly negatively affected and was associated with a reduction in self esteem both in males and females following a first stroke. There are several reasons' why this work needs replication. Firstly, Kreppel & Crowe (2000) used a retrospective design asking people to think back to how they felt before their injury; a study employing a carefully matched comparison group could highlight differences between those who have sustained an ABI and those who are neurologically and physically intact. Secondly, they looked at those who had suffered a first stroke, and it would be interesting to see if these effects are similar following TBI.

Thirdly, they used a group of 20 males and 13 females and mixed together the concerns of both genders, when the literature suggests that body image concerns differ in nature, direction and magnitude. Therefore it would be interesting to look at the body image concerns of males who had undergone a neurological accident such as stroke or TBI.

The present study adopts the position of Tyerman and Humphrey (1984) that while accurate self appraisal may be limited by cognitive impairment it is the subjective impairment that dictates psychological adjustment. The present study employed a between subjects design to examine the perceived effect of acquired brain injury on body image and psycho-emotional functioning in an attempt to come to a deeper understanding of how ABI affects male body image.

The specific hypothesis were (1) that there would be body dissatisfaction differences between the males with ABI and controls in this study. (2) That there would be psycho-emotional differences between the males with ABI and controls on measures of self-esteem, anxiety and depression. (3) That the way in which body image impacts psycho-emotional health would differ between the males with ABI and controls.

4.2 METHOD

4.2.1 *Participants*

The study was initiated after gaining ethics approval from the local research ethics committee. Fifty men were recruited for the study, twenty-five had had an ABI, and twenty-five were non-ABI controls. Participants with ABI were recruited from the local general hospital and Headway group. A clinical neuropsychologist referred males with ABI; only individuals who were outpatients were included in the study to control for acuteness of the injury. Control participants were recruited from members of the public. The exclusion criteria for controls included a traumatic brain injury (TBI), a stroke, epilepsy, any other neurological illness, psychiatric illness, drug or alcohol dependency.

In the ABI sample fifteen males (mean age 33.93 years, standard deviation 9.28 years), were identified as having had a TBI by their clinical psychologist. In the sample ten males (mean age 40.50 years, standard deviation 15.01 years) were identified as having had a stroke by their clinical psychologist. Each person in the clinical group was matched for age, education levels, pre injury socio-economic status, and body mass index (BMI), to form two control groups.

4.2.2 *Measures*

The assessment measures comprised of 1) disability measures, 2) psychosocial distress measures and 3) body image measures.

The actual measures are listed below;

1. The Mini Mental State Examination (Folstein, Folstein & McHugh 1975).
2. The Brain Injury Community Rehabilitation Outcome Scales (Powell, Beckers, Greenwood, 1998).
3. Rosenberg Self Esteem Scale (Rosenberg, 1979).
4. The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983).
5. The Body Dissatisfaction Index (modified version of Secord & Jourard 1953).
6. Male Body Image Questionnaire (Edwards, Green and Collins, in Prep).

All the relevant sections are described in detail in the materials section of chapter 3.

The Mini Mental State Examination (MMSE)

Refer to 3.2.5

Brain Injury Community Rehabilitation Outcome Scales (Bicro-39).

Refer to 3.2.6

Rosenberg Self Esteem Scale (RSE)

Refer to 3.2.7.

The Hospital Anxiety and Depression Scale (HADS)

Refer to 3.2.8

Swansea Male Body Image Questionnaire (SMBIQ) (Edwards, Green & Collins, in prep)

This questionnaire was designed specifically to investigate the body image concerns presented by males. The questionnaire consists of 18 statements relating to three general factors, the desire to lose weight (fat concern), the desire to gain a bigger build (thin concern) and gender stereotypes (gender stereotyping), this is concerned with opinions related to body image, such as the belief that "males should be bigger than females". For each factor there are six questions. All items are answered using a 7-point scale, where 1 is "definitely disagree" and 7 is "definitely agree". Scores range from 6-42, a higher score indicating a stronger agreement with that factor. Whilst this measure has never been used with brain-injured patients before it is linguistically simple and short, having only 18 items.

Body Dissatisfaction Index (BDI)

Refer to 3.2.10

4.2.3 *Personal and Ethical Information*

For ethical information refer to 3.2.3, for personal information refer to 3.2.4

4.2.5 *Procedure*

Refer to 3.2.11

4.3 RESULTS

Variable	Group	N	Mean	SD
Age (Years/ months)	TBI	15	33.93	9.28
	Stroke	10	40.50	15.01
	TBI control	14	33.00	12.63
	Stroke control	11	40.18	17.46
Educational level 1 = GCSE's – 2 = A-levels 3 = Degree +	TBI	15	1.60	0.74
	Stroke	10	1.80	0.79
	TBI control	14	2.00	0.96
	Stroke control	11	1.55	0.69
Original Socio-economic group 1=A, 2=B, 3=C1, 4=C2, 5= D, 6= E	TBI	15	3.80	0.86
	Stroke	9	3.56	0.53
	TBI control	13	3.38	0.77
	Stroke control	10	3.72	1.04
Present Socio-economic group 1=A, 2=B, 3=C1, 4=C2, 5= D, 6= E	TBI	15	3.80	1.08
	Stroke	10	4.60	1.45
	TBI control	13	3.38	0.77
	Stroke control	10	3.72	1.04
BMI	TBI	14	26.54	6.51
	Stroke	10	28.40	5.68
	TBI control	14	26.45	3.89
	Stroke control	10	27.07	4.78
Time Since Injury	TBI	15	7.02	7.53
	Stroke	10	6.89	6.29

Table 8. Means/ standard deviations, of age, educational level, old socio-economic group, new socio-economic group, BMI, and time since injury.

Table 8. shows the descriptive statistics (means and standard deviations are reported) of all four groups in the study. The TBI groups had a mean age of 33, the stroke groups had a mean age of 40, the stroke group were an older group by 7 years.

Independent t-tests revealed there were no significant differences between age, educational level, BMI, original socio-economic grouping (taken as the baseline measure for ABI groups) between each clinical group, and its matched control group.

2-way ANOVA (stroke versus TBI) x (ABI versus control) indicated that there was a significant difference in present socio-economic grouping between the ABI groups and the control groups, (F = 5.47, p<. 05). Since there was no significant difference in original socio-economic group, in practical terms this means that following brain injury socio-economic status decreased. There was no significant main effect of injury group, and there was no significant interaction between ABI and injury type. An independent t-test showed there was no significant difference in time since injury between the stroke group and the TBI group.

4.3.1 ABI Specific Measures: Overt Physical Characteristics

Variable	TBI	Stroke
Visible scars		
Yes	4 (26.7%)	1 (10.0%)
No	11 (73.3%)	9 (90.0%)
Wheelchair user		
Yes	5 (33.3%)	2 (20.0%)
No	10 (63.3%)	8 (80.0%)
Hemiplegia /weakness		
Yes	9 (60.0%)	8 (80.0%)
No	6 (40.0%)	2 (20%)
Motor spasticity		
Yes	4 (26.7%)	2 (20%)
No	11 (73.3%)	8 (80%)

Table 9. Number of individuals who have or have not got; visible scars, wheelchair, hemiplegia, or motor spasticity, following ABI

Chi-square tests of association were applied to see if there was a significant association between type of injury and overt physical characteristics.

On these 4 variables there was no significant association between type of injury and overt physical characteristics. This means that there were no overt physical characteristics that were particularly associated with injuries of either aetiology.

4.3.2 *Body Image Differences between those with ABI and Controls*

4.3.2.1 *Body Dissatisfaction Index: ABI versus Controls*

Variable	TBI M/SD	TBI Control M/SD	Stroke M/SD	Stroke control M/SD	ABI Vs Controls F value
Appetite	3.86 (0.87)	3.50 (0.76)	2.80 (1.14)	3.00 (0.63)	0.03
Physical Stamina	3.14 (1.19)	3.36 (1.22)	2.70 (0.95)	2.91 (0.94)	0.51
Reflexes	**2.93 (1.16)**	**4.07 (0.73)**	**2.00 (0.82)**	**3.36 (0.81)**	**24.61*****
Muscular strength	**3.53 (1.19)**	**3.79 (1.05)**	**2.10 (0.99)**	**3.18 (0.98)**	**4.14***
Energy level	4.07 (0.70)	3.43 (1.22)	2.10 (0.99)	2.81 (0.70)	1.29
Biceps	2.80 (1.08)	3.43 (0.760	2.70 (1.06)	3.09 (0.74)	3.85
Body Build	2.87 (1.13)	3.14 (1.170	2.70 1.06)	2.64 (0.81)	0.29
Physical Co-Ordination	**3.27 (1.16)**	**3.71(0.91)**	**2.40 (1.17)**	**3.91 (0.83)**	**11.49****
Buttocks	3.40 (1.12)	6.93 (13.28)	3.20 (0.63)	3.45 (0.68)	0.92
Agility	**3.13 (0.99)**	**3.57 (1.09)**	**2.10 (1.20)**	**3.64 (0.92)**	**11.59****
Shoulder Width	3.40 (0.91)	3.71 (0.730	3.40 (0.84)	3.36 (0.92)	0.27
Arms	**2.67 (1.40)**	**3.79 (0.80)**	**2.50 (1.08)**	**3.18 (0.60)**	**9.35****
Chest	3.80 (1.01)	3.50 (0.76)	3.00 (0.94)	2.81 (0.75)	0.58
Legs	**3.06 (1.28)**	**3.86 (0.77)**	**2.70 (1.16)**	**2.91 (0.54)**	**9.10****
Physique	3.20 (1.21)	3.43 (1.16)	2.90 (0.99)	2.55 (0.93)	0.00
Hips	3.33 (0.82)	3.43 (0.85)	2.70 (1.34)	2.90 (0.30)	0.10
Thighs	3.27 (0.82)	3.07 (0.83)	2.50 (0.97)	2.90 (0.54)	0.20
Stomach	2.93 (1.10)	3.00 (1.11)	2.50 (1.35)	2.27 (0.90)	0.08
Waist	2.80 (0.86)	2.71(0.83)	2.90 (1.52)	2.36 (0.67)	0.04
Sex organs	**2.93 (1.28)**	**3.92(0.86)**	**2.78 (1.39)**	**3.45 (0.82)**	**7.17****
Sex drive	**2.87 (1.10)**	**4.08 (0.76)**	**3.00 (1.14)**	**3.18 (1.08)**	**5.29***
Health	2.93 (1.33)	3.71 (1.270	2.60 (1.17)	2.73 (0.90)	2.47
Sex activities	2.87 (1.25)	3.92 (1.12)	3.10 (1.45)	3.27 (1.19)	3.33
Face	3.40 (1.06)	3.43 (1.02)	3.00 (0.67)	2.90 (0.94)	0.00
Weight	3.13 (0.92)	3.00 (1.24)	2.50 (1.27)	2.64 (0.67)	0.04

Table 10. Means and SD's for the four groups body part satisfaction scores and significant main effect of ABI. * p<. 05, **p <. 01, ***p <. 001.DF = 49 for all measures.

There was a main effect of ABI on several body parts.

Controls were more satisfied than those with ABI in their satisfaction with their reflexes (F= 24.61, p<.001), muscular strength (F= 4.14, p<.05), physical co-ordination (F = 11.49, p<. 01), agility (F=11.59, p<.01), arms (F=9.35, p<.01) and legs (F=9.10, p<.01). Controls were also significantly more satisfied with their sex organs (F=7.17, p<.05) and sex drive (F=5.29, p<.05) than those with ABI.

The profile of body parts that show a main effect of ABI on body dissatisfaction indicated there seems to be an emphasis on physical and sexual functioning.

4.3.2.2 *Male Body Image*

Variable	M/SD TBI	M/SD TBI control	M/SD Stroke	M/SD stroke control	TBI VS Stroke F	Clinical VS control F	Interaction F
Fat concern	14.67 (7.22)	22.21 (9.85)	17.49 (11.00)	17.91 (9.84)	0.09	2.24	1.18
Thin concern	16.20 (8.88)	12.86 (6.38)	17.80 (10.54)	15.00 (9.38)	0.56	1.50	0.01
Gender stereotyping	25.47 (9.55)	24.14 (8.22)	18.90 10.34)	26.09 (5.05)	0.89	1.43	2.16

Table 11. Mean, SD's and summary of F ratio's from the 2-way ANOVA'S for the four groups male body image scores. DF = 49 for all measures.

The 2-way ANOVA (stroke versus TBI) x (ABI versus controls) indicated that there were no significant main effects on this male body image measure. Furthermore no interaction reached statistical significance.

4.3.3 *The Effects of Cognitive and Physical Disability on Body Image following ABI*

To look at this area further it is first necessary to see if there are any significant differences on the cognitive or community functioning measures between stroke and TBI groups.

The mini mental state examination (MMSE) is not a questionnaire measure with a normal distribution. Rather it is an objective measure of cognitive function used by the medical profession in which you either score at the normal range for your age or below.

4.3.4 *MMSE Cut Off scores*

Variable	TBI	Stroke
Score Above Cut Off Point MMSE		
Yes	8 (53.33%)	7 (70%)
No	7 (46.67%)	3 (30%)

Table 12. Cognitive measure MMSE: association between type of injury and scoring above or below the cut off point

Chi-square tests of association were applied to see if there was a significant association between type of injury and scoring in the normal range on the MMSE. There was no significant association between cognitive scoring on the MMSE and aetiology of ABI.

4.3.5 *Community Functioning – Brain Injury Community Rehabilitation Outcome Scales (BICRO-39)*

Variable	M/SD TBI	M/SD Stroke	T
Personal care	5.33 (9.10)	0.70 (1.49)	1.59
Mobility	13.67 (9.89)	10.60 (10.97)	0.73
Self-organisation	14.00 (9.77)	11.20 (10.88)	0.67
Partner	6.73 (3.92)	5.10 (3.96)	1.02
Parent	6.13 (4.24)	6.30 (5.07)	-0.09
Social	15.27 (4.04)	12.00 (5.08)	1.79
Employment	17.80 (2.43)	15.90(3.04)	1.74
Psychological well-being	11.53 (6.48)	10.50(4.67)	0.43

Table 13. Means/SD's and t value for the independent t- tests on Bicro-39 scores for the clinical groups. DF = 49 for all measures.

There were no significant differences using an independent t-test on any of the Bicro-39 scores suggesting that the impairment in community functioning experienced following stroke and TBI was not significantly different.

Therefore there were no significant differences between stroke and TBI on cognitive and community functioning scores; on these measures there was no difference in functioning according to aetiology of ABI.

4.3.6 *Disability and Body Image*

Correlational analyses were conducted to assess the nature of relationships between body image and disability. To see if body image differences between males with ABI and controls are related to disability it is necessary to see if any of the body parts that had a main effect of ABI correlate with physical characteristics, cognitive function, and community functioning.

As physical characteristics and MMSE cut off scores were dichotomous variables, point biserial correlations were used, and as the community functioning scores were of interval nature a parametric Pearson's test was used.

4.3.7 *Physical Characteristics*

Body parts for which those with ABI were significantly less satisfied than the controls were correlated with physical characteristics: visible scars, wheelchair use, hemiplegia and plasticity.

The only significant correlation was between satisfaction with reflexes and visible scars (rpb = 0.47,p<. 05). Those who had greater visible scars were less satisfied with their reflexes.

There were no significant correlations between wheelchair use, hemiplegia, and spasticity and satisfaction with any of the body parts for which the ABI sample were significantly less satisfied.

4.3.8 *Cognitive Function MMSE cut off scores*

There were no significant correlations between the body parts that were significantly different between the ABI and control groups and MMSE scoring in the normal range.

4.3.9 *Community Functioning - Bicro-39*

Correlations between body parts that were significantly different between ABI and non-ABI groups were correlated with personal care, mobility, self-organisation, partner, parent, social, employment, psychological well being.

There was only one significant correlation between employment and satisfaction with muscular strength (r = 0. 52, p<. 01). Those who were unemployed had greater satisfaction with muscular strength. There were no significant correlations between body parts that were significantly different between ABI and control groups and personal care, mobility, self-organisation, partner, parent, social, and psychological well being.

4.3.10 *Self Esteem and Affect*

4.3.10.1 *Anxiety and Depression- Hospital Anxiety and Depression Scale (HADS)*

Variable	M/SD TBI	M/SD TBI control	M/SD stroke	M/SD Stroke control	TBI VS Stroke F	Clinical VS control F	Interaction F
Anxiety	5.73 (2.79)	6.00 (4.00)	7.40 (5.32)	8.27 (2.41)	0.17	3.08	0.25
Depression	5.40 (2.93)	4.00 (3.76)	5.30 (3.06)	4.27 (2.67)	2.27	0.00	0.00

Table 14. Means/SD's and summary of F ratios' from the 2-way ANOVA's for the four groups HADS scores. DF = 49 for all measures

There were no significant main effects or interactions for the 2-way ANOVA (stroke versus TBI) x (ABI versus control) on anxiety or depression scores.

4.3.10.2 *Self Esteem*

Variable	M/SD TBI	M/SD TBI control	M/SD Stroke	M/SD stroke control	TBI VS Stroke F	Clinical VS control F	Interaction F
Self Esteem	3.60 (1.76)	4.21 (2.08)	3.30 (1.16)	5.27 (1.01)	0.80	8.35**	2.40

Table 15. Means/SD's and summary of F ratios from the 2-way ANOVA's four groups self esteem scores, ** = p <. 01. DF = 49.

The ABI groups had significantly lower self esteem scores than the control groups. There was a significant main effect of ABI on self esteem, (F= 8.35, p<. 01). The males with ABI in this sample had significantly lower self-esteem than their matched controls.

4.3.11 *The Effect of Cognitive or Physical Disability on Self Esteem in the Head Injured*

No subscales on the Bicro-39 or the cut off scores from the MMSE correlated with self esteem.

4.3.12 *Body Image, Self Esteem and Affect in the ABI Group*

Self esteem and body part satisfaction were investigated. Self-esteem was correlated with the body parts that had a significant main effect of ABI in the body cathexis scale. There were no significant correlations between self-esteem and satisfaction with body parts.

To investigate by which self esteem is affected, self-esteem was first correlated with psychological well being, anxiety and depression. These results should be treated with some caution as multiple correlations increase the likelihood of significant results. Self esteem and psychological well-being correlated in the ABI sample (r = -0.66, p<. 001). Self esteem and anxiety correlated in the ABI sample (r = 0.43, p<. 05). Self esteem and depression correlated in the ABI sample (r = 0.54, p<. 01). Psychological well being and thin concern correlated in the ABI sample (r = 0. 51, p<. 01). Those who had poorer psychological well being had greater thin concern. Anxiety did not correlate with any body image variables in the ABI sample. Depression and reflexes correlated in the ABI sample (r = -0.41, p<. 05). Those who had greater depression had significantly less satisfaction with their reflexes.

4.3.13 *Relationships between Self Esteem, Anxiety and Depression in the Non ABI Group*

From the results of the 2-way ANOVA it appeared that there were significant differences in self esteem and body part satisfaction between ABI and control groups. The ABI sample were less satisfied with certain body parts and had poorer self esteem. Low satisfaction with reflexes was correlated with greater depression and greater visible scars. There was a positive correlation between lack of employment and satisfaction with muscular strength.

Having established the significant correlations in the ABI groups, it is important to establish if any relationships that are significant for the control sample, are absent in the ABI sample as this could help to explain the significant differences in body dissatisfaction scores.

Therefore correlations between self esteem, anxiety, depression and the body cathexis scale were carried out in the non-ABI Group. Furthermore relationships between anxiety and depression and the body cathexis scale were carried out in the non-ABI Group. Psychological well being following ABI could not be looked at in this group, as this is a measure unique to brain injury (BICRO-39).

4.3.14 *Correlates of Self Esteem in Controls*

There was a significant negative correlation between self esteem and anxiety (r = -0.44, p<. 05). Male controls that were more anxious had poorer self esteem.

There was a significant negative correlation between self esteem and depression (r = -0.49, p <05). Male controls that were more depressed had poorer self esteem.

Therefore the variables anxiety and depression correlated with self esteem for the ABI and control groups. Psychological well being correlations cannot be compared in this way as this is a brain injury specific measure (Bicro-39).

There was a significant positive correlation between self esteem and satisfaction with sex organs (r = 0. 43, p<. 05). In the male control sample higher self esteem was related to greater satisfaction with sexual organs.

4.3.15 *Correlates of Anxiety in Controls*

There was a significant negative correlation between anxiety and satisfaction with appetite in the controls (r =- 0.60, p<. 001). In the male controls greater anxiety was associated with lower satisfaction with appetite.

4.3.16 *Correlates of Depression in Controls*

There was a significant negative correlation between depression and satisfaction with agility in the control sample (r = -0. 47, p<. 05). In this group greater depression was associated with less satisfaction with agility. There was a significant negative correlation with depression and satisfaction with sex drive (r =- 0.48, p<. 05). In this group low satisfaction with sex drive was associated with greater depression.

4.3.17 *Comparison of the Profile of Significant Correlations Between ABI and Control groups*

The ABI sample had significant correlations between satisfaction with reflexes, depression and visible scars.

There was also a correlation between lack of employment and satisfaction with muscular strength. The controls showed significant correlations between self esteem and satisfaction with sex organ, and with depression and low satisfaction with sex drive. In the controls there was also a relationship between agility and depression, and with anxiety and appetite.

The results indicated that in the control group there was a relationship between sex functioning and psychosexual emotional health, which may help to explain the significantly higher scores in body satisfaction and self esteem in this group.

In the ABI group the relationship between sexual functioning and psychosexual emotional health, as observed in the non-ABI group, were absent. In the ABI groups the relationships focused on physical functioning (reflexes), appearance (visible scars), and depression. Again maybe this could help to explain the significantly lower body satisfaction in this group.

4.3.18 *What Body Image Differences occur due to other factors?*

4.3.18.1 *Body part satisfaction - stroke versus TBI*

Variable	TBI	TBI control	Stroke	Stroke control	Stroke VS TBI F
Appetite	**3.86 (0.87)**	**3.50 (0.76)**	**2.80 (1.14)**	**3.00 (0.63)**	**9.53****
Physical Stamina	3.14 (1.19)	3.36 (1.22)	2.70 (0.95)	2.91 (0.94)	2.00
Reflexes	**2.93 (1.16)**	**4.07 (0.73)**	**2.00 (0.82)**	**3.36 (0.81)**	**9.51****
Muscular strength	**3.53 (1.19)**	**3.79 (1.05)**	**2.10 (0.99)**	**3.18 (0.98)**	**12.37****
Energy level	**4.07 (0.70)**	**3.43 (1.22)**	**2.10 (0.99)**	**2.81 (0.70)**	**7.48****
Biceps	2.80 (1.08)	3.43 (0.760	2.70 (1.060	3.09 (0.74)	0.75
Body Build	2.87 (1.13)	3.14 (1.170	2.70 1.06)	2.64 (0.81)	0.85
Physical Co-Ordination	3.27 (1.16)	3.71(0.91)	2.40 (1.17)	3.91 (0.83)	1.31
Buttocks	3.40 (1.12)	6.93 (13.28)	3.20 (0.63)	3.45 (0.68)	0.83
Agility	3.13 (0.99)	3.57 (1.09)	2.10 (1.20)	3.64 (0.92)	2.54
Shoulder Width	3.40 (0.91)	3.71 (0.730	3.40 (0.84)	3.36 (0.92)	0.63
Arms	2.67 (1.40)	3.79 (0.80)	2.50 (1.08)	3.18 (0.60)	1.81
Chest	**3.80 (1.01)**	**3.50 (0.76)**	**3.00 (0.94)**	**2.81 (0.75)**	**7.60****
Legs	3.06 (1.28)	3.86 (0.77)	2.70 (1.16)	2.91 (0.54)	1.07
Physique	3.20 (1.21)	3.43 (1.16)	2.90 (0.99)	2.55 (0.93)	2.87
Hips	**3.33 (0.82)**	**3.43 (0.85)**	**2.70 (1.34)**	**2.90 (0.30)**	**5.27***
Thighs	**3.27 (0.82)**	**3.07 (0.83)**	**2.50 (0.97)**	**2.90 (0.54)**	**6.04***
Stomach	2.93 (1.10)	3.00 (1.11)	2.50 (1.35)	2.27 (0.90)	3.55
Waist	2.80 (0.86)	2.71(0.83)	2.90 (1.52)	2.36 (0.67)	0.73
Sex organs	2.93 (1.28)	3.92(0.86)	2.78 (1.39)	3.45 (0.82)	0.81
Sex drive	2.87 (1.10)	4.081 (0.76)	3.00 (1.14)	3.18 (1.08)	0.83
Health	2.93 (1.33)	3.71 (1.270	2.60 (1.17)	2.73 (0.90)	2.63
Sex activities	2.87 (1.25)	3.92 (1.12)	3.10 (1.45)	3.27 (1.19)	0.25
Face	3.40 (1.06)	3.43 (1.02)	3.00 (0.67)	2.90 (0.94)	2.33
Weight	3.13 (0.92)	3.00 (1.24)	2.50 (1.27)	2.64 (0.67)	2.17

Table 16. Means and SD's and F ratio's for the four groups body part satisfaction scores and significant main effect of injury type, N.B * p<. 05, **p <. 01, ***p <. 001. DF = 49 for all measures.

There was a significant main effect of injury type on several body parts.

The TBI group were more satisfied than the stroke group with their appetite (F = 9.53, p<. 05), reflexes (F= 9.51, p<. 05), muscular strength (F= 12.37, p<. 01), energy levels (F= 7.48, p<. 01) and chest (F= 7.60, p>01). The TBI groups were significantly more satisfied with their hips (F= 5.27,p<. 05) and their thighs (F = 6.04, p<. 05) than the stroke groups. The body parts that were significantly different between the stroke group and the TBI groups showed two profiles, one concerned physical functioning and one concerned areas that are related to weight gain (hips, thighs). There were no significant interactions for the 2-way ANOVA (stroke versus TBI) x (ABI versus control).

To see if these differences were due to age a 2-way ANOVA was applied with age as the dependent variable. There was no significant main effect of injury type (F = 3.16, p=. 08) or ABI (F =. 04, p>.05) or significant interaction (F = .01, p>.05).

A 2-way ANOVA (stroke versus TBI) x (ABI versus control) could not be applied to the disability measures, as controls were not given tests of cognitive functioning or community functioning. A chi square test showed no significant association between injury types and scoring below the cut off point on the MMSE. Furthermore as Table.13 shows there were no significant differences in community functioning when an independent t-test was applied to the stroke and TBI group.

When a 2-way ANOVA (stroke versus TBI) x (ABI versus control) (Table 14) was applied to scores of anxiety and depression there was no main effect of injury type between the TBI versus stroke groups.

When a 2-way ANOVA (stroke versus TBI) x (ABI versus control) (Table 15) was applied to self esteem scores there was no main effect of injury type; TBI versus stroke groups.

Therefore while there are some body part satisfaction differences between the groups in terms of injury type (appetite, reflexes, muscular strength, energy level, chest, hips and thighs), there are no corresponding differences in psychosocial functioning as measured using the Rosenberg Self Esteem and Hospital Anxiety and Depression Scale.

There was a main effect of ABI on body part satisfaction as measured by the body cathexis scale. Appetite, reflexes, muscular strength, physical co-ordination, arms, agility, legs, sex organs and sex drive were all body parts that the males with ABI were significantly less satisfied with than controls. In summary there was a concern with physical functioning and sexual functioning that differentiated ABI and control groups.

In the ABI group those who had greater visible scars were less satisfied with their reflexes. Those who had less satisfaction with their reflexes had greater scores of depression. In the ABI group those who were unemployed had greater satisfaction with muscular strength.

In the non-ABI there was a relationship between self esteem and sex organs. There was also a relationship between depression and satisfaction with sex drive and satisfaction with agility. In the non ABI there was a relationship between anxiety and satisfaction with appetite. All these relationships were absent in the ABI group.

There was a main effect of brain injury on self-esteem; individuals with ABI had a significantly lower self-esteem score than controls. There was no correlation between cut-off scores on a test of cognitive function, or subjective disability and self esteem. There was no direct correlation between body part satisfaction and self esteem. Treating the correlational data with caution would seem to suggest that there are several mediating processes between body image and self esteem. Self esteem is correlated with psychological well being and depression. Those who had poor psychological well being had greater thin concern. Those who had greater depression had significantly less satisfaction with their reflexes.

4.4 DISCUSSION

4.4.1 *Differences between the males with ABI and controls*

There are clear differences in the two groups in terms of body image and psycho-emotional health. The body parts that those with ABI were significantly less satisfied with were: appetite, reflexes, muscular strength, physical co-ordination, agility, arms and legs.

The emphasis on physical effectiveness supports previous work by Grant & Fodor (1986) and (Halliwell and Dittmar, 2003) who found that males focused on physical effectiveness and functionality as important in evauluations of body image.

Those with ABI were also significantly less satisfied with their sex organs and sex drive. Again this supports previous work that found that men placed more importance on bodily functions directly related to sex (Franzoi & Shields, 1982). Therefore following brain injury it is these areas that become the focus of body dissatisfaction. The finding that on several items those with ABI were significantly more dissatisfied with their body image than the controls does not support work done by Stensman (1989) who found no differences between the acquired and congenitally disabled and a non disabled group in body dissatisfaction scores. However this work mixed together the body image concerns of males and females, which might help to explain the clear pattern of dissatisfaction in the areas of physical and sexual functioning shown in the present group of males with ABI.

On the male body image measure no significant differences were found between those with ABI, and controls, in terms of fat concern, thin concern and gender stereotyping. This suggests that following ABI these concerns are fairly robust and resistant to change. This finding lends support to previous work by Drewonski & Lee (1987) and Silbertsein et al (1988) that male body image concerns are split between those who wish to lose weight and those who wish to gain. Gender stereotyping also seems a fairly robust construct, an attitude that seems resistant to change following ABI.

The results from the above measures indicate that body image does change for the worse following brain injury. These body image concerns are more to do with functioning than appearance. This finding supports previous work that acquired illness and disability are accompanied by increased somatic preoccupation and focusing of awareness upon physical sensations. Secord and Jourard (1953) have demonstrated in physically normal college students an association between increased somatic concern and lower body dissatisfaction. Nursing guidelines suggest patients shift in attention from social to physical needs with chronic illness (Shontz, Fink, Hallenbach, 1960).

4.4.2 *Self Esteem*

There were significant differences between the males with ABI and controls in this sample. The males with had significantly worse self-esteem than the controls. This suggests that acquired brain injury affects the way people see themselves. Whilst there has been little work that directly explores self esteem following ABI (McGuire & Greenwood, 1990), Mateer & Sohlberg (2002) pointed out that any perceived decline in functioning or ability may be accurate and that this can very damaging to self image.

4.4.3 *Affect*

There were no significant differences between the males with ABI and controls. Both ABI groups and both control groups scored in the normal range for depression. The TBI group and its matched control scored in the normal range for anxiety, the stroke group and its matched control had anxiety scores that indicated low-mild anxiety might be present in this group.

This trend may be explained by the way the individuals perceive the event. Age would fulfil the criterion of an attribution that is internal, stable and global, an attributional pattern that has been linked in negative events to low perceived control and hopelessness (McKee, 1988). In the case of the stroke group the brain injury may be attributed as a feature of the ageing process and thus an indication of continued decline, an attribution that may be absent in the traumatic brain injury group.

An alternative explanation is that a notable proportion of the general population suffer from anxiety. Crawford, Henry, Crombie and Taylor (2001) found that 20.6 % of their sample of 1792 suffered from mild anxiety, and that 33% exceeded what Zigmond and Snaith (1994) considered to be normal. They suggested that the cut off point for anxiety should be raised and the present study might lend support.

4.4.4 *Physical and Cognitive Disability*

No significant differences in physical or cognitive disability were found between the stroke and TBI group suggesting that they can be treated as one ABI group. This lends tentative support for the idea that when using these measures in future it might not be necessary to split groups according to aetiology.

4.4.5 *ABI Correlations*

There was a significant positive correlation between depression and satisfaction with reflexes in the ABI group, suggesting that those who were less satisfied with this area of body functioning were more depressed. There was a correlation between satisfaction with reflexes and visible scars, suggesting that those with more visible scars were less satisfied with their reflexes.

There was a significant negative correlation between employment and satisfaction with muscular strength; this might suggest that those who were unemployed were more satisfied with their muscular strength. The types of jobs that people can potentially return to following head ABI might explain help this finding. White collar or desk jobs are less likely to require high levels of physical functioning and are more adaptable to accommodating physical disability than manual work, which requires high physical functioning and effectiveness. However because of the spurious effect of multiple correlations this finding needs further investigation and replication.

There was a significant negative correlation between self-esteem, anxiety and depression, suggesting that those who had greater self-esteem had lower scores of depression and anxiety. This lends support to Robson (1988) in that self esteem, anxiety and depression were related in an ABI sample. There was a relationship between psychological well being and self esteem, those who had greater self esteem had greater psychological well being. There was a relationship between psychological well being and thin concern. Those who had poorer psychological well being had greater thin concern. The findings support and extend the work done with first stroke survivors (Kreppel & Crowe, 2000) who found that body image and psycho-emotional health were related. The present study extends this work by showing that these relationships exist in males with traumatic brain injury as well as in male stroke groups

4.4.6 *Relationships in the Control Group*

Because control males have significantly higher self esteem than the males with ABI it is important to look at correlates in this sample and to see if any relationships are present in one group but absent in the other. Self esteem was correlated with anxiety and depression in the same way that it was for the ABI sample, again supporting Robson (1988), but this time in a non-clinical sample.

Self esteem was also correlated with satisfaction with sex organs. Those who had greater self esteem were more satisfied with their sex organs. This confirms earlier reports that sexuality and intimacy are of uppermost importance to young men (Aloni, Keren, Rosentul, Grosswasser & Cohen, 1999).

Anxiety was related to satisfaction with appetite. Those who were more anxious were less satisfied with their appetite. Depression and agility was related, those who were less satisfied with their agility were more depressed. Those who were less satisfied with their sex drive were more depressed. In the non head controls there was a relationship between sexual functioning and emotional health, but this relationship is not present in the males with ABI, despite this group having less satisfaction in this area and lower self esteem. This suggests that there is no linear relationship, and ceiling effects may help explain this finding, for example the ABI sample scored at the top end in body dissatisfaction and low self esteem.

4.4.7 *Other Body Image Differences*

There were significant differences according to injury type in satisfaction with: appetite, reflexes, muscular strength, energy levels, chest, hips and thighs. The profile of dissatisfaction related to physical functioning and weight. To explain this finding age was investigated and failed to reach significance in the statistical analyses. Considering all the other variables, age remains the most likely explanation for such differences in body satisfaction. The TBI group were younger than the stroke group by a gap of 7 years (mean age 33 and 40 years), the existence of such an age gap seems likely to be important. Perhaps larger samples would find a significant difference between ages according to injury type, stroke versus TBI. In addition the dissatisfaction with body parts implicated in weight gain (hips, thighs) would lend tentative support to the suggestion that age could explain these body image differences.

There were no significant differences in the male body image questionnaire, again suggesting these concerns are relatively stable. There were no significant differences in self esteem or affect according to injury type. Therefore whilst some body dissatisfaction looks like it could be due to age, there were no corresponding differences in emotional health.

4.4.8 *Conclusion*

The present study indicates that males with ABI are less satisfied with their physical and sexual functioning, and have significantly lower self esteem than a matched control group. This suggests that an important sequalae of ABI is a decline in the way the individual feels about them self and their body. Furthermore the present study replicates and extends previous work (Kreppel & Crowe, 2000) that suggested that for males following ABI, body image and psycho-emotional health are related. A future study looking specifically at the body image concerns of females following ABI is warranted.

Relationships between sexual functioning and psycho-emotional health that were present in the controls were absent in the ABI group. This discrepancy between a linear relationship in one group and lack of such a relationship in the ABI group, despite significantly worse self esteem and sexual functioning, needs further investigation.

There were differences in satisfaction with several body parts according to injury type. This finding is perhaps best explained by the age difference between the two injury groups. There were no corresponding differences in terms of the male body image subscales, self esteem, or affect.

4.4.9 *Rehabilitation Implications*

Body image and self esteem has been found to be negatively affected following ABI. Physical and sexual functioning satisfaction scores were lower in the ABI group than in the control group, self esteem scores were also lower in the ABI group. The indication is that whole body image schema is different, physical and sexual functioning is particularly highlighted. Perhaps this should be addressed in future rehabilitation strategies as these are areas that are the most difficult to tackle and the most likely to be overlooked (Kreppel & Crowe, 2000), often because rehabilitation professionals may feel embarrassed about the subject or feel they lack expertise in this area (Ducharmes & Gill, 1998).

There is limited work on body image following brain injury and the few studies that do exist have not developed fully the rehabilitation implications for ABI (Kreppel & Crowe, 2000). This is perhaps surprising as it is known that issues surrounding the body and sexuality are of uppermost importance to young men (Aloni, Keren & Cohen, 1999) and it is precisely this group is most at risk from TBI. Following stroke the evidence suggests that sexuality remains something that requires a carefully targeted response from rehabilitation professionals.

The literature on physical disability has looked at body image in other clinical populations. Stensman (1989) conducted interviews with individuals who had sustained a spinal cord injury or cerebral palsy. He found it was important for the physically disabled to acknowledge their gender role, for example participants wanted to stress they were a man in spite of their disability. Carleton (1995) has looked at sexual dysfunction following stroke and stresses that it is important for those individuals to feel they can be uninhibited about their needs; this is important because sexuality can be an uncomfortable subject for families and professionals to discuss. It has been argued that sex therapy by skilled, qualified professionals can make the difference between a life of misery and a life of at least some relationship satisfaction (Miller, 1993). Carleton (1995) also advocates the use of drugs such as viagra that can help overcome physical causes of sexual dysfunction.

Dewis (1989) looked at spinal cord adolescents and interviewed them about the meaning of body changes. The areas that were the focus of negative feelings clustered around loss of musculature and physique, deterioration of physical appearance and hygiene, and intrusion of rehabilitation appliances.

Whilst in depth qualitative work on body image remains to be conducted in a specific ABI population, some of the themes highlighted (loss of musculature and physique) have parallels with the findings of the present study such as the greater dissatisfaction with muscular strength, physical co-ordination, agility, arms, legs, and reflexes.

Stensman (1989) asked his participants for possible ways to improve body image for the physically disabled. He found that some of the most common answers were; ordinary training, sports for the disabled and being out together with the non-disabled. Social comparison theory states that social comparison can be upward or downward in a positive of negative direction (Dibbs & Yardley, 2003). In both situations social comparison is associated with adjustment (Dibbs & Yardley, 2003), it is possible that ordinary training, sports for the disabled and being out together with non disabled persons (Stensman, 1989) are all methods that can exploit the positive effects of social comparison.

Research suggests that maintenance of physical appearance, in particular grooming and hygiene, were important for a spinal cord injured sample (Dewis, 1989). This is perhaps because such basic activities can be an expression of sexuality (Blackerby, 1999). These findings together with future ABI specific studies could be the start of the development of therapeutic strategies for addressing the body image and sexuality concerns presented by individuals with ABI.

The second area the present study highlighted was significantly lower self esteem in an ABI group compared to a matched control. Fostering personal empowerment is a therapeutic goal for those with ABI advocated by Mateer and Sohlberg (2001). They state that a self mastery and self efficacy approach can be applied to a broad range of therapeutic issues. Psychosocial counselling has been suggested as a method for assisting realistic, positive self evaluation and assertive transactions with others in the community (Ylvisaker, 1998).

Mateer and Sohlberg (2001) further suggest that increasing the individual's sense of responsibility both for self and others, for example volunteering, can help increase social cohesiveness and build self esteem.

The present study provides empirical evidence that for males self esteem and body image are negatively affected following ABI. This suggests that the clinician should be alert to the possibility of negative feelings concerning the self and the body in males following ABI. Further work is needed to understand the meaning and process of these changes in body and self image.

5.1 MALE AND FEMALE BODY IMAGE AND PSYCHOLOGICAL HEALTH POST ABI: A FOLLOW-UP STUDY

5.2 INTRODUCTION

Previous work in this area has investigated body image following stroke. Kreppel & Crowe (2000) found that following a first stroke in young adults, all measures of self esteem correlated with body image. Piotrowski (1982) found that following a stroke women with poor body image were more dependent on others and were more anxious about their illness. The results from both these studies suggested that dissatisfaction with bodily parts and functioning was involved with emotional distress.

In chapter 3 and chapter 4 a number of variables relating to cognitive changes, community living, psychological adjustment and body image were investigated. The results indicated that males with head injuries have significantly lower self esteem and greater body dissatisfaction on a number of items relating to physical and sexual functioning than controls (chapter 3). Significant differences between stroke and TBI groups on these measures were limited to body image differences, which may be explained by differences in age. In a separate study it was found that ABI women had significantly lower self-esteem and greater depression than controls, factors also associated with body image (chapter 4). A generalised concern with health was particularly highlighted as sequelae of acquired brain injury in women.

The purpose of the present study was to explore whether the overall structure of psychological distress and body image concerns, observed in the initial study, were stable over time. At a 1 year follow up were these patterns of body dissatisfaction and psychological distress robust or subject to change? A second objective of the study was to look at the way relationships between variables occurred and to investigate any consistent patterns of response.

5.2 METHOD

5.2.1 *Participants*

The study was initiated after gaining approval from the local research ethics committee. All participants were recruited from the local general hospital. A clinical neuropsychologist referred thirty-eight patients with ABI. Twenty-five men completed the study at time 1; twenty-three men completed the study at a 1 year follow up (termed time 2). Thirteen women completed the study at time 1 of which eleven women were able to complete the study at time 2. Criteria for selection included documented evidence of traumatic brain injury or stroke, time lag since injury of at least 6 months, aged between 18-65, and absence of severe comprehension problems.

Group	Mean Age Time 1	N	Mean Age Time 2	N
Male TBI	33.69 (9.99)	13	33.92 (10.01)	12
Male Stroke	40.50 (15.01)	10	41.80(15.10)	10
Female brain injury	42.64 (12.87)	11	43.82 (12.94)	11

Table 17. Mean ages and standard deviation of participants at time 1 & time 2.

In the male sample thirteen males were identified as having had a TBI and were able to complete the questionnaires, whereas ten males were identified as having had a stroke by their clinical psychologist. The female sample was not large enough to split according to aetiology of injury. However in this heterogeneous group of women, who had completed the questionnaires, seven women had had a TBI and four had had a stroke.

5.2.2 *Ethical Information*

Ethical approval was granted from the Local Research Ethics committee and the University of Wales, Swansea.

5.2.3 *Personal Information*

The women were asked to provide some personal information see 3.2.4. Personal information was obtained from the men in using the same methods as in chapter 4. 2.4.

5.2.4 *Measures*

The assessment measures comprised of 1) disability measures, 2) psychosocial distress measures and 3) body image measures. The women were assessed using the measures described in 3.3.2. The assessment materials used on the male participants are described in chapter 4.3.2.

In addition a new measure was added to the assessment battery on the advice of the clinical neuropsychologist. This new measure is called the dysexecutive questionnaire and is described in detail below.

Dysexecutive Questionnaire (Burgess, Alderman, Wilson, Evans & Emslie 1996).

The dysexecutive questionnaire (DEX) is designed to assess behavioural dysexecutive symptoms. It has been used in the cognitively impaired (Amevia, Phillips & Sala, 2003) and in non-clinical samples (Chan, 2001). The DEX is a 20-item questionnaire that can be given to a ABI person (self) and also to their partner or main carer (other). The participant is asked to read the 20 statements and to rate them according to their personal experience. Each item is scored according to its frequency: from "never" (0 point) to "very often" (4 points).

5.2.5 *Procedure*

The questionnaires themselves were ordered according to a cyclic Latin square design. All instructions were given in verbal format and repeated in a written format on the questionnaires. The experimenter conducted the MMSE and was present throughout the completion of the questionnaires to assist with any comprehension difficulties. The EDI was only given to female participants and the SMBI questionnaire only given to male participants, as each questionnaire addresses the body image concerns specific to each gender.

At the end of the study participants were debriefed and once the results were analysed feedback provided. All data were analysed using the statistical package for social sciences (S.P.S.S). The study was a longitudinal repeated measures design where participants were assessed at baseline (time 1) and at a 1 year follow up (time 2).

5.3 RESULTS

5.3.1 *Significant differences between time 1 and time 2.*

5.3.1.1 *Female differences over time*

Related t-tests were performed between the data collected at time 1 and time 2 for the demographic data, the MMSE scores, the MMSE cut off scores, the BICRO-39, RSE, HADS, EDI, and the body cathexis scale. On all these measures no significant differences were found in the females between time 1 and 2. The women in this study did not show any significant changes in cognitive function, community functioning, psychological functioning and body image over time.

5.3.1.2 *Male TBI differences over time*

Related t-tests were performed for the demographic data, the MMSE scores, the MMSE cut off scores, the BICRO-39, RSE, HADS, MBI and the body cathexis scale. No significant differences were found with any of these measures with the exception of the BICRO-39 and the BCS.

BICRO-39

There was a significant difference between the social scores at time 1 (mean =15.85, SD = 4.00) and the social scores at time 2 (mean= 13.38, SD = 4.09), t (13) = 2.34, p<. 05. The higher the score the greater the difficulties in that area, so social difficulties decreased over the year for the traumatically brain injured males.

BCS

There was a significant difference between satisfaction with reflexes at time 1 (mean = 2.00, SD = 0.82) and satisfaction with reflexes in time 2 (mean = 3.00, SD = 1.25), t (9) = -2. 74, p<. 05. The higher the score the greater the satisfaction with their reflexes, therefore males with TBI have significantly greater satisfaction with their reflexes over time.

Male stroke

Only a single MBI subscale showed a significant change over time.

MBI

There was a significant difference between concern with thinness between time 1 (mean = 15.44, SD =7.91) and time 2 (mean = 18.44, SD = 5.85), t (9) = -.2.60, p<. 05). Concern with thinness increased significantly over time.

5.3.2 *Correlational analyses*

One objective was to look for consistent patterns of variables. Therefore variable were correlated with each other at time 1 and time 2. If a variable is abbreviated in the table, the full variable name appears underneath. Each variable appears without a number at baseline (time 1), but data from time 2 are indicated with a numerical 2 following the abbreviated name.

5.3.3 *Correlates of dysexecutive syndrome*

To assess dysexecutive syndrome, two measures are taken; a "self" rating from the person with ABI and a rating from their closest relative or main carer, which is termed a rating from the "significant other". To assess the impact of dysexecutive syndrome "self" and "other" ratings of dysexecutive were correlated with all other variables, see Tables 18, 19 and 20.

Variable	**Male stroke**	**Male TBI**	**Female**
MMSE cut off	N.S	N.S	R =. 886*
Psychological well being	N.S	R =. 722*	R =. 986***
Psychological well being2	N.S	R =. 721*	R =. 643*
Social2	N.S	N.S	R =. 775**
Mobility	N.S	N.S	R = .771**
Physical staminia	N.S	N.S	R = -.764**
Physical staminia2	N.S	N.S	R = -.797**
Muscular strength2	N.S	N.S	R = - .801**
Energy level	N.S	N.S	R = -.746*
Energy level 2	N.S	N.S	R = -. 682*
Physical condition2	N.S	N.S	R = - .669*
Health2	N.S	N.S	R = -. 950***

Table 18 Significant correlations of DEX Other rating of dysexecutive syndrome: N.S = Non-significant, * p <. 05, ** p <. 01, *** p<. 001, DEX = Dysexecutive syndrome

The results indicate that significant other's ratings of dysexecutive syndrome were significantly related to psychological well being in males with TBI.

In women significant other's ratings of frontal behaviour was significantly related to cognitive and psychological functioning, social and mobility levels and a generalised satisfaction with several body aspects. The body aspects particularly highlighted included physical stamina, muscular strength, energy level, physical condition and health.

These relationships were not significant in the male stroke group. These results highlighted the big differences in the role of other ratings of dysexecutive syndrome between clinical groups; the small number of significant correlations between variables in the TBI group; the large number of significant correlations in the female group and the lack of any significant correlations in the stroke group. These findings indicate that these relationships do not show a uniform pattern and are certainly not the same for every person with ABI. The clear differences between groups provide some support for the validity of the data, that each group has a particular pattern of concerns and that nature of injury and gender affect the profile of statistical results.

In addition to the rating of dysexecutive behaviour taken from the "significant other" a further rating of the persons own assessment of their dysexecutive behaviour was taken. To assess the impact of "self" ratings of dysexecutive behaviour on the overall functioning and psychological health of the person with ABI, this variable was correlated with all other measures for all three groups.

Variable	**Male stroke**	**Male TBI**	**Female**
Psychological wellbeing	N.S	N.S	R =. 710*
Psychological wellbeing2	R = 765*	R = 691*	R =. 680*
Anxiety	N.S	R = .781*	R = .869**
Anxiety	N.S	R = .681*	R = .777*
Depression	N.S	R = .782*	R =. 761*
Depression	R = .757*	R = .707*	R =. 678
Energy level	N.S	R = -.695*	N.S
Energy level2	N.S	R = -.680*	N.S
Arms	N.S	R = -.765*	N.S
Arms 2	N.S	R = -.827	N.S
Physique2	N.S	R = - .793**	N.S
Sex drive	N.S	R = -.668*	N.S
Sex organs	N.S	R = -.743*	N.S
Stomach2	R = -.832*	N.S	N.S
Health2	N.S	R = -. 811**	R =-.525*
Sex activities	N.S	R = -.871***	N.S
Sex activties2	N.S	R= -.679*	N.S

Table 19. Significant correlations of Self ratings of dysexecutive syndrome: N.S = Non-significant, * p <. 05, ** p <. 01, *** p<. 001

The results of this study suggested that greater self reported frontal behaviour is associated with poorer psychological functioning, poor general male body image and sexual satisfaction in the TBI group but this pattern was not repeated in the stroke group.

In the female group greater self-rated frontal behaviour was associated with poorer psychological health and greater dissatisfaction with health. To explore whether this clear dissociation between male groups according to nature of injury was an affect of age, further correlations were carried out controlling for age (Table 20).

Variable	**Male Stroke**	**Male TBI**	**Female**
Psychological wellbeing	N.S	R = .919*	R =. 709*
Anxiety	N.S	R = .897**	R = .879**
Anxiety2	N.S	N.S	R = .786*
Depression	N.S	R = .821*	R =. 868**
Depression2	N.S	R = .707*	N.S
Arms 2	N.S	R = -.882*	N.S
Physique2	N.S	R = - .882**	N.S
Stomach2	R = -.832*	N.S	N.S
Health2	N.S	R = -. 766*	N.S
Sex activities	N.S	R = -.871***	N.S

Table 20. Significant correlations of Self-ratings of dysexecutive syndrome partialed out for age: N.S = Non-significant, * = p <. 05, ** = p <. 01, *** = p<. 001.

The results suggested that some significant effects might be a result of age as several effects were no longer observed (for example differences in energy level or satisfaction with sex drive and sex organs). However this explanation only accounts for a small amount of the interrelationships, because the effects observed in Table 19 are on the whole repeated in Table 20. Psychological well-being, depression and anxiety were associated with self rating of dysexecutive syndrome in TBI males. In addition self rating of dysexecutive behaviour was associated with satisfaction with sexual activities at time 1 and satisfaction with arms, physique and health at time 2 for TBI males.

For females, psychological well-being, anxiety and depression were related to self ratings of dysexecutive behaviour, a similar pattern to TBI males. However the association between body part satisfaction and self ratings of frontal behaviour was not significant. The stroke group did not show any of the significant interrelationships that the other groups did; the sole significant correlation was a relationship between self ratings of frontal behaviour and satisfaction with the stomach at time 2.

This is the first real evidence of clear differences between injury groups. The type of injury seems to have a profound effect on other and self ratings of frontal behaviour and the corresponding relationships with other variables. It seems that other's ratings of dysexecutive syndrome were more significant for females, showing a relationship with cognitive, affect, social, mobility and body image scores. Other's ratings of frontal behaviour had a minimal effect on other variables in the TBI group and none of the relationships observed in the other two groups were significant for the stroke group.

The self ratings of frontal behaviour were most significant for the TBI group, showing interrelationships with psychological well-being/affect and body image, even when age was partialed out. The stroke group showed a relationship between self ratings of dysexecutive syndrome and body image. The female group showed a positive correlation between self ratings of dysexecutive syndrome and affect, indicating that those with dysexecutive syndrome may be at greater risk of anxiety and depression.

5.3.4 *Correlates of socialisation variables*

To assess the impact of ABI on social functioning over time multiple correlations were carried out. Correlations of social functioning at time 1 were conducted for all three groups and this was repeated at time 2. To assess the role of a partner in functioning and psychological health post injury, contact with a partner at time 1 was correlated with all measures and this was repeated for the time 2 data.

Variable	**Male stroke**	**Male TBI**	**Female**
Partner	R = .647*	R = .647*	N.S
Partner2	R = .721*	R = .721*	N.S
Social2	R = .559*	N.S	R = .777**
Mobility	N.S	N.S	R = .709*
Mobility2	N.S	N.S	R = .684*
Sex drive	N.S	R = -.774**	N.S
Sex activities	N.S	R = -.634*	N.S

Table 21. Significant correlations of Social Functioning time 1: N.S = Non-significant, * = p <. 05, ** = p <. 01, *** = p<. 001

In the stroke group greater social difficulties were associated with less contact with a partner at time 1 and time 2; it was also associated with poorer social functioning at time 2. In the TBI group greater social difficulties were associated with less contact with a partner, and greater sexual dissatisfaction. In the female group greater social difficulties at time 1 was associated with greater mobility difficulties at time 1 and 2 and greater social difficulties at time 2.

Variable	**Male stroke**	**Male TBI**	**Female**
DEX Other	N.S	N.S	R = .775**
Depression2	N.S	N.S	R = .786**
Mobility	N.S	N.S	R = .657*
Mobility2	R = .585*	N.S	N.S
Partner2	R = .556*	N.S	N.S
Social	R = .559*	N.S	R = .777**
Employment	R = .565	N.S	R = .621*
Sex activities2	N.S	R =-.649*	R = -.756**

Table 22. Significant correlations of Social Functioning time 2: N.S = Non-significant, * = p <. 05, ** = p <. 01, *** = p<. 001. NB: DEX = Dysexecutive syndrome.

For male stroke patients' social difficulties at time 2 are associated with mobility difficulties at time 2, employment difficulties at time 1, less contact with a partner at time 2 and social difficulties at time 1. For the male TBI group social difficulties at time 2 were associated with greater dissatisfaction with sexual activities.

In the female group greater social difficulties at time 2 were associated with greater other rating of dysexecutive syndrome and greater depression scores at time 2. Greater social difficulties at time 2 were associated with greater mobility difficulties at time 1, greater employment difficulties and decreased satisfaction with sex activities.

Variable	**Male TBI**	**Male Stroke**	**Female**
Partner 2	R = .902***	R =. 883***	R = .656*
Parent	R = -.807***	R = -.781**	N.S
Parent2	R = -.868***	N.S	N.S
Social	R = .774**	R =. 647*	N.S
Employment2	R = .598*	N.S	N.S
Mobility	N.S	N.S	R = -.614*
Energy level	N.S	N.S	R = .628*
Energy level 2	N.S	N.S	R = .616*
Sex drive	N.S	R = -.675*	N.S
Health2	N.S	N.S	R = .657*

Table 23. Significant correlations of Contact with a Partner time 1
: N.S = Non-significant, * = p <. 05, ** = p <. 01, *** = p<. 001.

The results indicated that for male TBI participant's contact with a partner in time 1 was associated with contact with a partner in time 2; greater contact with a partner was associated with less contact with parents. Lack of contact with a partner was associated with greater social and employment difficulties.

The results indicated that for the male stroke group, greater contact with a partner at time 1 was associated with greater contact with a partner at time 2. Greater contact with a partner was associated with greater social activity but less contact with parents. In addition lack of contact with a partner was associated with less satisfaction with their sex drive.

In the female group lack of contact with a partner was associated with less mobility difficulties. Lack of contact with a partner was associated with greater satisfaction with energy levels and health.

Variable	**Male TBI**	**Male Stroke**	**Female**
Partner	R = .920***	R =. 883***	R = .656*
Parent	R = -.621*	R =-.710*	N.S
Parent2	R = -.666*	N.S	N.S
Social	R = .885**	R =. 721*	N.S
Social2	R =. 556*	N.S	N.S
Sex drive	N.S	R =-.797*	N.S
Health2	N.S	N.S	R =. 777*

Table 24. Significant correlations of Contact with a Partner time 2: N.S = Non-significant, * = p <. 05, ** = p <. 01, *** = p<. 001.

For the male TBI group the results showed that contact with a partner at time 1 was correlated with contact with a partner at time 2. Lack of contact with contact with a partner at time 2 was associated with less social activity at time 2. Greater contact with a partner at time 2 was associated with less contact with a parent at time 2. The results for the male stroke group indicated that lack of contact with a partner at time 2 was associated with less social activity. The results indicated that lack of contact with a partner at time 2 was associated with less satisfaction with their sex drive.

The results from the female group indicated that greater contact with a partner is associated with less dissatisfaction with health. The results from the correlates of socialisation highlight the role of the partner and a social life on many variables. The results suggested that having regular contact with a partner is important for social life, activities of daily living (particularly employment and mobility), and body image (especially sex drive, energy levels and health).

There also exists an inverse relationship between contact with parents and a partner. The correlates of social activity showed that interrelationships with a partner, mobility, employment and sexual activities are significant.

5.3.5 Correlates of affect

To assess the impact of anxiety and depression on functioning, these variables were correlated with all other measures, for all three groups, at times 1 and 2.

Variable	**Male stroke**	**Male TBI**	**Female**
DEX Self	N.S	R = .783**	R = .869**
DEX 2 point	N.S	N.S	R = .976***
Psychological well being	R =. 649*	R = .578*	R = .607*
Psychological well being2	N.S	R= .722**	N.S
Self esteem	N.S	N.S	R = .605**
Self esteem2	N.S	R = .785***	R =. 663*
Anxiety2	R =. 725*	R = .679*	R = .810*
Depression	N.S	R = .557*	R = .522*
Depression2	N.S	R = .666*	N.S
Appetite	N.S	R = .590*	N.S
Appetite2	N.S	N.S	R = .661*
Biceps	N.S	R = -.569*	N.S
Body build2	N.S	R = -.619*	N.S

Table 25. Significant correlations of Anxiety scores at time 1: N.S = Non-significant, * = p <. 05, ** = p <. 01, *** = p<. 001. DEX = Dysexecutive Syndrome.

The results indicated that for the male stroke group anxiety was associated with poor psychological functioning at time 1, and anxiety at time 2.

For the male TBI group time 1 anxiety was associated with DEX self rating of frontal behaviour, poor psychological well being at times 1 and 2, low self esteem at time 2, anxiety at time 2, depression at times 1 and time 2, satisfaction with appetite and low satisfaction with biceps and body build.

For the female anxiety scores at time 1 were associated with greater DEX self rating of frontal behaviour, a 2 point difference between self and significant other rating of dysexecutive syndrome and poor psychological functioning at time 1. Greater anxiety scores at time 1 were also associated with low self esteem at time 1 and time 2, anxiety at time 2, depression at time 1 satisfaction with appetite.

Variable	Male stroke	Male TBI	Female
DEX self	N.S	R = .681*	R =. 777***
DEX 2 point	N.S	N.S	R = .853**
Self organisation2	N.S	N.S	R = .656*
Psychological well being	R = .702*	R = .578*	R = .649*
Psychological wellbeing2	N.S	R = .792***	R = .780*
Self esteem	R = .725*	N.S	N.S
Self esteem2	N.S	N.S	R = .922***
Anxiety	R = .725*	R = .679*	R = .810**
Depression	R = .764*	N.S	R = .830*
Depression2	N.S	R = .675*	N.S
Biceps	N.S	R = -.731**	N.S
Body build2	N.S	R = -.758**	N.S

Table 26. Significant correlations of Anxiety scores at time 2.: N.S = Non-significant, * = p <. 05, ** = p <. 01, *** = p<. 001.DEX = Dysexecutive Syndrome.

The results showed that for the stroke group anxiety at time 2 was associated with psychological well being, low self esteem self esteem, anxiety and depression at time 1. In the male TBI group anxiety at time 2 was associated with DEX self ratings of frontal behaviour, psychological well-being at time 1 and 2 and anxiety and depression at time 1. In the male stroke group anxiety at time 2 was also associated greater dissatisfaction with biceps and body build at time 1.

The results indicated that for females, anxiety at time 2 was associated with DEX self ratings of frontal behaviour, DEX 2 point gap between self and other rating of frontal behaviour and self organisation difficulties. The results also indicated that anxiety at time 2 was associated with poor psychological well being, self esteem, anxiety and depression.

Variable	Male stroke	Male TBI	Female
DEX Self	N.S	R = .782**	R = .761*
DEX 2 point	N.S	N.S	R = .842**
MMSE Cut off	R = .655*	N.S	N.S
Self organisatio2	N.S	N.S	R = .687*
Employment2	N.S	R = -.722**	N.S
Anxiety	N.S	N.S	R = .522*
Anxiety2	R = .764**	N.S	R = .830**
Depression2	R = .693*	N.S	R =. 698*
Psychological wellbeing	N.S	N.S	R = .687**
Psy-wellbeing2	N.S	N.S	R = .790**
Self esteem	N.S	N.S	R = .717***
Self esteem2	N.S	R = .629*	R = .749*
Fat concern1	R = .690*	N.S	N.A
Fat concern2	R = .702*	N.S	N.A

Table 27. Significant correlations of Depression scores at time 1 : N.S = Non-significant, * = p <. 05, ** = p <. 01, *** = p<. 001.

The results indicated that male stroke patient's depression scores were associated with cognitive cut off scores, anxiety and depression at time 2 and fat concern at time 1 and 2. The results indicated that TBI male depression scores at time 1 were associated with ratings of dysexecutive syndrome, employment at time 1 and self esteem at time 1. The results indicated that female depression scores at time 1 were associated with dysexecutive syndrome, self organisation difficulties, depression at time 2, anxiety, poor psychological functioning and low self esteem at times 1 and 2.

Variable	**Male stroke**	**Male TBI**	**Female**
DEX Self	R = .757*	R = .707*	R = .678*
MMSE Cut off	R = .636*	N.S	R =. 760*
Self organisation2	N.S	N.S	R = .749**
Social2	N.S	N.S	R =. 786**
Depression	R = .693*	N.S	R = .698*
Anxiety	N.S	R = .666*	N.S
Anxiety2	N.S	R = .675*	N.S
Self esteem	R = .653*	N.S	N.S
Self esteem2	N.S	R = .701*	N.S
Psychological wellbeing2	N.S	R = .569*	N.S
Body dissatisfaction	N.A	N.A	R = -.718*

Table 28. Significant correlations of Depression scores at time 2.: N.A = Not applicable, N.S = Non-significant, * = p <. 05, ** = p <. 01, *** = p<. 001, DEX = Dysexecutive syndrome.

The depression scores at time 2 indicate that male stroke patient's depression scores were related to dysexecutive syndrome, cognitive cut-off scores, self esteem at time 1 and depression at time1. Male TBI patient's time 2 depression scores are associated with self ratings of dysexecutive syndrome, anxiety and self esteem and psychological well being at times 1 and time 2.

The female depression scores at time 2 were correlated with dysexecutive syndrome, cognitive functioning, social functioning, depression, low self esteem and body dissatisfaction. The female group showed many significant correlations between depression scores at times 1 and 2; and dissatisfaction with body parts.

Variable	Depression Time 1	Depression Time 2
Appetite	R = -.758**	N.S
Physical stamina	N.S	R = -.666*
Physical staminia2	N.S	R = -.819**
Muscular strength2	R = -.647*	R = -.785**
Physical co-ordination	N.S	R = -.771**
Arms2	N.S	R = -.628*
Breasts2	R = -.662*	N.S
Sex organs2	N.S	R = -.709*
Health	R =-.688*	R = -.382*
Health2	N.S	R = -.619*
Face	R =-.693*	N.S

Table 29. Significant correlations of Female Depression scores correlated with body cathexis scores.: N.S = Non-significant, * = p <. 05, ** = p <. 01, *** = p<. 001.

The results show that depression is heavily associated with poor body image in women with ABI. Depression seems to be particularly associated with low satisfaction with physical stamina, muscular strength, and health and sexual activities.

The male stroke group had a significant negative correlation between depression at time 2 and satisfaction with sex organs at time 1 (r= -.713, p<. 05) and time 2 (r =-.693, p<. 05).

The male TBI group had significant negative correlations between depression at time 1 and satisfaction with appetite (r = .714,p<. 05) and face (r= .707,p<. 01) at time 2. The TBI group had significant negative correlations between depression at time 2 and satisfaction with energy at time 1(r = -.694,p<. 01), arms at time 2 (r = -.626,p<. 05), and sexual activities at time 2 (r = -.630, p<. 05).

The correlates of affect appear to suggest that psychological well-being, anxiety and depression are consistently related. The relationship between self ratings of dysexecutive syndrome and depression is consistent, showing a significant positive correlation in the TBI male group and female group at time 1, and all groups at time 2.

The relationship between affect and body image also seems consistent but shows different manifestations in the three groups. In the male group there was a relationship between anxiety and dissatisfaction with biceps and body build. In the stroke group there was a relationship between depression and fat concern at time 1, but not at time 2. In the male TBI group a relationship between depression and satisfaction with several body parts on the BCS. In the female group depression was related to body dissatisfaction on the EDI subscale and a range of body parts on the BCS. In particular satisfaction with physical stamina, muscular strength and health were consistently correlated with depression.

The overall picture from the longitudinal data is that for all three groups, there are remarkably few changes at a one year follow up, in terms of poor body image and psychological distress. The results of the correlational analyses suggest a pronounced difference in dysexecutive syndrome ratings (self and other) between stroke and TBI in male patients, which warrants further investigation. This dichotomy may be present in the female group, a larger sample size may be able to split female groups according to aetiology of injury and thus examine if this effect exists for both sexes.
The importance of socialisation variables in recovery is highlighted. The correlation between self reported dysexecutive syndrome and depression again suggests further research is warranted, especially considering the spurious effect of multiple correlations. The relationship between body image and affect is a consistent theme that was expressed in different patterns for all three groups.

5.4 DISCUSSION

The aim of this study was to replicate findings of chapter 3 and 4 that found that body image and affect appeared adversely affected following acquired brain injury when compared to matched controls. In chapter 4 it was found that body image satisfaction in the areas of physical and sexual functioning decreased in males with ABI . Self esteem decreased in males following stroke and TBI . In chapter 3 females body image changed with a new focus on health, and self-esteem and depression was significantly negatively affected following ABI. This work replicated and extended earlier work by Kreppel & Crowe (2000) who found that in a retrospective study body image and self esteem were negatively affected following TBI.

The present study looked at significant differences in a repeated measures design, at the 1 year follow up, for each clinical group. The results also looked at correlations between those variables over time.

The lack of any significant differences between scores on any of the measures between time 1 and time 2 for the female data, and relatively few significant differences in the male data suggested that these profiles of body dissatisfaction and psychological distress are relatively stable over time.

That body dissatisfaction and psychological distress are relatively pervasive is concerning as it has been previously established that individuals with brain injuries are at risk of body dissatisfaction and psychological distress (Kreppel & Crowe, 2000, Piotrowski, 1982, Howes et al in press, see also chapters 3 and 4) and that body dissatisfaction and psychological distress are connected following acquired brain injury (Kreppel & Crowe, 2000, Piotrowski, 1982, Howes et al in press, see also chapters 3 and 4).

In previous studies the measures used had been sensitive enough to pick up fundamental differences between the brain injured and non-brain injured (Howes et al in press, see also chapters 3 and 4). In the present study the same measures, were unable to detect subtle changes over time, using a within subjects repeated measures design. The few significant differences were confined to male groups.

The TBI group showed that social difficulties decreased and satisfaction with reflexes increased over the year indicating that these changes occurred in a positive direction. These improvements could be linked the rehabilitation process, for example the social support provided by the local Headway group and occupational therapy that could improve body image. The change in social functioning is especially interesting as the correlational analyses reveal how social functioning impacts on other variables important in recovery.

Lack of social contact and feelings of isolation have been identified as a consistent problem for individuals with acquired brain injuries (Oddy et al, 1985, Klonoff, Snow & Costa, 1986, Lezak & O'Brien, 1988, Tate, Lulham, Broe, Strettles & Pfaff, 1989, Kwasnicka & Heineman, 1994). The fact that this sample actually improved in levels of social functioning over the 1 year follow up is a real achievement set against these earlier findings. The patients were all attendees of Headway, a British based charitable organisation that provides a day centre for those with acquired brain injuries. In the present sample it served as a central point at which other specialist services can be accessed, such as occupational therapy, psychological services, psychiatric and social services. For the patient it provides a chance to meet with other ABI individuals in a non-threatening and controlled environment. Perhaps most importantly it gives attenders a sense of purpose and routine. Pearson (1986) stated that social supports have been conceptualised as the attributes of socially legitimate roles that provide for the meeting of dependency needs without loss of self esteem. It seems likely that a local Headway group would perform this role and thus may explain the improvement in social functioning observed in this group over time.

The significant difference in satisfaction with reflexes between time 1 and time 2 indicates further change in a positive direction. Using interview data Klonoff, Snow & Costa (1986) found that the most common physical complaints at 2-4 years post injury included limb weakness and reduced strength or power, and suggested that these are evidence of chronicity of dysfunction and residual disability. That the male TBI group showed an improvement in an area that has been previously thought to be one of the most common complaints is evidence that significant positive changes in a seemingly residual disability can occur. The increase in satisfaction with reflexes is further significant because correlational analyses might suggest how body image relates to affect. This finding must additionally be placed in the context of the greater importance of physical functioning in male evaluations of body image (Halliwell and Dittmar, 2003).

The stroke group had a single significant difference between time 1 and time 2; thin concern increased over this time period, indicating a change in a negative direction. This single change was unexpected; if anything given the greater age of the stroke group an expectation of increased fat concern might be expected. This surprising result may be explained by the nature of the brain injury, strokes frequently result in hemiplegia, or muscle plasticity and so perhaps for these individuals muscles may atrophy following injury. This might be a possible explanation for this increased thin concern.

5.4.1 *Correlational analyses*

The addition of a new measure to the original battery of tests and questionnaires proved to be illuminating. The DEX questionnaire, a behavioural measure of dysexecutive syndrome was employed in the time 2 assessment following consultation with a neuropsychologist. Executive function is an umbrella term covering cognitive functions of the highest order including organising, ordering and integrating thoughts and experiences. The clinical symptoms that a patient might display are impatience, rigid repetitive behaviour, inappropriate behaviour and inability to cope with change. In addition the patients family might perceive them to be irritable, lazy and lacking in motivation as a result of dysexecutive syndrome.

Results indicate that using this new measure of dysexecutive syndrome clear dissociations are visible between the stroke group and the TBI groups. These significant differences were something that was not highlighted in the initial study, except in the realms of body image differences, which could feasibly be explained other variables such as age differences (which just failed to reach statistical significance).

Dysexecutive syndrome seems more significant for the TBI group, showing a number of significant correlations between this measure and other variables. The dissociation on dysexecutive syndrome could be due to the nature of injury. Strokes are more likely to cause focal injuries around the temporal and parietal lobes, for example resulting in specific deficits of language or visual agnosias. However the pattern of injury in traumatic injury is more likely to involve the frontal lobes as result of impact on the skull as a result of *coup* and *contra coup* injury (Mateer & Sohlberg, 2002).

The importance of other ratings of dysexecutive syndrome showed a dissociation between male and female clinical groups. Significant others rating of dysexecutive syndrome correlated with many variables for the female group but not for the male groups. One explanation is that the female significant others were more accurate, or truthful in their ratings of dysexecutive syndrome and therefore there were more significant correlations with other outcome measures in this group. However the DEX asks about the individual's personal experience so this should not be a legitimate explanation. Another explanation is that the female participants were more '"in tune" with their significant other and thus the greater number of significant other's correlates of dysexecutive function, however, due to the small sample size and multiple single correlations this finding requires further investigation.

It is perhaps not surprising that the TBI group shows more evidence of dysexecutive syndrome, which is associated with frontal lobe damage. The pattern of significant results suggest that self rating of dysexecutive syndrome was related to a wide variety of psychosocial indexes such as psychological well being, anxiety, depression and male body and sexual satisfaction. These effects were repeated on the whole, even when age was partialed out. This would suggest that dysexecutive syndrome has an impact on many other variables, which need to be taken into consideration in rehabilitation. The results suggest given this knowledge clinicians should be vigilant for any self or other reported signs of dysexecutive syndrome in TBI groups.

The results of the correlates of socialisation highlight the important role a partner plays in many aspects of life post injury. Regular contact with a partner is implicated in social activity, mobility, and employment as measured using the BICRO-39 (a specific measure for use with acquired brain injuries). Using a non-specific measure (Sickness Impact Profile, Bergner, Bobbitt, Pollard, Martin & Gilson, 1976), similar results were found assessing closed ABI 2 - 4 years post injury (Klonoff, Snow & Costa, 1986). Klonoff et al (1986) found that the primary areas of residual impairment were psychosocial functioning, social role functioning and recreation and leisure activities. The present study both replicates and extends these findings by suggesting the important role a partner plays in generalised improvement in social outcome.

In the present study contact with a partner also correlated with patient's satisfaction with energy levels, health and sex drive. The importance of contact with a partner for satisfaction with intimate body image areas such as energy levels, health and sex drive shows again how important relationship status is for all round well being post injury.

Previous work on relationships and cerebral tumours suggests differences in outcome in married versus single patients (Kaplan & Minor, 2000). The authors suggested that having a partner contributed to adaptation and provided meaning to life, patients may feel more secure in a committed relationship and less threatened by changes in physical appearance and inability to work than unmarried patients.
It seems reasonable that these observations could explain the improved social outcome and body image in the ABI patients with partners, observed in the present study.

Lezak & O'Brien (1988) found that problems with significant relationships were evident in 22% to 36% of patients in a 5 year follow up study. McCelland (1988) noted high rates of marital breakdown following ABI. The present results suggest that in the arena of socialization and intimate body image, those with a partner would be expected to have a better outcome. Adequate support to maintain existing relationships and establish new ones seems paramount, especially set against existing research which suggests that there is no indication that relationship problems improve spontaneously (Lezak & O'Brien, 1988).

The inverse relationship between contact with a partner and parents may reflect the schism in care giving responsibilities. The relative youth of many who sustain an acquired brain injury is reflected in the fact that many are living with parents at the time of injury. In addition the injury often occurs before lasting attachments with a significant other have formed. The core problems of neurological impairment render the adolescent or young adult socially dependent on their parents (Lezak, 1988). Given the comparatively better outcome of socialization of those with a partner, those living with their parents may form a group who have greater needs and thus require additional targeted social support.

Levels of social contact correlated with contact with a partner, levels of mobility/employment and satisfaction with sexual activity. Again the importance of socialisation for activities of daily living and sexual satisfaction can be seen.

The results of the correlates of affect show that psychological well being, anxiety and depression consistently occur together. Robson (1988) had previously stated that low self esteem has been linked to depression and anxiety in the clinical literature and these relationships have been observed in non-clinical samples (chapters 3 and 4).

The relationship between the self reported symptoms of dysexecutive syndrome and depression was consistent. This positive correlation was present for the male TBI group and the female group at time 1. At time 2 all groups had a significant positive correlation between dysexecutive syndrome and depression. It is important to place the findings in the context of multiple simple correlations, some of which may be spuriously significant. However the consistency of the correlation between dysexecutive syndrome and depression for all groups certainly warrants further investigation. The results suggest that those who have greater reported dysexecutive syndrome may be at greater risk of depression following acquired brain injury. Regular screening for depression in those with dysexecutive syndrome would be suggested.

The correlates of affect suggest that affect and body image are correlated in all clinical groups but that these relationships are different. The male TBI group showed a correlation between anxiety and satisfaction with biceps and body build. Depression was also correlated with satisfaction with a range of body parts (appetite, face, energy level, arms, sex activities) for TBI males. These findings support work done with stroke survivors (Kreppel & Crowe, 2000) that found that body image and psycho-emotional health are related following acquired brain injury. This work extends previous work by showing that these relationships exist in male TBI groups as well as following stroke.

Male stroke patients showed a relationship between depression at time 1 and fat concern. This is interesting because it was this group that also showed a significant increase in thin concern over time. This seems to confirm earlier work by Drewonski & Lee (1987) and Silbertstein, Striegel-Moore, Timko & Rodin (1988) that male body image concerns are split between those who wish to lose weight and those who wish to gain. It seems that in the stroke group both thin concern and fat concern are relevant, and that fat concern is implicated in depression for this group.

Satisfaction with sex organs correlated negatively with depression at both time points, this confirms earlier reports that sexuality is of uppermost importance to men (Aboni, Keren & Cohen, 1999) but extends this by highlighting it's possible significance for those who are affected by stroke and TBI.

Taking the results of the male stroke and TBI groups together it seems that poor body image is related to depression following acquired brain injury. The importance of sexual functioning for psycho-emotional health in these male groups is particularly highlighted. This is of some concern as these are precisely the areas that are likely to get over looked in rehabilitation strategies (Kreppel & Crowe, 2000). The study would suggest that attempts to tackle poor body image and sexuality would be likely to be beneficial.

In the female group two different measures of body dissatisfaction (BCS, EDI) correlated with depression, which would lend support to the reliability of these findings. Whilst the EDI has body dissatisfaction as a single construct, the BCS highlighted several body areas (appetite, muscular strength, breasts, face, physical stamina, physical co- ordination, sexual organs, and health). Satisfaction with muscular strength and health were the most consistent over time. This supports earlier work that has emphasised the importance of health variables following ABI for psychological well being in women (chapter 3).

5.42 *Conclusion*

The results from the related t-tests show that on the whole the pattern of body dissatisfaction and psycho-emotional distress observed at time 1 are in the main repeated at time 2. There were important improvements in socialisation and body image in the male TBI group showing that gradual improvements in residual disabilities can and do take place. The male stroke group showed an increase in thin concern over time.

The female ABI group showed no change on any of the measures. However due to the lesser incidence of females affected by ABI, the present study used a small and heterogeneous sample. A future study might be able to split the female group according to aetiology.

The correlational analyses highlighted three areas; correlates of dysexecutive function, correlates of socialization and correlates of affect. The male groups showed dissociation on correlates of self rated dysexecutive syndrome, suggesting that this has an impact the lives of the TBI group to a greater extent than the stroke group. The female group showed the greatest number of correlates with the significant other's rating of dysexecutive syndrome, something that warrants further investigation, as it was a small and heterogeneous sample.

The correlates of socialisation indicate the important role a partner, or lack of one has post injury. The relatively better outcome on those with a partner suggests support should be targeted at maintaining existing relationships. Those without partners may be at greater risk of social isolation, again suggesting targeted social support for this group.

The correlates of affect highlight how anxiety, depression, and low self esteem occur together in these samples of adults with acquired brain injuries. Self rated dysexecutive syndrome correlated with depression in all three groups, suggesting therapists should regularly screen for depression in those who score highly on self rated dysexecutive syndrome.

The correlation of poor body image and depression was evident in all three groups although it was expressed in different ways, suggesting targeted therapeutic work, as outlined in chapters 3 and 4.

WOMEN'S EXPERINCE OF ABI: AN INTERPRETATIVE PHENEMOLOGICAL ANALYSIS[3]

6.1 INTRODUCTION

Krefting (1989) commented that previous research on brain injury has concentrated on two approaches. The first approach to consider is outcome after ABI. One example of this is the neurosurgical approach that counts the survival rates; another is the Glasgow Outcome Scale (Jennett & Boyd, 1980) that uses a 5-point scale (good recovery, moderate recovery, severe disability, persistent vegetative state, and dead). The second approach is to use formal test batteries that concentrate on one or two aspects of ABI. Much of this type of research has focused on cognitive deficits assessed using neuropsychological tests. Although there has been less emphasis on the broader spectrum of psychosocial change (McKinley et al, 1981) attempts at investigating these more complex psycho-social sequelae have relied on " objective accounts" from a third person. Cognitive deficits and a lack of insight have justified much of the research from the relative or carer's perspective (Thomsen, 1974).

As the severity of the damage increases, it is thought that the capacity for self-awareness decreases (Lezak, 1998) and Fordyce (1986) highlighted a tendency to minimize or deny dysfunction. Such findings have contributed to the generation of studies that take account the relatives perspective (Prigatano et al (1986b) or the clinicians perspective (Lezak, 1978).

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[3] A version of this chapter has been accepted for publication and is currently in press at Psychology & Health.

It has been argued that these accounts are more objective. However, recently such accounts have been criticised for seeing the views of individuals with ABI as less important than the views of the medical professionals who seek to understand ABI (Judd & Wilson, 1999).

Whilst it might be true that relatives, staff and the brain-injured people themselves have different perspectives about the nature and magnitude of brain injury (Fordyce, 1986) it also true that the ABI person's own perspective had been sadly neglected (Tyerman et al, 1984). Many survivors report fervent feelings of the experience that outweigh the physical changes in their bodies and they lack understanding about the event (Russell, 2001). Tyerman and Humphrey (1984) suggested that even though accurate self-appraisal is limited, the subjective impairment is the reality for these patients. A person's subjective experience provides important information to the researcher and the therapist. An individual's conscious experience provides an indication of what is required to help them understand better their reaction to their illness, thus guiding therapy and facilitating the adjustment process (Prigatano, 1997). Furthermore women's experience of brain injury is often neglected because of the greater incidence of males with TBI. However, if the male to female ratio is 2:1 and 1 million are affected per annum (Teasdale, 1995) then 330,000 women are affected each year. Not a single qualitative paper taking account of the female perspective exists in the literature.

This study adopted the position of Tyerman & Humphrey's (1984) that research "should be seen through the eyes of the head injured person as well as her closest associates." Qualitative research operates on the micro-level trying to capture a particular individual's beliefs and responses.

Moustakas (1994) stated that a common characteristic of human scientific research is that it studies human experiences that are not approachable through quantitative approaches. He suggested that you could search for meaning by obtaining descriptions of experiences through first person accounts in informal conversations and interviews. A logical positivist would take the position that you would uncover a factual record and a person's responses could be independently verified for accuracy.

A phenomenological perspective believes that there is some relationship between what the person says and the beliefs he or she holds. IPA is concerned with an individual's personal perception or account of an object or event as opposed to an attempt to produce an objective statement of the object or event itself. This type of qualitative research examines a smaller sample of respondents who have a greater similarity of characteristics such as age, gender and health situation.
Previous research examples include those waiting genetic testing (Smith, Michie, Allanson & Elwy, 1996), women in their first pregnancy (Smith, 1999), and patient's experience of haemodialysis (Smith, 1996). This method uses semi-structured interviews to explore in greater detail how the individual responds to a particular topic. The purpose of using IPA is to provide a richer account of how the person is thinking about and dealing with a complex and ongoing health situation. Therefore this study used IPA (Smith, 1996) to investigate the experience of acquired brain injury "through the eyes of the head injured person" (Tyerman & Humphrey, 1984).

METHOD

6.2.1 *Participants*

A convenience sample of women who had received a TBI more than 6 months before the injury was used from referrals made by a Clinical Neuropsychologist at a district general hospital. The participants were aged between 30-51 years, with a mean age of 37 years. The study was a cross sectional design in that the women were represented in two clusters, those who had recently been injured (7 months, 1 year and 1 month, and 1 year and 5 months) and those whose injury was several years ago (5 years, 8 years and 3 months, and 15 years ago). Two of the women were in relationships and four of the women were single. See Table 29, for descriptive statistics, all names have been changed to protect the identity of the women who took part.

Name	Age	Injury	Severity GCS	Time Since Injury (yrs/mths)	Highest Ed.Level	Previous SES	Present SES
Lauren	30	TBI	Mild	0.7	Degree	B	B
Heather	51	TBI	Severe	1.5	A-level	C1	C1
Amy	31	TBI	Moderate	1.1	Degree	B	Unknown
Melody	34	TBI/Other	Mild	5	A-level	C2	Unknown
Claire	42	TBI	Severe	8.3	GCSE /O-level	C2	D
Sophie	36	TBI	Severe	15	GCSE /O-levels	C1	D

Table 30. Descriptive Statistics of Participants;

NB: GSC = Glasgow Coma Score, Ed = Educational, SES = Socioeconomic status; Socio-economic information at initial interview. Socio-economic status classified according to the Market Research Society 2003; B= professional, C1 = white collar, C2 = skilled manual worker, D = semi-skilled/ unskilled manual worker.

All the women had received a moderate to severe traumatic brain injury, except one who had hydrocephalus and TBI. Severity of injury was classified according to period of posttraumatic injury and the Glasgow Coma Scale (Teasdale, Jones & Van der Sande, 1978).

6.2.2 *Interview schedule*

The interviews were semi-structured with five broad questions used to facilitate further discussion. The interview schedule outlines the areas of interest, but it was not prescriptive and allowed for further probing of any areas of interest as they developed.

1. How do you feel in yourself since you had your head injury?
2. Have you noticed anything that has changed for you since you had your head injury?
3. What has been most helpful to you since you had your injury?
4. What has been less helpful?
5. How would you describe your experience to a recently head injured person?

6.2.3 *Data Collection*

A patient's information sheet was provided, along with the opportunity to discuss any queries with a researcher. All the women approached agreed to take part on the basis of informed consent and were interviewed in a private consultation at the hospital from which they were referred. Patients were asked to complete a patient consent form and to provide basic socio-demographic information. Face-to-face interviews were recorded on a tape recorder and then transcribed verbatim. The University of Wales, Swansea and the Local Research Ethics Committees gave full ethical approval. The women were interviewed at two different time points, each a year apart, in order to capture the evolving nature of their experience.

6.2.4 *Analysis*

The interviews were analysed using IPA as described by Smith (1996). The first transcript was looked at in detail, following an idiographic approach to analysis, beginning with particulars and slowly working up to generalisations (Smith et al 1995). The first transcript was read over several times and potentially interesting passages were highlighted. Emerging themes were documented and clustered into potential groups; attention was given to meaning and not just the frequency of a theme. The text was then further reviewed and contrasts and comparisons were made of different narratives, enabling preliminary themes to be drawn out. The data were then clustered into thematic categories enabling the identification of superordinate themes.

The texts were reviewed by an independent rater who produced a table of similar themes. Following discussion of conforming and disconfirming themes, a consensual position was reached that produced a master list of superordinate themes. The study brought up several themes, which can be translated into standardised questionnaires in order to triangulate the findings. Therefore questionnaires of community functioning (BICRO-39), body image (body cathexis, eating disorders inventory) and psycho-emotional health (Rosenberg self esteem, hospital anxiety and depression scale) were administered to the women and this forms part of the methodology for chapters 3 and 5.

6.3 RESULTS

The experience of brain injury seen through the eyes of this sample of women with acquired TBI can be summarised by the following major themes, see appendix III.

- Awareness of Change in Self
- Grief Response
- Searching for Meaning
- Comparisons with Past Selves
- The Reconstructed Self

6.3.1 *Awareness of a Change in Self*

The core theme was the change in self. The women felt somehow different from the way they perceived themselves to be before their injury, they could not grasp what having a ABI would mean for them and what the consequences would be.

> I just feel different somehow and I don't know why or how I'm different but I just know I am. (Heather).

The feeling of being different somehow, is gradually replaced by some insight in to how and why they might be different to the person they felt they were before the ABI. The changes the women identified were represented in three categories; changes in mental or cognitive functioning, physical changes and changes in their experience as social beings. The meaning of the cognitive changes came under the umbrella of mental slowness. The women talked about being slowed down, unable to cope with simple cognitive tasks such as reading a book.

> Concentration is also a big one; I have trouble reading a book. I can read a book but only a chapter at a time, and then I have to have a break because my brain gets too tired. (Melody).

The women felt that because they were talking about mental slowness, the degree to which this was a major disability that interferes with quality of life was trivialised. This experience was echoed by all women and stopped them from carrying out routine activities that they had previously taken for granted.

> I haven't been able to read books from the start, front to back. I can read magazines and short articles, a newspaper. I even find it difficult when I'm reading recipes, I'll read the first bit then I'll skip and I'll just chuck in anything I feel like because I haven't got the concentration to read it. (Lauren).

Another feature of the mental slowing was the accompanying tiredness, because everything was more effortful and draining than it had been before.

> I don't have as much energy as I used to. I get tired far more easily, when I say tired I don't really mean tired I mean exhausted. (Melody).

> I can have weeks upon weeks where I cannot get up before 9 o clock, and then I feel tired all day, almost dizzy, you know a bit like jet lag. (Lauren).

As well as the cognitive changes, physical changes such as difficulties associated with balance and spatial awareness made the body seem more present, it was not functioning as before and felt awkward and clumsy, almost alien.

> I feel light headed.... I will have problems with my balance, my hearing, my vision. I will actually be a danger to myself if I go outside the house. I will fall over things and not be able to judge distances. (Melody).

Any condition that impacts on the physicality of the body, such as having to have assistance with walking, falling or bumping in to things, can lead to negative self image. In a sense these comparatively young women had to learn to deal with an "old body", a body that was clumsy, awkward, and frail.

Despite the physical changes that can be overwhelming to the head injured person, to outsider's ABI can be a disability that is not always obvious. Living with this "hidden disability" can be difficult for the women when out in public.

> When people see me in the street because I blend in so well, they can't see the head injury. They find it hard to sort of say "there's something wrong with you". I mean the only way they can see something's wrong is when something happens.... like two weeks ago.... the colour drained from my face and I felt light-headed. (Melody).

As well as the visibility of changes in body function to others, weight changes were salient and concerning to the women themselves.

> Because I'm less active I have put on a lot of weight, which is very difficult to shift. (Claire).

> I did put on an awful amount of weight by accident and I couldn't get into any of my clothes and that just seemed to me like oh my God, I'm sitting at home doing nothing, achieving nothing, and now I'm a big fat slob. (Lauren).

Because the women became less active as a result of the head injuries, they put on weight, which they found disturbing. Their bodies are in flux and thus their concept of self. The women thought it was their fault they had gained weight and linked it to a lack of activity and eating because of boredom. Feelings of guilt and self-blame were associated with the weight gain.

> To me it's just awful but the more you stay at home the more you're tempted to eat things because you're bored. (Lauren).

> I only went in once or twice a week and did over 50's classes (laughs) just to get a bit of exercise..nothing heavy.. it made me feel better you know..I'd feel great but by 5 o' clock I was just like out of here, I felt so tired..but I've got to the stage now where I don't want to go down there again. (Lauren).

There was a tension between the desire to do something about their weight and the reality of their physical condition, which made physical exercise very tiring. It was almost a catch 22 and untangling this by pacing physical exertion and realistic targeted exercises, could be helpful.

The third aspect of self that the women identified as having changed significantly was as social beings. The women had noticed a decrease in the level of social interaction through loss of work, routine and friends following their injury and perceived this negatively, often feeling isolated and experiencing loneliness.

> I think because I don't see people very often, it's not like when you are out at work every day, when you know you are going to be seeing people. You've always got someone to talk to, there's always someone there, and I've found, I mean I get quite lonely. (Amy).

There was also a change in the dynamics of personal relationships, the balance and perhaps roles seemed to have changed. The women felt at times more like children who had to be looked after, and this brought up complex emotions like guilt and concern for their partners or carers.

> Before I used to be the main wage earner and he probably feels the sense of... he hasn't had the responsibility before, like fathers with new children, they have that sort of responsibility.. but he's never had that so he probably thinks he should be working harder and do things right and all the rest of it. (Lauren).

Therefore support and assistance that enables women to maintain existing relationships and establish new ones is likely to be helpful.

6.3.2 *Grief Response*

Some women reported feelings of frustration and anger that was usually directed at those held responsible in some way for the loss, in this case health professionals.

> He has taken to diagnosing me with a crystal ball. I don't have much time or patience with him. (Melody).

However, some women remained angry or fearful for periods that indicated complicated grief processes. Therefore it is suggested that the anger remaining months post injury is indicative of the women getting stuck at the angry stage because of litigation like circumstances, preventing the women moving on to later reactions, which might be further emotional distress such as anxiety and or depression, or alternatively might be preventing them from starting to look externally, for information and solutions to their residual disabilities.

> Things that didn't ever use to bother me that I used to cope with and never think twice about, now I get really anxious about . It's silly trivial little things that are really just of no significance; I can build them up into real big issues and worry about them. (Amy).

The women's capacity to deal with stress seems diminished, they are unable to get a sense of perspective, worries bubble up, overwhelming them and causing psychological distress. The women have become more vulnerable and are aware of a loss of independence and perhaps strength or resilience that they felt they had before.

> I feel I need a bubble, you know I need a bubble with a very strong shell. I learnt about it in stress management, you have to have a shell; my shell doesn't seem to get very strong these days. (Melody).

> Now that I have had a head injury..I'm not so independent, I can be on the odd day but I need the back up of friends and family to get me through life really." (Melody).

Apart from the recurrent feelings of anxiety and depression, other types of clinical distress such as panic attacks and social phobia were a problem for some, being particularly associated with dealing with big groups of people.

> When we used to go shopping in crowded areas I used to get a bit panicky if I lost sight of my partner. (Claire).

To some extent this fear was rational, as they had prior experience of negative reactions from others. An example of this was mistaking balance problems for being drunk, or others thinking they were 'mad'. This social fear seemed to be connected to the subtle physical effects of these women's brain injury, causing people to have misconceptions about aetiology. The general public's lack of knowledge and understanding about ABI was highlighted.

> It's always that aspect of my mind, they're probably thinking I'm mad, I'm not, but I don't like other people thinking I'm mad. (Melody).

> With my other work colleagues I went away with them for a weekend camping. I just got so down.. I can't explain it.. Anything I said they looked at me like I wasn't there. (Lauren).

6.3.2 *Comparisons with Past Selves*

There was a consistent comparison between past/present/future self in the narratives of the women.

> Before I had the accident I had a high flying job with a lot of responsibility, and confidence had to ooze out of you to get the job done. Ah it's very different, I have my days when I'm not confident at all and I just want to hide away and crawl under a stone. (Lauren).

The building of bridges between past and present selves seems important. There was a need to connect with who they felt they were before the injury, who they were immediately after their injury and who they are now. The women continually used comparisons with these different selves, again this seems to have an adaptive function, the women seem to be saying, 'hey I'm not as well as I was before my injury but I am getting better'.

> I would say that my confidence level has risen. When you look back to just after I had the accident I didn't have the confidence to even talk to anyone on the phone let alone face-to-face or go back to work or anything like that. So it has definitely risen but it's much worse than it was before the accident. (Lauren).

The dynamic quality to recovery is continually emphasised, they can see themselves changing, getting stronger, having a bad day, or a set back.

> I have spells of difficulty where I can't do things I actually want to do, which I class as bad days.. it's just a case of learning to give in to these bad days rather than fighting against them because the more I fight the longer I'm on a bad day. (Melody).

6.3.3 *Making Sense of the New Self*

We are all under the illusion that we have some control in our destiny but the experiences of these women confirms that external control (powerful others/ or chance) can have devastating consequences (especially true in traumatic injury) and thus shatters these illusions. The women were forced to realise that external events could determine the outcome of their lives. It seemed to affect their worldview, they could no longer believe in a just world and this led them to feel vulnerable and insecure. The themes of uncertainty and safety were reflected in the women's narratives.

> I don't really feel safe you know..sort of like.. help get me out of here, I don't feel safe I need to go home. (Melody).

Some of the women appeared not to be able to imagine what their future self might be, and were thus unable to make plans. There may be huge discrepancies between past, present selves, and potential future selves; not planning for the future appears to be a symptom of this.

> I've stopped making plans, if someone asks what I was doing in two months time, I'd say I don't have a clue. (Heather).

Partly this seemed linked to the gaps between their reality and other people's reality and this can be a very frightening and disconcerting experience.

> I personally thought it went really well..but then work suspended me on grounds of not being able to do the job, so there was my perception and their perception and they were completely different.. (Lauren).

> Now it's got to the point where I am sick of people saying to me " oh no you don't look very well". And I look at myself and I think well to me I look ok and then I think maybe I'm not seeing myself properly. (Heather).

A technique that can be used to gain control over the present, and make sense of this experience, make the world seem a safer, more predictable place, is to turn to others who are seen as experts, those able to provide explanations for what is happening.

> She's helped me in terms of telling me who to get in contact with, in terms of general sort of info. (Lauren).

> Half of it's understanding what's going on then you feel heaps better. One of the best things that ever happens is when I was talking to D, and she said take it more easy. And I didn't have a clue, then she drew up a timetable and then I understood how easy I was meant to be taking it. Then things started getting easier, yeah knowing it's normal. (Amy).

> That's why I need to try and get help down different avenues to see what will help. I mean I have alternative therapies, like healing and massage because that helps. It doesn't cure but it helps. (Melody).

However, it was not only medical knowledge that was seen as beneficial. Having dedicated support from health professionals, as good listeners, seems to validate their distress and reassured them that their worst fears were not going to be realised, that is they were not going mad.

> Headway are good because they have been trying to get to the root of the problem, my roots go down a very long way.. just sitting and talking about the problems helps. When you find people who are willing to do that. (Melody).

> J made me realise that I wasn't the only person in the world who was suffering in the way that I was, and that there were lots of other people who had the same or similar problem's to me and there were people who could help. (Amy).

6.3.4 *The Reconstructed Self*

Some of the women were more comfortable with their present self-concept.

> It's recognizing that you can do some things, which is good. As oppose to trying to be like you were before. (Heather).

The women did have to accept some losses as they reconstructed these new identities, losses of jobs, friends, the furniture of their old life.

> The friends that understand are very good, but ones that sort of say "oh I'm not sure about that" well I've learnt they're not really good friends... I don't think they could handle it...I said well that's their loss. (Lauren).

One of the positive lessons that came across was the ability to value life in a different, more meaningful way.

> I value life more. I don't take it for granted. Every time I go out I think..you learn to live for the moment..I think you appreciate things more. (Lauren).

> I'm not the pubbing and clubbing type of girl anymore, I did that when I worked and had the hangovers and that was enough. (Melody).

Took a while because after 15 years one woman wanted to stress;

> You are not completely different, you are still human. (Sophie)

6.4 DISCUSSION

Tyerman et al (1984) found that 72 % of his participants who had suffered an acquired brain injury felt that they have changed as a person. This finding was extended in the present study as the women highlighted the cognitive, physical and social changes as being the most concerning post injury.

The women talked about mental slowing as the most salient but trivialised cognitive change post injury. Van Zomeran (2002) talked of mental slowness following brain injury as being an attentional disorder and highlighted impaired divided attention, slowness of attention processing and impaired supervisory control. This awkwardness and slowing down of the body, as perceived by the women post injury, has parallels with the literature on physicality and ageing. Specifically the literature on older people and falls has produced the concept of a body drop (McKee, 1988), a traumatic event that is perceived as the body letting you down in some way.

It is known that weight is important for self esteem in women (Jackson, Sullivan & Rostker, 1988). It perhaps seemed to the women that not only were their bodies no longer functioning as before but that they were also a different size than prior to their injury.

The women talked of a change in their experience as social beings post injury. Harrell and O'Hara (1991) stated that brain injury does not occur in a vacuum, rather it is one event in a long continuum of life events and its significance must be evaluated within the survivor's social sphere. Ciocca (1995) pointed to a status of social limbo, significant difficulties in interpersonal relationships, and intimacy in marital relationships, were significant sequelae experienced three months to twenty years after brain injury.

Following brain injury there are multiple losses with which to contend; "loss of mobility, loss of weight, loss of continence, loss of role, loss of control, loss of dexterity, loss of vision, loss of sensible thoughts" (Salter, 1997).

The women all talked about experiencing reactions such as anger, depression, anxiety and fear that are all similar to the features of the loss or grieving process (Bowlby, 1969, Stroebe, Hansson, Stroebe & Schut, 2001). Although there has been a debate about the validity of applying grief models to TBI (Wortman & Silver, 1989) recent studies have lent support (Persinger, 1993, Macfarlane, 1999, Meredith & Rassa, 1999 and Raskin & Stein, 2000, Cotezer & Corney, 2001). Compounding the natural loss process any person with an acquired brain injury might be expected to go through, it has been found that women are expected by health professionals to express more grief type emotions and feel greater shame when they become disabled (Westbrook & Chinnery, 1990).

There are two interpretations that can explain the incidence of intense feelings of anger. Firstly that it can reflect the personality of the individual (Parkes, 1998). The second explanation is to do with the circumstances surrounding the loss.

It is suggested that complicated mourning can occur when the circumstances surrounding the loss are unclear (Littlewood, 1992). This view would be supported in the present study; as two women of the women in the recently injured cohort had unresolved circumstances surrounding their injury. One woman was involved in ongoing litigation; the other woman was waiting further medical assessment.

Such unresolved circumstances are problematic, for example in the case of litigation if the decision was unfavourable, feelings of persecution and helplessness could be overwhelming. Research suggests those who were responsible for the accident often develop self-blame and a significant loss of self-esteem (Raskin & Stein, 2000).

In 'normal' grief as time passes anger features less, while episodes of apathy and depression remain (Parkes, 1998). Most women went through periods of anxiety and depression something that has been identified as a key problem for individuals with TBI (Morton & Wehmann, 1995).

In the narratives the women linked these clinical manifestations with social functioning. Hahn (1986) stated, "attitudinal discrimination is the major problem people with disabilities encounter in interpersonal interactions" that is curiosity, pity, unwanted help, ridicule, exclusion, and expectations about how they should behave.

Psychologists looking at difference have concluded that people with disabilities arouse anxiety and discomfort in others and as a result are socially stigmatised (Imrie, 1997). This attitudinal discrimination is supported by many other studies that have found that chronic illness and disability can become grounds for a "spoiled" identity, being perceived as being of lesser social value (Goffman, 1963). Goffman stated, "by definition, of course, we believe that a person with a stigma is not quite human," as one women wanted to stress she was 'still human'.

The consistent comparison between past/present/future self in the narratives of the women was supported in Charmaz's (1989) study of chronic illness and Tyerman et al's (1984) study of brain injury. Tyerman et al (1984) found people rated themselves more positively than their view of a typical head injured person. Taylor, Lichtman & Wood's (1984) work with women with breast cancer demonstrated that such patients often redefine their situation by making downward comparisons between their own situation and those who are less well off. Tyerman et al (1984) also found consistently more positive ratings for the past self than for a typical person of the same age and sex.

The fact that head injured individuals identify strongly with their pre-morbid identity (Ford, 1976) was supported in this study. Charmaz (1989) argued that some individuals may choose to locate themselves more firmly in the past, possibly because of the disparity between their present lived experience and the reconstructed past is so great.

In the present study it was suggested that comparisons with past selves can be used as an index of adjustment, as those who were most recently injured talked much more of their "former, perhaps somewhat glorified" selves (Tyerman et al 1984). The mechanism underlying the comparisons can be partly explained by looking at how we define ourselves in time; Charmaz suggested the "glorified" past might take on greater meaning when looked at from the present circumstance. Parkes (1998) believed that we need to make sense of loss, and the women did report struggling to make sense of the circumstances they found themselves in post injury. Irretrievable loss of physical or mental functioning undermines our understanding of our selves (Charmaz, 1989). Experiencing irretrievable loss creates a fundamental a loss of control. Control over one's circumstances, control over choices, and control over defining images of present self (Charmaz, 1989). It was a shocking experience for the women to realise how quickly things had come out of their control. Earll (1995) pointed out that perceived control may not be an effective concept to use in recovery following acquired brain injury, certainly the present study would lend support to this idea.

Some of the women appeared not to be able to imagine what their future self might be, and were thus unable to make plans. There may be huge discrepancies between past, present selves, and potential future selves; not planning for the future appears to be a symptom of this. Parkes (1998) referred to psychosocial transition (PST) as a process that occurs when we are faced with the need to make major changes to our assumptions about the world.

The women talked about using information from health care professionals to make sense of the process of adaptation they were negotiating. Wilson-Barnett (1980) suggested that giving the right information reduces anxiety and also aids rapid adjustment to stressful events, as patients can be prepared before they occur. Westbrook et al (1990) found that women are expected to be more proactive than men

in regards to their medical condition. They were more likely to find out about their condition, investigate treatment options, and comply with medical advice.
Earll (1995) highlighted the role of the "active problem solver" fully engaged in their own recovery. This role suggests an opportunity for health professionals who can provide information about possible therapies or techniques that might help reduce distress.

Whilst some have questioned whether it is appropriate to speak of reaching a stage of acceptance (Silver & Wortman, 1980), Parkes (1998) stated that the building of a new identity is part of the recovery process when overcoming loss. This has parallels with Folkman and Moskowitz's (1996, 2000) and Moskowitz, Acree and Folkman's (1998, 2000) work on AIDS related bereavement. In particular the revised coping model, that highlights meaning based coping and positive appraisal. They thought that positive appraisal (reframing a situation in a positive light) helped the individual to continue coping with an ongoing stressful situation. In the present study the women talked about assigning different values post injury and appreciating life more, which suggests meaning based coping and positive reappraisal has taken place. The women seemed to revaluate their goals and what was important to them had changed, this fits in with the ideas of Charmaz (1989) who found that people created new "reconstructed identities". Parkes (1998) stated that the new identity may still be somewhat fragmented and it may actually take years before it is firmly established.

6.4.1 *Methodological Limitations*

The sample size was small, and the exploratory nature of the study meant that generalisations should not be made to all brain injured women. The group of women had different types of injury, multi-focal and diffuse, moderate to severe, which again means that conclusions should be treated cautiously.

However, severity of injury did not relate to reported phenomenological experiences of distress, suggesting further research in this area is warranted. Current research emphasizes the importance of recognising that the onset of a chronic condition brings with it a range of difficulties, there is however considerable variation in the way they are perceived by the patient (Williams 1997). The notion that there will be a linear relationship between severity of disease or injury and psychological variables is unlikely to be correct as it assumes passivity on the part of patients (Fortune, Richards, Giffiths & Main, 2002); the present study supports this view, it is the meaning for the individual that is important following brain injury, not necessarily the severity of their deficits.

6.4.2 *Summary of Core Findings*

That there was a process that resulted in a fundamental change from the old to a new self was the core finding of the study. The women were faced with a new self that they didn't recognise and in some circumstances had no desire to, as they effectively existed in the world as an undesired self.

The women had to grieve for their old selves and went through many common reactions to loss such as anger, depression anxiety and fear. Some of the women seemed to pass through these stages with relative ease whilst it presented greater difficulties for others.

The women felt isolated because they had noticed a marked decrease in social contact because of the combination of unemployment and their reduced physical capabilities. There was an inherent tension in this state because although they wanted more social interaction they also feared it, a consequence of experiencing negative reactions from others (a consequence of common misconceptions about ABI).

The women continually compared the present/future/past selves. This can be seen as a positive method for making sense out of what has happened, and both self comparison and social comparison seemed to facilitate change. The information and support supplied from healthcare professionals was also seen to facilitate change. Some of the longer-term brain injured women had less features of the grief process; they made fewer comparisons and were less fearful of how others might react to them. In addition they were more socially engaged and displayed altruistic behaviour. It was suggested that they had successfully reconstructed their identities.

6.4.3 *Implications for rehabilitation*

The present study has a number of implications for rehabilitation. The first major theme was the awareness of a change in self following brain injury. The mental changes reported suggested that those with diffuse brain damage may have a wide range of deficits that may be subtler than the effects of focal injury but nevertheless interfere with quality of life. The women talked about their physical changes in weight, balance and appearance and this is seen as something tangible, whereas cognitive changes seemed less so, even though it is the cognitive changes that result in this "hidden disability". The women reported being less socially engaged and experienced this as problematic.

The second theme was the grief reaction; the need to grieve adequately and decently was highlighted (Lezak, 1978). The theoretical principles of Bowlby (1981) and more recently Stroebe et al (2001) could be used effectively in psychotherapy, specifically the experience of loss and the idea of working through the complicated feelings of grief.

The third theme was searching for meaning and suggested enabling patients to be "active problem solvers" (Earll, 1995) who are engaged in their recovery. Providing information reduces anxiety and distress, an example would be in the area of mental slowness. One woman had been told to take it easy, it wasn't until the therapist wrote it down as a timetable that she understood just how easily she was meant to take it, emphasising the need for information to be spelt out literally.

The fourth theme was the comparisons with the past self. These comparisons suggested an adaptive function that seemed to emerge over time. Possibly therapy could employ autobiographical work to build bridges to connect past and present selves. It seems important to remember there is a feedback loop and that these comparisons can trigger a regression to the grief response.

The fifth theme was the reconstructed self. Here it seems important to note McKnight and Kretzmann's (1990) belief that we should focus not on problems but on capability. Prigatano (1991) stated that presenting alternative symbols to give life meaning could be important. Research has also shown that mastery and competence increases self-esteem (Diener,1984).

6.4.4 *Conclusions*

The present study suggests an intervention based on these themes might be a useful tool in rehabilitation. The profound physical, cognitive and social changes need to be recognised and addressed. Body image is an important variable for women in rehabilitation, and following TBI exercise at the right level, self-presentation, and healthy eating can give a sense of control and mastery. The cognitive changes following diffuse brain injury may be less obvious than focal injuries, however recognizing "mental slowness" as a disabling condition and the value of pacing should be emphasised.

Relationships with others were important and adequate support to enable women to maintain existing relationships, and establish new ones, seems essential. Interaction with others who have similar disabilities and lead full and active lives could offer positive role models (Drench, 1994), assisting in the construction of the new self.

The grief process could be incorporated using the work of Bowlby (1981) and Stroebe et al (2001). Encouraging the women to be "active problem solvers", engaged in their own recovery (Earll, 1995), and providing the necessary information and support to do this might be helpful.

In autobiographical work, comparisons with past selves could be used to build bridges between past, present and future selves. Finally while recognising there may not be a definite end point, rather series of phases in the reconstruction of self, it is a good sign when there is planning for the future and social engagement, which are seen as positive signs of adjustment.

The present study supports the idea that we should present the notion of a series of phases to adaptation following brain injury, interpreting the threat to the self as meaningful and coherent, as these processes play an important role in our adaptation to challenging events. Anything that will facilitate thinking about the experience and assist in positive reappraisal, for example; focusing on the positives and looking to the future has the potential to be helpful. It seems that it is important that these processes are recognised by both therapist and patient.

MEN'S EXPERIENCE OF ABI : AN INTERPRETATIVE PHENOMENOLOGICAL ACCOUNT

7.1 INTRODUCTION

Dealing with cognitive deficits has been the traditional focus of rehabilitation research (Cognitive rehabilitation conference, Cardiff University, 2003). However, recent studies have started to direct attention to the broader issues of psychosocial change. Such research tends to look at carefully controlled studies isolating one or two aspects of ABI (Krefting, 1989).

There has been some pioneering work by Tyerman & Humphrey (1984) who attempted to investigate the perspective of the head injured person, a perspective that has been neglected in the literature. Partly this was been justified by the diminished capacity for awareness that is a feature following some ABI (Lezak, 1988). However as Wilson (2003) pointed out there is no baseline for awareness in the non-brain injured and it is not certain how fully aware any individual is at any one time and whether this is a stable phenomenon. Tyerman and Humphrey (1984) suggested that even though accurate self-appraisal may be limited following brain injury, the subjective impairment is the reality for these patients. Therefore the present study will adopt the position that research "should be seen through the eyes of the head injured person". Interpretative Phenomenological Analysis (IPA) is a research method that operates at the micro-level and illuminates the beliefs and responses of a particular individual. For a detailed explanation of the theory and practice of IPA see chapter 6.

7.2 METHOD

7.2.1 *Participants*

A convenience sample of men, who had had an ABI, and were currently more than 6 months post injury. These men were referrals from a clinical psychologist at a district general hospital. The participants were aged between 21- 59, years with a mean age of 36 years. The study was cross sectional in design in that the men were represented in two clusters, those who had recently been injured and those that had received their injury several years previously. See Table 30 for descriptive statistics, all names have been changed to protect the identity of the informants.

Name	Age	Injury	GCS	Years Since Injury	Highest Ed.Level	Previous SES	Present SES
Sid	59	Stroke	Severe	4	GCSE/O-level	C2	E
David	27	TBI	Severe	3	GCSE\O-level	E	E
Freddie	45	TBI	Severe	6	GCSE\O-level	C2	D
Luke	30	TBI	Severe	1	A-level	C1	D
Eric	25	Stroke	Moderate	2	Degree	C1	C1
Mark	38	TBI	Severe	1	Degree	C1	E
James	50	Infection	Moderate	2	A-level	C1	D
Jack	21	TBI	Severe	2	A-level	C1	C1
Stephen	31	TBI	Moderate	6	A-level	C2	C2

Table 31. Demographic and injury data of the participants. NB GSC = Glasgow Coma Score, Ed = Educational, SES = Socioeconomic status.

Severity of injury was classified according to period of posttraumatic amnesia and the Glasgow Coma Scale (Teasdale, Jones & Van der Sande, 1978).

7.2.2 *Interview schedule*

Refer to 6.2.2

7.2.3 *Data Collection*

Refer to 6.2.3

7.2.4 *Analysis*

Refer to 6.2.4

7.3 RESULTS

The experience of acquired brain injury through the eyes of brain-injured men can be summarised by three superordinate themes: a reframing of the self, navigating the social world following acquired brain injury, and the personal rehabilitation story.

7.3.1 *Reframing the self*

A past identity remembered

ABI brought about a change in the perception of self. The injury involved a painful loss.

The identity that is held in memory of their former selves as a capable autonomous, individual was contrasted with a sense of self that is in some ways, less capable and less autonomous.

> Everything's a lot more effort, I have to put a lot more effort in to what I do nowadays, whereas some of the memories I have is that it was a lot more easier. (Jack).

Someone who felt them self secure in a role as a man within the family, or within a sports team, or even as an autonomous individual could no longer rely on this as a basis for their identity.

> Can't spend a lot of time doing what Daddy used to do with the children. (Sid).

> Recreation wise the sport I could do, the activities that I could do that I can't do now...such as my team sports and my scouting which has been difficult with my physical condition after my head injury. (Jack).

Included with the lost leisure activities, but emphasised as unique, was the loss of independence associated with the loss of a driving licence.

> I can't do as many things I used to be able to do like driving, get very depressed but unable to get to places I used to, or to do a lot of things I used to do, get into town, go to the shops. (Sid).

All of these masculine roles are no longer secure and in some areas are lost all together. This is a tremendous loss for the individual and requires a renegotiation of who they feel themselves to be.

A person who is different in some aspects

The men were gradually realising the significance of the brain injury and what this would mean for them. They were becoming aware of some of the cognitive, physical and emotional changes in the way they felt themselves to now be. With a damaged brain the men were confronted with the difficulty of routine tasks such as remembering to have a bath. The neurological damage became apparent, as there were deficits of information processing, memory and motivation.

> I cannot take in as much information as I did before. Before I could just take in the important bits but now I listen to everything, yeah a bit agitating. (Stephen).
>
> I'm a bit lazy, sometimes I don't have a bath or a shower as much as I could. I have to be asked". (Luke).
>
> I think motivation has certainly been affected by the head injury (James).
>
> My short term memory has completely gone. (James).

In addition to the cognitive deficits, were various physical changes that accompanied the injury, such as changes in appearance due to surgery or weight change.

Changes in physical functioning were also due to the neurological damage, although interestingly were noted less than changes in appearance.

> I don't like the scar because I never used to have a scar before. (David).

> I feel my face is out of shape, it's got a lump on my face. (Luke).

> I don't feel as I was before, it has changed and that's because I lost a lot of weight initially and it has taken this long to put it back on. (Stephen).

> Well I know that my body is different to all the rest but that's life. (Eric).

The men talked about being at times, disconnected from their emotions, or experiencing them more intensely. Some thought their behaviour had changed and realised they were acting in a more childlike way.

> What I've noticed it's not a problem or anything, I'm not more emotional than I was before, but I feel them more. When I was in hospital it took my emotions away, now that I am at home I feel them more. (Stephen).

> The way I am, I don't act like a 27 year old, and I swears I act like a bleeding child, sometimes I act immature. (Luke).

But also a person who feels in some ways unchanged.

It is very important to the men to hang on to the bits of their identity that remain unchanged since the ABI. It gave them a sense of continuity and is a way of connecting two identities that are sometimes disparate. The parts of their identity that were resilient to the effects of the injury were retained skills and activities that could be continued after the injury.

> In my abilities very confident still, I still drive. I had to sit this special sort of test because of my head injury in order to get my licence back. I just sort of sailed through it. (James).

> Going back to my scouting after my head injury, it has been made more difficult regarding my physical condition now, but it's, I can take part in certain things with a little help. (Jack).

> When the co-ordinator came round to me saying "what are my skills?" I happened to mention I'd been in the printing industry, and now for my sins I'm editor of their newsletter. (James).

> Not much different to what I used to be, well I am different obviously, but um.. that doesn't worry me I'm still nosy, if anything happened, if anyone needed my assistance or anything like that I'd still do it .(Sid).

Imagining the future

A significant part of the reframing of the self-post injury was being able to imagine the future. The individual with ABI has to process the loss of their previously imagined future, often ordinary things such as finding a job, finding a partner and having children seem less certain after a brain injury, the individual has to re-negotiate all these aspirations.

> I'm more confident about talking about myself, my past my future, what I can do in my future and how I can cope without the help I've needed in the past or recently. (Jack).

The future physical self was something with which the men were consistently concerned; the desire to be stronger, slimmer and even the possibility of plastic surgery was discussed. The intact body was eluded to, the hope that the body might become whole again, the hope that plastic surgery might remove scars, or tracheotomies could be removed to restore the body to it's previous physicality.

> I'm fat and I'd like to loose weight but a lot of the tablets I'm on say no, you know they make you overweight and some make you underweight but I'd still like to loose a bit of weight but that's about it. I'd like to be stronger. (Sid).

> Well I think the right side of my body will get whole again, not sure about the left eye, but I know that the right side of me will be whole again soon. (Eric).

> When I said about plastic surgery it was to remove the scar on my head, that's what I'd like to change. That's what I'd like to change on my body. (David).

> My throat, this thing (points to tracheotomy). I wish I could get rid of this tube in my throat. (Luke).

Part of body awareness was the prospect of sexuality in the future. Some men questioned whether they would still be sexually desirable. This was a fear that reflected the relative youth and single status of many young men following ABI.

> I've asked my mum about it and if I meets a lady and takes my clothes off and I've got this thing (tracheotomy). It makes me loose confidence makes them loose confidence 'I don't want to go to bed with someone and look at this thing every night'. (Luke).

7.3.2 Navigating the Social world following ABI

The second main theme that ran through the dialogues with the men was the struggle to navigate the social world following ABI. It was apparent that social interaction was difficult for most following their injury. In addition to the practicalities of communicating with others with a damaged brain, the men also had to contend with direct negative reactions from other people and general stigma associated with disabled. The challenge of everyday social activity was alluded to; conversations and crowds (or even groups of people) were particularly challenging.

> Sometimes in conversations I find something funny or humorous and other people don't seem to know if I'm being funny or serious. (Stephen).

> Couldn't find the proper word for the right situation, having a conversation was very difficult. (Mark).

> Agitation among large groups. I cannot take in as much information as I did before. Before I could just take in the important bits, but now I listen to everything. Yeah a bit agitating. (Stephen).

> If I go into town too many, depends really, say Thursday, Friday, Saturday, lots of people in town, it's too many people for me. I used to watch the football, lots of crowds, but now there are too many crowds for me. (Freddie).

Negative reactions from other people were directly experienced, expressed as people looking down on you, or not being treated as an equal. A more general "felt" stigma was discussed concerning people misconceptions about people with disabilities.

> I've found that especially in the beginning a lot of people were patronising almost condescending. They would look down on you, not treat you as an equal. (Stephen).

> I get very frustrated that there are people that think that anybody that walks with a stick or sits in a wheelchair has lost all their abilities to think and carry out normal functions and everybody's treated as one box. As far as there concerned you are an idiot or stupid or whatever. (Sid).

Avoidance was used as a coping strategy, because social interaction was problematic it was easier to avoid such activity, and some men talked about adopting reclusive behaviour such as not leaving the house for long periods of time.

> For the first year and a half I didn't like going out. (Mark).

> It took me a long, long time before.. um to want to go out of the house, months even. I felt so conspicuous. (James).

Young men without partners seemed especially vulnerable to social isolation. Without work or any regular routine outside Headway, it was difficult to meet new people. Friendships formed before injury rarely withstood the event, this lead to the men being vulnerable due to their need for new friendships.

> You'd like to go somewhere with this particular person or whatever and you just cannot.. so you do feel quite isolated. (Mark).

> I think if there wasn't the right people you could get very lonely. (David).

> He hopes he can see me again, he wants to, he says he'd ring. I haven't got any friends, my own friends. (Luke).

Relationships : *Break Down*

One of the psychosocial changes the individual with a brain injury may face is the change in relationships that can occur. Some marital relationships break down unable to withstand the stress, relationships with children may alter and younger children may not be able to grasp what has happened to their father, and why he isn't quite the same as before.

Marriage relationships were especially vulnerable to breakdown. Sometimes the men were able to perceive that from their wife's perspective, they were no longer the man that she had married and could often see the reasons that the marriage no longer worked as it did before.

> It also broke my first marriage, just couldn't cope because my whole attitude changed really, I became very self-centred. (James).

> I'm not the man she married… so as far as she was concerned I might as well be dead, a lot of trouble, it makes me very depressed, upset whatever um it's one of those situations where we're still married but ah that's it. (Sid).

Relationships with children deteriorated in some cases, this was especially true for those with young children whose relationship was based upon shared activities and enjoyment. When this is taken away it was very frustrating to young people who do not understand fully the reasons why.

> Can't go on the roller coasters, can't spend as much time with the children, playing football, tired, that sort of thing.. so I can't spend a lot of time doing what Daddy used to do with the children and they get fed up with me. (Sid).

Relationships develop and continue.

While some relationships break down, some relationships were able to adjust and continue. The relationships that survive seem to be a great source of comfort and support to the men. In some ways the men talk about being closer to significant others following injury; the experience can bring some relationships together and make them stronger.

> I love walking I guess. Like I says I go one, two steps, so my wife does the same. (Freddie).

> My daughter is an absolute credit. Since the split my daughter has been great, without her and the grandchildren I don't think I would still be around personally. (James).

Set against the sometimes bleak reports of relationship breakdown and social isolation where the few cases in which new relationships have formed post injury.

> Then I met my present wife on the internet. We were chatting for about 12 months, she decided to move from America over here, used to go to the chat rooms, flirt, which is totally against my nature. (James).

Headway:

The importance of Headway was echoed by all attendees. The day centre was a facility in which they were able to support each other.

> Coming to Headway has certainly helped in that respect, talking to people in a similar situation to myself, who have been there done that, brought the T-shirt. (James).

> I think the support that we give each other, it's not support, I mean well quite often we don't sort of help each other in any way. I think the other mental side of that is along as we listen to each other and we talk about what we can talk about, and what we know perhaps we can do this. (Mark).

> Being able to speak to other people who have the same sort of problem, on the same basis. (Sid).

One of the ways that Headway facilitated adjustment was through social comparison with other attendees.

> I say to myself well I can do better than that person and the other person as well, well you can do that better, so it is support. (Mark).

Headway was seen as an active place where there were things to do, tasks that were purposeful and provided stimulation and a routine.

> The activities we do here.. there are days when you … I suppose I mean… start from the literacy group, then in the afternoon you're doing art. (Mark).

> Now it's just Tuesday (his attendance) but it's good. Like doing the maths, using the brain for the maths, this and this, reading and this. (Freddie).

At Headway the access to trained and empathetic support workers was important to some men.

> He's really nice. I think he's travelled the world and he just seems so cool, to sit next to him and just talk to him. You don't feel like you've had an injury you know he treats you like a friend. The manager here is very, very helpful. Anything you want to talk about she will understand me. (David).

7.3.3 *The personal rehabilitation story.*

The final theme was the evaluative process that these experiences were filtered through. Each man had his own personal rehabilitation story. The narratives contained accounts of the good experiences, the interactions with rehabilitation staff especially physiotherapists and nurses were perceived as helpful and beneficial. The men talked about particular individuals who were able to impact on their recovery or look at things in a more positive way.

Whenever a rehabilitation specialist was able to empower an individual, for example teaching them skills, or helping them with speech or movement this was held in high regard.

Medical intervention.

> People at the (district general) Hospital, some of the ladies there have been really good and cheered me up, made me laugh and altered my happiness, change my life, get on with it. (Luke).

> The nurse that was really helpful when I had my stroke. Er the OT who taught me to do things with my right hand. (Eric).

> The physiotherapist who taught me to walk again. (Eric).

> The person I've found most helpful, or the people I've found most helpful post head injury are my therapists, who've helped me, teach me, helped me to learn, helped me recover, help to adapt to the things I can and cannot do. I'd like to say I've done it all myself but there are many, many people involved. (Jack).

However medical intervention was not always so well regarded. The interventions the men particularly objected to were the operations, scans, medication and intrusion of medical appliances. Some men felt they would have benefited from counselling, which was not offered but this was not something reflected by everyone.

> The second op which caused all the problems I now suffer from. (James).

> Then the tablet medication, I'm on 23 tablets a day.. a lot of the tablets I'm on say no, you know, they make you overweight. (Sid).

> Something that I think would have helped but I didn't receive is counselling, [although] lots of people with head injuries don't want to talk about it. I felt as if people were there to do there jobs, they had their guidelines to stick to. (Stephen).

Blame

A further feature of the rehabilitation story was the existence of blame. Some individuals blamed themselves whereas others placed the blame externally. This can be seen as the men's struggle to make sense of what has happened. There is perhaps a need to hold someone accountable.

> I mean it's not your fault that you've had a head injury. Here (Headway) there are teachers, all sorts of people from all different walks of life and it's not their fault they are like the way they are, they're still people. (Sid).

> If I couldn't change not having a head injury, I'd change my past after my head injury. My past to this point. The way I've done things. I can only now see how I could have done better, made more of an improvement, and created better opportunities. (Jack).

> I still feel that if I had more immediate sort of physio when other things were going wrong I might have been a bit better. (James).

The narratives emphasize that recovery is dynamic and that it takes time. One coping mechanism utilized by the men was a kind of peaceful acceptance of their present position.

> Getting better but I found myself in a position when I'm not in a hurry to get better. I just take it as it comes. (Stephen).

Furthermore the interviews are the personal accounts of nine men and although there were some similarities, there were also differences. This was especially obvious in social relationships, some relationships lasted, some broke down, and this was due to the unique dynamic of those relationships. It was also apparent with the very individual nature of pattern of deficits and disabilities following ABI. Whilst the men shared global features of the same disturbance for example heimplegia, visual disturbance, medication, weight gain or loss, the profile of overall disability within each participant was unique.

> It definitely does affect everybody in different ways. (Stephen).

7.4 DISCUSSION

The three central themes that came from the men's perspectives were reframing the self, navigating the social world and the personal rehabilitation story. The structure of these narratives was unique to each man but they shared these common superordinate themes. The men talked about a process of gradual change and adaptation. The individual's story was highlighted as well as the common themes shared by men following ABI.

7.4.1 *Reframing the Self*

This was a story of personal adjustment. It was reflected in the men's understanding of themselves and it progressed from a vague feeling that things were different, to a more concrete understanding of the physical, social and cognitive changes that constituted a threat to their sense of self. The reframing of the self had to accommodate the memory of the pre-injury self and the awareness that things were different now. Charmaz (1989) thought that when memory is used as a source of self-validation it is often fragile and tentative.

The physical, cognitive and behavioral changes took priority in the men's accounts. Most men noted the cognitive changes and McKinley et al (1981) noted that the most common reported deficits were mental slowness, tiredness, irritability and poor memory.

This was echoed in self report data reported by Martin et al (2001) who stated that some of the most common cognitive deficits included memory problems, difficulty in making decisions, planning, concentration, slowness and feelings of impotence. Such cognitive changes have also been linked to reduced working capabilities (Gainotti, 1993).

The men mentioned physical changes and perhaps these seem more tangible than the more nebulous "cognitive changes" outlined above. McMillan and Greenwood (1993) said the consequences of ABI were long term physical disablement and deficits in independent living skills.

Apart from the practical difficulties involved with the deficits in independent living skills, the physical changes also have an impact on body image. Body image is a part of self concept that involves attributions and experiences pertaining to the body, including notions about masculinity and femininity, physical prowess, endurance and capabilities (Drench, 1994).

The men talked about being whole again; expressing the belief that in the future they would be "whole again". Drench (1994) found that the need to remain physically whole is strongly associated with remaining completely intact physically, mentally and emotionally. Taking these results together it would suggest that having a disturbed body is related to the perception that the self is also disturbed.

Body image is also a social creation (Norris, 1970) and it has been found that only a "normal" appearance as dictated by society, is acceptable in a society that places a high value on physical attributes and prowess and finds it difficult to accept physical disability (Drench, 1994). Price (1994) stated that the reactions of others towards our bodies would be felt deeply; certainly the men expressed concern post injury about how others would react to their bodies.

Recently the concept of shame and the body has been explored by shame theorists (McKee and Gott, 2002). With shame experiences it is not so much the distance from the ideal self but the closeness to the "undesired self" that is thought to be crucial (Oglive, 1987). In shame what matters is the sense of personal unattractiveness, being in the social world as undesired self, a self one does not wish to be (Gilbert, 1988). It is though that an experience of shame occurs as an involuntary response to awareness that one has lost status and is devalued as an object to others, and this can meld into one's own identity as for example as being flawed, worthless and unattractive (Gilbert, 1988).

It could be said that ABI involves a transformation in how one experiences one self as an object to others (related to various cultural stereotypes) and a transformation in the internal experiences of changing abilities and capabilities.

The transformation of an individual from a person, who considers himself or herself young and valued, to seeing themselves as frail and disabled, is considered a move from a desired state to an undesired state (McKee and Gott, 2002).

The changes within the self had diverse and widespread consequences; so cognitive changes affected social interaction, which could then impact upon marriage and family relationships. The men were very honest about their changed behaviour, acknowledging in some cases that they had become more selfish or childlike. Prigatano (1988) found that many with TBI claim to be more "emotional"; he believes the basic neurostructures that maintain arousal and interpretation of feeling are more frequently affected than is commonly appreciated. The men's reflections on their selfish or childlike behaviour contradict the commonly held belief that those with ABI have deficits of awareness that prevent introspection or "subjective" understanding of their condition.

The men seemed to swing between talking about how things were in the past and how things are now post injury. Inevitably this involved some loss; loss of relationships, status, physical functioning and employment. This multiple loss had an impact on identity and the men seemed to struggle with self-acceptance. The contrast between present and past selves was sometimes disjointed and the men tried to reconcile this.

Strauss and Corbin (1984) noted that people move between their remembered past, present and future situation.

It was apparent that this was a very unusual and strange experience to go through. Gradually they became aware of changes within themselves, having a memory of a previously intact self that took some time to fully accommodate.

Against the mass of changes were feelings that some aspects of self continued, seemingly resilient to the effects of the injury; examples included aspects of personality, skills, activities and hobbies that could accommodate the shift in such fundamental aspects of self. These threads of continuity were very important and acted as bridges between disparate selves. It is thought that efforts to define and maintain identity form part of the rehabilitation process and are necessary to find meaning (Strauss & Corbin, 1988).

Part of the reframing of the self involved imagining the future. The men talked about how they would like to be in the future; often this involved how they would like to be physically together with a consideration of future prospects with an intimate partner. Management of the body is thought to be central to a person's identity and also the ability to construct a version of the self that is preferred rather than stigmatizing (Goffman, 1963).

Sexual aspects of body image are thought to be important for male body image. Franzoi and Herzog (1987) found that males judge sexual drive, sexual activities and the sex organs as important. This is of some concern because Griffiths (1990) noted that ABI affects sex drive, interest, beliefs, attitudes, behaviour, activities and responses.

Reduced sexual opportunities are common following cerebrovascular accident (Kreppel & Crowe, 2000) and the ability to integrate sexuality with disability is thought to have a profound impact on adjustment (Best, 1993). Given that TBI is most frequently seen in the 15 to 24 year old age group, and given that this is a time period when this age group is likely to be developing their ideas about sexuality, it can be suggested that rehabilitation should target this area.

Harvey (2001) stated that ABI was equivalent to a major loss, this was especially true for the young men who had to deal with prospective loss, they had to reframe their selves, perhaps making adjustments to future expectations, such as the expectation that they might meet a partner, find employment or have children. In this area the loss seemed particularly severe.

7.4.2 Navigating the Social World

The social world was expressed as the external world, the world outside the self. Social interaction of any kind can be a challenge for the person with brain-injured ABI. The problems of crowds and groups of people were highlighted. This may be best explained by the cognitive changes, the slowing of thinking and responding, the difficulties of detecting slight vocal nuances or subtle humour with a "fuzzy brain". Martine et al (2001) found that social interaction was highlighted by those with ABI as a significant problem post injury. Areas of social interaction specifically highlighted as problematic were self assertion, being critical of others, being bossy, being dominating and items relating to a lack of self control (Martine et al, 2001).

The men in the present study had experienced negative reactions from others, which compounded the neurological damage and cognitive deficits. Hahn (1983) stated that obvious symbols such as a wheelchair, crutches, cane, provide unmistakable indicators of an individual's status and of the response, which he or she may receive from others. Disabled persons not only possess apparent physical deficits, but also display mannerisms and social cues which others find awkward to translate. As a result, physical disabilities may inspire deep seated fears and strong feelings of repugnance and aversion. Hahn (1983) suggested that handicaps arouse anxiety by reminding people of departures from standards of beauty and perceived competence. The stigma associated with visible disability was highlighted and it was felt that at times people looked down on individuals with ABI, or assumed the men were stupid. It was also felt by some men that they were lumped together in a disability box and not treated as individuals.

The notion of felt stigma is not a direct negative experience from another, rather it concerns expectations within the person about how others will behave towards them and is closely related to the psychological notions of social anxiety, fear of a negative reaction and poor body image (Kent & Keohane, 2001). Goffman (1963) stated that people view those with a stigma "as not quite human".

Perhaps because of the problems negotiating negative experiences and felt stigma, social avoidance and isolation have been consistently mentioned as a behaviour pattern adopted post ABI (Morton at al, 1995), and loneliness has been suggested as the greatest burden faced by individuals post injury (Oddy, et al 1985). Following injury friends and relatives visit less often, and individuals engage in markedly fewer social activities (Kwasnicka et al, 1994). Furthermore following other physically disabling conditions social avoidance has been identified as an adopted behaviour pattern. Jahanshahi and Marsden (1990) looked at those with torticollius and found well established patterns of social avoidance behaviour, which had become partly independent of abnormality and mood. In the present study the men talked about not going out at all for periods as long as a year. It is suggested that this might become an established pattern of behaviour that is engaged to cope with the combination of cognitive deficits, negative experiences from others and felt stigma experienced by many post injury.

Another example of loss post injury is the relationships that irretrievably break down, which was something experienced by a considerable proportion of the men sometimes this loss concerned partners, children or both. In the arena of personal relationships different perspectives following ABI can lead to distress between patient and cohabitating relatives (Lezak 1978, McKinley et al, 1981).

Lezak and O'Brian (1989) found problems in significant relationships were evident in 22-36% of patients; Kwasnicka (1994) similarly reported high rates of marital breakdown. In a much needed study of sexuality post injury Kreutzer & Zasler (1989) found that 38% rated communication worse post injury and 62% reported diminished intercourse following injury. Miller (1993) stated that survivors of TBI and their partners react to injury differently and according to pre-morbid personality and relationship dynamics. From extensive clinical reports it has been suggested that the wife often became the passive tolerant partner because the patient lost the capability for sensitivity and intimacy that make sex mutually enjoyable (Lezak, 1978).

In the arena of parent child relationships, a reduction in parental attention, frustration and anger at having a different family, are reported sequalae following ABI, as well as an absence of good times within the family (Lezak, 1978). However parent child relationships are considered more resilient than husband wife relationships (Thompsen, 1974).

However despite some reports of relationship breakdown it has been pointed out that we still need much more information on the strategies used by people with disabilities to negotiate interactions and to build enduring personal relationships with those around them (Asch, 1984). Set against the reported loses were the experiences of those whose relationships that had continued, developed and grown stronger through the experience.

Cramer (1988, 1989) found a significant positive relationship between self esteem and the extent to which ones closest friend is seen as displaying empathy and congruence. Successful partnerships were a great source of comfort for some men post ABI. In the arena of communication, research has found that communication levels will be preserved for the majority (50%) and some partnerships can actually improve post injury (12%). It is also suggested that stroke sufferers with a caring, understanding and able partner or carer seem to have a more positive rehabilitation outcome (Dombovy, Sandok & Bosford, 1986).

Relationships changed inevitably and seemed to be an example of individual differences within the narratives. The relationships that survived seemed important to the men and even took on added significance. Relationships with partners or children were cited as a source of strength that assisted coping resources.

Some relationships were unable to survive the strain. The men acknowledged that they were different and in many senses were not the person that their partner had married. Relationships with children altered. Adult children who could grasp what was going on seemed to adapt more easily. Young children seemed less able to comprehend what was going on and became frustrated with their altered father.

The importance of Headway was highlighted. This is day centre run by a charitable organization that acted as a point of contact for other people with ABI and offered access to statutory and voluntary services. The men talked with great affection for this organization, it provided a routine and stimulation in the absence of employment. Krefting (1989) has pointed to the platform that is needed on which to build a new identity, due to a lack of opportunity to fill legitimate roles in society. It is thought that if an individual's personhood is not acknowledged by others, it is difficult for him or her to develop a sense of identity, as they are neither acknowledged nor valued by society. If a person with a disability has no way of obtaining meaningful employment and lacks this opportunity to succeed, then there is no basis upon which to build a new identity (Krefting, 1989). Effective social supports have been conceptualized as the attributes of socially legitimate roles that satisfy dependency needs without a loss of self esteem (Kwasnica et al, 1994). It is probable that Headway provided such a platform for the men post injury as well as meeting dependency needs.

Meeting other people with ABI seemed important for the men and the social support from others who had similar experiences was reported to be invaluable. This finding supports Trulsson et al (2003) who found that participants sharing the same experiences of going through head trauma can listen to each other with empathy and also give each other important social support.

The participants also talked about comparing their progress to other people with ABI. Looking at others to monitor their progress seemed to have an adaptive function and social comparison has been hypothesized to aid adaptation (Dibbs & Yardley, 2003). It seems that this process can operate in a positive or negative direction; both directions can aid adjustment (Dibbs & Yardley, 2003). Krefting (1989) reported an individual with ABI who attended a social group because it made her look more "normal"; in this case it decreased her sense of disability. However social comparison can also facilitate adjustment through positive role models. Drench (1994) found that interaction with people who have similar disabilities, but lead active, full lives, could facilitate transitions. A disabled person who enjoys a vital lifestyle can be a positive role model as someone who has made a successful adjustment and necessary adaptations (Drench, 1994).

Access to dedicated support staff was important to the men, and being listened to was rated as perhaps most important. Being accepted and treated with respect were the main benefits of interactions with the staff at the day centre Headway. It could be argued that such organizations can help build esteem, and the rarity of meaningful social interactions between those with disabilities and those without has been previously noted (Richardson, 1974). The overwhelmingly positive experiences with the staff at Headway were in great contrast with experiences with the general public. Misconceptions held by the general public about those with brain injuries have been highlighted before (Swift & Wilson, 2002).

7.4.3 The Personal Rehabilitation Story

Each man had a unique story concerning aftercare following ABI. This has to be worked through on an individual basis and assimilated into something that made sense to the individual. The personal brain injury story was each man's account of what had happened to him, their understanding of what they had gone through and why this had happened to them. From these personal accounts some common themes emerged.

The dynamic quality of rehabilitation was emphasized; previous research has reported rapid or marked initial improvement, followed by slower improvement over time (Lezak & O'Brian, 1988). In the present study the men reported at times making progress but also suffering set backs, this suggested the need for sustained and flexible responses to their disabilities from the men. The descriptions from the men suggested that there was not a simple linear relationship between recovery and time, or even adjustment and severity.

The individual nature of recovery was also highlighted by the differences in the men's accounts of their post injury experiences. Wendell (1996) argued that seeing people with disabilities as one social group de-emphasizes differences based on race, ethnicity, class, gender and age and falsely universalizes the social experiences of disability.

Charmaz (1989) thought that the content that an individual takes from his or her experiences of illness might differ considerably, again suggesting that rehabilitation post ABI cannot be conceptualised as a simple linear relationship between recovery and time, or adjustment and severity. However Wendell (1996) also acknowledged that living with a disability provides social experiences different to that of persons without disabilities; this was reflected in the present study. Although there are individual differences in accounts of family relationships post injury and medical interventions, these were set against common experiences such as negative reactions from others, positive experiences at Headway and a personal story.

The personal rehabilitation stories of the men often contained reflections about what was good about their recovery and what could have been better. This was the cognitive appraisal of the brain injury rehabilitation experience. It was not a neutral factual account of the events surrounding their injury but included assessments of the distress they had experienced. Backman (1987) thought that the psychological distress that people may experience as they attempt to cope with the late effects of disability was not appreciated by health practioners or the community at large. This view would be supported by the present study. The parts of ABI rehabilitation that were highlighted as positive experiences were individual nurses and rehabilitation professionals such as occupational therapists and speech therapists, who had a constructive impact on life post injury.

The parts of the rehabilitation story that were not appreciated or were seen as destructive were intrusion of medical appliances and procedures. Operations, scans and drugs were resented, in fact anything that was seen as a medical intrusion into daily life. Visible reminders of the injury or period in hospital were resented; scars, tracheotomies, walking aids, wheelchairs were all perceived negatively. They were reminders of what had happened to them and the stigma associated with visible physical changes.

Blame was part of the accounts, suggesting that it is not purely a cognitive process. Blame suggests the need to hold someone accountable and this was a possible outlet for suppressed feelings of anger. Raskin and Stein (2000) thought that in the case of TBI those who were victims are likely to focus their anger externally (for example to the perpetrator of injury), and those who were responsible for the injury themselves often developed self-blame. Whatever form of blame occurs, it is thought that shame will be a predominant accompanying emotion, for in Western society's victim blaming is common in many health situations (McKee, 2002).

7.4.4 Implications for Rehabilitation

The findings suggest that men often struggle to adapt to the cognitive, physical and emotional changes following ABI. The use of social skills training in conjunction with attendance at day centres is likely to be helpful.

In addition to boosting self mastery and self worth, they offer opportunities for social comparison (Dibbs & Yardley, 2003) a technique thought to facilitate adjustment to chronic conditions. The choice of psychotherapy should be available to those that want it. The fears about future prospects and negotiation of existing relationships may require a level of reflection beyond the capability of those with severe cognitive deficits. . It is suggested that an intervention based on the results of these findings would be amenable to inclusion in current rehabilitation strategies.

7.4.5 Conclusion

The present study would suggest that men's experience of ABI is a gradual process of change and renegotiation. The changes noted within the self are often in a downward direction, with most men noticing a loss of functioning in cognitive and physical areas, which had a practical impact on the way they could live their lives. Then men had to renegotiate their future aspirations. The men valued the aspects of their lives that could continue post injury and this facilitated adjustment.

For most men social functioning was a struggle post injury; they had to use a damaged tool to communicate and had to face the discriminatory attitudes of others. The importance of Headway, a community based day centre, was emphasized. Finally the individual nature of recovery from brain injury was highlighted. Whilst many themes were shared, it was apparent that each individual will react differently to this event.

DISCUSSION

8.1 *The Move from a Desired to an Undesired State following ABI*

It is known that the damage associated with ABI causes physical changes that can be significant for the person post injury. The literature review highlighted the perceptual changes following disturbance to the sense organs; eyes, ears, nose, tongue and somatosensoray receptors (Carter, 1998). Many neurological deficits translate to a seemingly physical disability (apraxia, hemiplegia and neglect being obvious examples). Furthermore the individual with ABI is likely to have associated changes in weight and appearance.

The present findings have established the body as a significant factor in recovery and adjustment to ABI, as it is the medium in which the associated disabilities and impairments are best understood. Following injury the perceptual, motor and cosmetic changes are immediately apparent and especially concerning for the individual, whereas the more nebulous cognitive changes may seem less so.

Under normal conditions the body is the focus of an individual's identity and it is the boundary that separates a person from their environment. The body is considered to be the only object that completely corresponds spatially and temporally with personal existence, and yields experiences that cannot be directly shared with others (McDaniel, 1976).

Physique is thought to be integrally involved with the core self. All of these features would suggest that a damaged body following illness or disease would have serious implications for the psychological health of the individual.

Price (1990) believed that the body reality and body ideal were important concepts in the assessment of personal body image. The body reality refers to the body as it really exists, constrained by the effects of human genetics and the wear and tear of life in the external environment (also affected by illness, disease, and abuse). It is believed that body image is formed in a social as well as personal context, and the reactions of others toward our body are significant. The body ideal includes norms of body weight, appearance, and function. It is profoundly influenced by cultural norms, by advertising and by the changing attitudes towards fitness and health. A current conception of the body ideal includes youth, beauty, vigour, intactness and health and there is likely to be a resulting decreased self-esteem, insecurity and anxiety among those who deviate from this ideal (Salter, 1997).

It has been argued that any significant and enduring change in experience or sensation relevant to the body would produce a corresponding change in body image and self-perception. A modified body image, if an accurate representation or estimate, should reflect relevant changes. In terms of body image ABI presents several interesting challenges to the survivor.

Illness and disability have been found to be associated with an increased bodily preoccupation and the focusing of awareness upon physical sensations and changes (Salter, 1997).

There is some evidence that would suggest ABI would be a particularly difficult condition to adapt to. For most persons an illness or injury that affects the head or brain is closer to the self core and is thought to be more threatening to self esteem than is a disorder of the extremities (Gilles, 1984). In addition rapid, unexpected, uncontrollable, and unwanted changes in body image are believed to be particularly difficult to accept (Piotrowski, 1982).

The body in illness and ageing has been described as speaking an unfamiliar language (Gadow, 1980). Drench (1994) thought that body image could be viewed as the source of an individual's new identity as a "sick" person". Once back in the community, if patients cannot effectively cope with disfigurement or dysfunction, they are at a higher risk of infection, non-compliance with therapeutic care, depression, social isolation, obsession with or denial of the changes in body image (Dropkin, 1989).

The phenomenological body of work in the thesis makes clear that there are social factors involved with the body image and identity of "a person with ABI". It is suggested that there are generally held misconceptions about ABI (Swift & Wilson, 2000) that can be interpreted in a derogatory way. It would seem that sexuality is affected, and especially for men there may be a sense of fear and apprehension about future sexual desirability and prospects.

The concept of shame is thought to be significant when discussing the body and the self concept. (McKee & Gott, 2002). Gilbert (2002) makes the case that it is not so much the distance from the ideal self but the closeness to the "undesired self" that is significant for self perception (Oglive, 1987) and that this would seem to be the important relationship following ABI.

It is thought that a sense of unattractiveness comes from a sense that you now exist in the social world as an undesired self, a self one does not wish to be. The idea that one has lost status and is devalued as an object to others, and this can meld into a sense of one's identity (Gilbert, 1998). The expectation of others can also have a profound psychological effect, which corresponds to the associated feelings of shame (Salter, 1997).

The ideas of shame theorists are especially relevant because they predict that if the body, as experienced to others, is devalued, and then there will be associated feelings of shame. With brain injury you go from a self with which you are relatively comfortable to a self that is more cognitively damaged, more physically disabled and less socially valued.

A brain injury involves a transformation in how one imagines oneself as an object to others. If damaged body image, identity and shame are influential in recovery following ABI, then psychological input to address these issues seems essential.

The concept of the body drop was developed from work on the self perceptions of the elderly following falls (McKee, 1988). However many of the central tenets can be translated to the experience of those who have suffered an ABI. ABI brings with it a traumatic experience of the body failing. This is something that we all experience, as we get older, but do not expect to experience until we reach old age. ABI brings with it multiple impairments, handicaps and disabilities, comparable to a decline in functioning during ageing. Taken in the context of a body drop, it can be argued that in ABI the body stops functioning as it was before. Following ABI there is the sense of loss, grief, and regret over loss of function, similar to that which occurs in the elderly following a sudden fall.

With ABI the onset of decline is more disturbing, and even though it is similarly associated with a single incident (as with the original model of the elderly and falls), it is more severe and in the majority of cases occurs with individuals who are relatively young and comparatively healthy. For the affected individual ABI is an event that often seems "out of time".

How the person interprets this event seems significant. An older person might think a stroke is a sign that they are getting old, a sign of things to come. A younger person may have a different perspective, perhaps it is more traumatic, seems more pathological, as doesn't fit with expected ideas about the body and decline. Or perhaps as it is so out of time, it is interpreted as unlucky but discrete, an event that has happened but one to be overcome as best you can. An event limited to time and not generalised. It seems that there are several appraisals available to the person with ABI. It would seem to suggest that we should start to think of the role of these appraisals, as researchers have been doing in psychological gerontology research, in recovery from ABI.

The body drop is a useful concept to explain the significance of the body following ABI. If falling has been found to trigger a change in self perception in the elderly, it would seem to follow that the arguably more traumatic experience of ABI also has the potential to impact on identity.

8.2 *Gender Differences*

8.2.1 *Men with ABI*

The meaning of the body post injury is different for men and women. Different body schemas take shape following injury for each gender.

The findings suggest that following ABI male body image satisfaction decreases and men are particularly concerned with physical and sexual functioning.

Physical functioning and what this means to the men has been investigated in this thesis through quantitative and qualitative techniques and they inform each other. An example would be that the empirical work highlighted the particular areas of concern relevant to men with ABI. The phenomenological work puts this concern in a real world setting. Every day functioning was remembered as less difficult. It was the case that the men had a memory of self that was more capable, able to take part in team sports, work manually, be the source of strength in the family. Someone who was independent, autonomous and mobile. This contrasted with the self post injury, who was perhaps less independent, autonomous and mobile.

Sexual functioning was important to the men post injury and this came out in the empirical work. The phenomenological work revealed that the young men without partners were concerned with their sexuality and future prospect with a partner. In particular whether their chances of meeting and sustaining a relationship with a partner had been affected.

The empirical work found no relationship between the existence of specific disabilities and body dissatisfaction (chapters three, four and five).
This would suggest that the scale of physical injury is not proportional to the amount of subjective distress experienced by the individual. The concern with physical and sexual functioning expressed by the men in the qualitative research seemed to be very much on a practical level, rather than being threatening for the self.

This finding would tie in with the concept of shame and the body. It was the ABI that has placed the body in the foreground; following ABI the body no longer functions as before. The body is no longer co-ordinated, balanced or intact. In a sense the men are faced with a prematurely aged body that doesn't respond as efficiently to neuronal signals, is clumsy and awkward.

The concept of shame and the body is particularly relevant in the sexual arena. The men with ABI were significantly less satisfied with their bodies in areas related to sexual functioning, such as satisfaction with sex organs and sex drive.

The ABI has taken them from a desired to undesired self and this is particularly apparent in intimate relationships and when talking about sexuality.

In the quantitative study in chapter four it was found that males with ABI had significantly lower self-esteem than controls. The interviews and the questionnaire data supported each other in that low self-esteem didn't appear to be associated with a catastrophic deep emotional response.

The empirical work in chapter four revealed essentially no differences in anxiety and depression between controls and ABI. It was been suggested before that a considerable proportion of the population suffer with anxiety (Crawford, Henry, Crombie and Taylor, 2001).

When considering the impact of ABI on male self concept, the effect is not central to core self; it does not fundamentally affect how brain injured men see themselves. Although they have body image concerns and low self esteem, suggesting that the ABI does have a negative psychological impact in these areas. However, the impact of these negative psychological changes does not seem so catastrophic for their sense of identity. There does not appear to be an intense emotional reaction. These problems are in a sense compartmentalised. They are problems, and they are real, but they are restricted in their power and not so overwhelming. It seems that the men are able to see themselves as a man (with a brain injury) and that because of this it is not so significant for their sense of identity.

In the social arena, the men talked about experiencing negative reactions from others. These could be split into directly experienced negative reactions and the felt stigma as a disabled person. The men talked about being talked down to, being patronised and treated with perhaps less respect than they felt before the injury.

The men talked about the more general stigma that just because you had a visible disability this seemed to determine lesser status or treatment from others. The feeling that they were being put into a box as a disabled person was resented.

The men's experience of ABI as revealed by the qualitative research was summarised under three major themes. Reframing the self, navigating the social world following ABI and the personal rehabilitation story. The qualitative work would support the empirical findings that the men did not perceive the injury as presenting a fundamental threat to self. The men had concerns in discrete areas that were limited in their disruptive power. This would support the quantitative findings that the men showed low self-esteem, but did not register clinical anxiety or depression.

The qualitative work helped to elucidate the coping strategies employed by the men which seemed to centre on seeking social support, accepting responsibility, escape-avoidance and planned problem solving. However social support has recently been argued to be a resource for coping (Endler & Parker, 1990) and deserves special attention. The longitudinal data supports the qualitative reports; there was a significant improvement in social functioning over time. This was a highly significant finding in that previous work (Oddy et al, 1985) has placed the social isolation experienced by many post injury as potentially one of the serious consequences for the survivor.

The interview data placed the men's main social resource as being the day centre Headway. In the narratives, the men spoke of the dedicated support they received from health professionals, volunteers and most importantly each other, as other men with ABI. This provision seemed important to the attendees and may account for the reduced power the injury had on the men's overall well being. The combination of the two research methods has been able to demonstrate that positive improvements take place in problematic areas over time in a controlled study, and that it appears connected to a particular resource (Headway). This type of finding has real world application for future allocation of resources.

8.2.2 *Women with ABI*

Previous work suggested that sexual/facial attractiveness (Franzoi & Shields, 1984), weight issues and physical functioning are important for body image and affect self esteem in healthy women. The quantitative data in chapter three suggested that following brain injury sexual/ facial attractiveness is no longer important, effectively there is no room for this concern any more.

The concern with waist and the EDI figures, suggest a risk of body image disturbance in ABI group. There is an interesting phenomenon with waist satisfaction/ EDI subscales. The female questionnaire data (chapter two) seems to suggest that this weight and eating disorder symptomology concern is fairly pervasive in all women.

A small group of women seemed to be effected by neurotic and potentially pathological disorders of body image. Women who have an ABI are no different, and in fact there is tentative support for the idea that women with ABI may have an elevated risk from these types of body image disorders. Elevated risk for body image disorders has been found in other medical conditions (Gross et al, 2000).

Chapter three revealed that in the sample of women with ABI the body schema was dominated by the health concern. Health seemed to be connected to multiple things e.g. social functioning, employment, age, self esteem and depression. The findings would suggest that brain injury affects identity in a profound way. Satisfaction with health was of central importance in the sample of women with ABI, and had many correlates such as social and employment difficulties after ABI. Satisfaction with health was also related to age and again suggested the role of perception in the determination of psychological health post injury.

The relationship that age seemed to play in satisfaction with health is interesting in the context of the ideas of McKee (1998) and the body drop. Such a finding would support the idea that the way you appraise a brain injury has an impact on recovery. There seemed to be no relationships between any disability measures and the psychological distress reported. This finding replicates the results of the male study and would suggest that the meaning the individual attaches to their injury is more important than any objective measure of disability or dysfunction.

There was no significant difference in anxiety scores between ABI and control groups. This finding again supports Crawford et al (1994) and their research that found that anxiety is elevated in the general population in a large-scale study using the HADs.

Depression was significantly greater in ABI group, compared to a control group. Depression correlated with many daily living variables in ABI group such as, social functioning, anxiety and psychological well being. Depression also correlated with satisfaction with several body parts (appetite, physical stamina, biceps, physical condition, health).

Self esteem correlated with health in women with ABI. This can be taken as evidence that the women appeared to internalise their condition, having an ABI made the women feel less good about themselves. This can be seen in light of the body drop (McKee, 1998) and the idea that this single injury dramatically affected the way the body appears, functions and is understood. It is now talking an unfamiliar language (Gadow, 1980). Any attempt to understand female body image post injury needs to take account of these negative evaluations, and the possibility that the process of adjustment may involve living in the world as an undesired self (Oglive, 1987). The findings from chapter three would provide evidence that ABI is a move from a desired to an undesired state.

The findings would suggest that having an ABI is extremely significant for the female self concept. The suggestion is that they have internalised their condition, and the injury provokes a catastrophic emotional reaction.

The quantitative work was able to elucidate differences between healthy and brain injured women. The work was also able to track differences over time, although the major finding was that the negative effects of ABI (chapter 2) are remarkably resistant to change (chapter 3). However while we can state that women have an overwhelming concern with health that dominates post injury and is replicated at two time points, it is the qualitative work that provides the tools able to elucidate the meaning for women with ABI.

The Results of the IPA study suggested that women's experience of ABI can be summarised within 5 major themes. Awareness of change in Self, Grief Response, Searching for Meaning, Comparisons with Past Selves and the Reconstructed Self. The qualitative research therefore provides the model for how women with ABI respond to this event.

The women's accounts suggested that at times during the adaptive process they are overwhelmed by feelings of intense distress. Pennebaker (1997) and Pennebaker and Ball (1986) have stated that emotional expression initially produces an increase in negative effect.

However they believe that the long term effect is an increase in adaptive outcomes such as better health and higher levels of positive effect (Pennebaker, 1997, Pennebaker& Ball, 1986). Perhaps this period of intense emotional distress, termed the grief response, has an adaptive function for women with ABI.

Furthermore the qualitative work revealed the active engagement of the women with their recovery. The women wanted to find out about their condition and findings suggested that an active, engaged, form of coping was associated with better health prognosis, whereas passive avoidant coping strategies were associated with worse prognosis (Billings, Folkman, Acree, Moskowitz & Tedlie, 2000). There are obvious consequences for tailoring rehabilitation by using both these models.

8.3 *Rehabilitation implications: evidence from quantitative and qualitative techniques.*

Male body image is affected following ABI, being primarily concerned with physical and sexual functioning. Men with ABI are affected by body image dissatisfaction and low self esteem. There is no impact on measures of anxiety or depression. This would suggest that such body dissatisfaction is not fundamentally connected to how they see themselves.

Men have dissatisfaction with sexual and physical functioning but it does not affect identity in a powerful way. The evidence from qualitative work suggested that men notice the changes in physical and cognitive functioning following injury, but primarily in terms of the direct changes in their lifestyle. The fact that deficits impair the ability to take part in team sports, manual work or play with children. All the observed changes were concerned with the loss of functioning in a real world setting.

Men seemed able to say I'm a man (with a ABI) and their identity would appear to be less threatened. The findings suggested rehabilitation should be targeted to address these concerns, especially as sexual problems are less likely to be dealt with (Aloni, Keren & Cohen 1999). This would suggest that current rehabilitation models could be able to incorporate these issues. For example that rehabilitation should address body image, boosting confidence in physical and sexual functioning for men with acquired brain injury.

Assessment, treatment strategy, evaluation, modification (the current rehabilitation model) would work if directed at sexual and physical functioning. Support to maintain existing relationships, personal and sexual therapy, having a sexual role, being acknowledged and accepted, as a sexual being are all likely to increase the satisfaction with sexual functioning.

Physical effectiveness could be increased by physical activity; sports, outdoor adventure and even walking will improve physical confidence and expression. The findings also highlight the role of Headway as an important social resource. These seem practical findings that would be amenable to inclusion in current practice.

With women the impact of ABI is of a totally different arena. The women do not have a normal female body image except with exaggerated concerns in an expected direction, with perhaps the exception of weight/ eating disorder symptomology. Even here it is suggested that they might be at elevated risk of eating disorder symptoms, so perhaps their concerns are more pathological than non-ABI women.

What does seem clear is that physical health has emerged as the primary concern, dominating body image dissatisfaction, it seems there is little room for anything else. Certainly there is no room for the facial / sexual attractiveness dimension of female body image concern (Silberstein et al, 1988, Franzoi & Shields, 1984). Concern with facial/sexual attractiveness is no longer relevant to the ABI women.

The powerful affect of health dissatisfaction can be seen with the many significant correlations with social functioning, employment, and psychological health as measured by self esteem and depression.

It seems that whilst there are fewer body parts that ABI women are dissatisfied with, those that they are dissatisfied with are potentially more powerful. It could be suggested that the body drop is relevant. The brain injury has fundamentally affected these women's self concept, their whole identity.

The findings of chapter three are supported in the qualitative research in chapter six; the intense emotional reaction to their injury is a central theme. They realised that they are different. Then reacted to this profound loss, and then started to cope and adapt and accept their new self.

The coping strategies that the women employed were seeking social support, planned problem solving, positive reappraisal and infusing ordinary events with positive meaning. The special role of meaning based coping (Folkman, Moskowitz & Tedlie, 2000) was supported in the qualitative work. This is the personal story that came through from the women's interviews.

The implications for rehabilitation are different for women with an ABI than men with an ABI. Whilst male body image dissatisfaction was at a practical level, being concerned with physical and sexual functioning, (behavioural therapy, social skills training) such an approach is not applicable to women with an ABI.

If the clinician started talking to women about their concerns with physical and sexual functioning, and how best to treat them on a practical and behavioural level, they are likely to think you are missing the point of what it means to have a brain injury and to be a women.

The women felt that they were no longer the same person, and had to deal with the resulting emotional response. This would suggest that clinicians should approach brain injured women in a holistic way. With women it is no good using the assessment, diagnosis, treatment strategy, evaluation method, as any problem is not seen in isolation. Trying to untangle them in a mechanical way may be counter-productive.

It would be advantageous for the clinician to start from the angle of saying how do you feel, the individual may say they don't feel that they are the same person that they were before the injury, and from that you can try to establish in what ways. However the clinician will need time and a non-interventionist approach, so that the individual can tell you about the issues that are affecting them and not the other way round.

It seems important to work from a non-interventionist principle and then go backwards, rather than starting with assessment measures and trying to isolate specific deficits. An approach based on the cognitive models of rehabilitation is likely to miss out a lot of significant details for the woman involved.

For the women it is the way everything fits together that is important, not the isolated parts, hence you get to the statement " I'm not the same person that I was before the injury". The findings would suggest that it is very much about seeing the bigger picture and not getting locked into a narrow conception of the problems encountered by those with ABI.

The implications seem to be that psychotherapy, on an individual or female group basis, might be of benefit. Certainly there is an adaptive process that needs to be worked through. Comparisons of present, past and future selves, seem to have an adaptive function. Working through these feelings of loss seems inevitable, and the clinician should be prepared for an intense emotional response. Trying to manage these feeling seems important for any successful rehabilitation strategy. The evidence would suggest that in the long term such an approach is likely to be beneficial (Pennebaker, 1997, Stoebe et al, 2000).

8.4 *Methodological critique*

The research had several strengths and weaknesses, which need to be explored in relation to the utility of the study. The study has several important features; it had a clinical perspective, it used a combination of methodological approaches, it used existing and novel approaches to investigate the research questions posed. Each of these features will be discussed and addressed in detail.

The clinical design was used specifically to conduct research with individuals with ABI. There are certain limitations imposed with this research approach, which will be discussed. The study had to demonstrate very clear ethical considerations before research could begin. The Local Research Ethic Committee had to give ethical approval, as the participants were NHS patients.

At this early stage in the research process external limitations were put on the design of the study. One example was the assessment of cognitive function. Initially a complete cognitive assessment was suggested. Tools such as the Weshler Memory Scale III or the Conners Continuous Performance Test II could have been used to give more detailed information regarding cognitive functioning. In the original proposal multiple discrete tests were suggested to assess various aspects of cognitive function (memory, attention, executive functioning, information processing, general intelligence).The Local Research ethics committee expressed concern that the complete battery of cognitive assessment in combination with the other body image and mood questionnaires would be too long and demanding for their patients. As a compromise we were allowed to select one alternative cognitive measure. The MMSE was selected for brevity as it was a single global cognitive measure. (Hodges, 1994). It is also one of the most commonly used measures in clinical trials and thus has a considerable advantage in that the widespread use of the same rating scale allows the comparison of different trials. However this measure is not considered substantial enough to permit firm conclusions on distinct aspects of cognitive functions to be drawn. Furthermore the relatively crude nature of the measure will ensure that only substantial improvements in functioning will be registered.

That a complete cognitive battery was left out of the research design is a limitation of the study. Future research could use additional tools to get a complete assessment of cognition. In particular memory, attention, executive functioning, information processing, general intelligence are areas that suggest deeper assessment. Such an approach would allow stronger conclusions regarding the effect of cognitive function to be made.

The study used multiple comparisons the implications are considered in the results. When using ANOVA statistical techniques increasing the number of ANOVAS would not increase the likelihood of getting significant results for any given ANOVA.

The notion of probability is problematic when making multiple comparisons. The probability of finding a significant effect is 1 in 20 (5%). Therefore when you consider 20 tests and only find one of them significant you cannot exclude the possibility that the single significant effect would be due to chance (and not a genuine effect). Indeed this is true for any situation where you use a significance of 5%.

The Bonferroni t test statistic is very similar in conception to the Tukey/Sheffe/Neuman-Keuls/Duncan Multiple Range Tests i.e. it is only really employed after ANOVA to test for differences between groups. A particular feature of this approach is that you are interested in specific planned comparisons after the ANOVA. This is clearly different to the scattergun post hoc approach because you are only going to carry out a limited number of planned comparisons. Because you have planned this before even doing the ANOVA itself, the Bonferroni approach is known as an a priori rather than a post hoc approach (planned prior to the ANOVA rather than merely sorting out any significant effects after the fact). The Bonferroni approach is most often used when you have a control group and a number of treatment groups, and you are most interested in comparing each treatment to the control and not with each other. This approach, just like all other post hoc tests, is to protect against type 1 errors (an "optimistic error").

The impact of multiple comparisons and the interpretation of results are slightly different. Since one ANOVA in every twenty will be significant due to chance is an inherent feature of the system (and there is certainly no universally recognized approach to the problem). It comes down to a question of accumulating evidence of the effect being genuine rather than a type one error. With any experiment it is less about producing a blockbuster experiment that "proves" something beyond all possible doubt- rather it is accumulating a pattern of evidence that leads to a particular conclusion. In the case of this thesis it is a question of whether we are looking at occasional significant results that do not really hang together in a rational way (which suggests perhaps that what we are really dealing with a succession of type 1 errors) or whether the evidence produced across the various studies considered is cohesive, consistent and persuasive.

The combination of quantitative and qualitative approaches is a feature that could be evaluated and considered in regard to future research. The study used both methods and the strengths of this approach are that generalisations can be made about particular groups, as well as accounting for the individuals experience. This approach might be considered to use all available tools to answer the research question. A limitation of this approach is that most academics are aligned more closely to one tradition. One perception is that this type of research is messy and shows a lack of commitment to either an empirical or interpretative ideology. A strength is that by considering both traditions we are likely to get more information as both have considerable merit.

Future research could incorporate the mixing of quantitative and qualitative methods, this would allow the research design to be replicated. However one strength is that researchers from both traditions could investigate a smaller component in isolation if they felt that they were drawn to one aspect of the research. By using both approaches this option is left open.

8.5 *Future Research Directions*

The present research was able to expand existing findings by separating male and female concerns. The separation of male and female body image concerns following ABI highlights several areas that might require further investigation. The present research showed that male body image concerns following ABI focused on functionality and sexuality. The men in this study had essentially the same concerns as non-ABI males but differed in magnitude.

The female group presented a different picture. This group did not express typically "female" concerns (for example with facial attractiveness) in a more extreme form. The female group had qualitatively different concerns from the non-injured women. This was reflected in a lack of concern with facial attractiveness and a new central concern with health. The importance of health was further confirmed with the qualitative interviews. These new dimensions of body image concern indicate a new body schema has developed.

Further research into how this new body image schema develops is indicated. As this schema it is not consistent with the non-injured women in the present study, or the published work on typical female body image, further replication is indicated.

If it is established that this new body schema is distinct and present for a significant number of women post injury, comparisons with other chronic conditions could prove to be illuminating. If such comparisons were made it would be important to separate out neurological and non-neurological conditions to take account of any important cognitive aspects. The neurological groups might include women with spinal cord injury or Bell's palsy. The non-neurological group might include other non-neurological chronic conditions. Examples might include women with psoriasis, cardiac disease, and burns victims.

A further factor to control for is that you are comparing like with like, because the women in the present research had an acquired injury it would be important to make comparisons, with women with acquired conditions. For example cerebral palsy from birth would not be a suitable comparison group as it is a developmental disorder.

The research indicated other areas as being potentially rich for future exploration. A further significant area would be the female group, which was heterogeneous, in brain injury terms; it included women with ABI and stroke. Whilst the male groups were large enough to be split according to aetiology of injury (stroke versus TBI), this was not possible (partly due to the lesser number of women with TBI). Studies that could replicate the comparisons made within the male group could be usefully employed here. A larger cohort of women with acquired brain injuries is indicated in order to allow discrete aetiologies to be compared.

The longitudinal study was only a one-year follow up (all that was reasonable in a three year period of research). However rehabilitation professionals acknowledge that recovery from ABI should be conceptualised in years not months, so perhaps

12 months was too soon to expect to see differences within body image constructs. A longititudinal study that was able to track changes within a cohort every year for a period of 10-15 years would perhaps reflect the dynamic nature of recovery from ABI.

The final and potentially most useful area of future research would be to assess the effectiveness of psychological interventions to improve body image post injury. As outlined previously, exercise, applied social comparison theory, social support, engagement in activities with healthy and disabled peers are all methods that have published successful results in the field of general body image research. A study designed to assess the utility of these methods for improving body image post injury could translate into practical use in rehabilitation.

Depending on the size of the clinical group available a between groups analysis could compare the effectiveness of all of these interventions on improving body image post injury. As male and female body image concerns differ it may be that gender specific interventions are indicated.

8.6 *Conclusion*

It seems clear that when trying to rehabilitate those with ABI, it is not only the cognitive deficits that will have significance for that person's well being post injury. ABI causes physical changes that are significant for the person; furthermore such changes are often, the most salient change for the person. The findings provide the first attempt to build a model of body image concern following ABI for both sexes. In addition the findings connect body image concerns with psychological distress in males and females following ABI.

The findings can be connected to existing theory, in particular the role of a traumatic event in changing the physical self, which in turn triggers a self reappraisal termed the "body drop" (McKee, 1988). This study contributes to a literature previously only concerned with gerontology and falls, and expands the model to account for young people following ABI. The findings can be can be seen as a contribution to research in this area, to be considered part of a larger picture.

The research is firmly located in the social structure of the participants and takes account of their lived experience. This type of research has important practical value. The best strategies to translate these findings into rehabilitation are considered in depth, with the hope that they can be practically applied.

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I GOT LIFE

Ain't got no home, ain't got no shoes
Ain't got no money, ain't got no class
Ain't got no friends, ain't got no schoolin'
Ain't got no wear, ain't got no job
Ain't got no man

Ain't got no father, ain't got no mother
Ain't got no children, ain't got no folks
Ain't got no earth, ain't got no water
Ain't got no ticket, ain't got no token
Ain't got no love

I got my hair, I got my head
I got my brains, I got my ears
I got my eyes, I got my nose
I got my mouth, I got my smile

I got my tongue, I got my chin
I got my neck, I got my tits
I got my heart, I got my soul
I got my back, I got my sex

I got my arms, I got my hands
I got my fingers, Got my legs
I got my feet, I got my toes
I got my liver, Got my blood

Got life , I got my life

NINA SIMONE

Appendix I

Parc Singleton, Abertawe SA2 8PP Singleton Park, Swansea SA2 8PP

Psychological effects of Brain Injury

Please tick one of the boxes, beneath each statement.

Have you read the information booklet?
Yes [ ] No [ ]

Have you had the opportunity to ask questions and discuss this study?
Yes [ ] No [ ]

Have you received satisfactory answers to all your questions?
Yes [ ] No [ ]

Have you received enough information about the study?
Yes [ ] No [ ]

To whom have you spoken?..

Do you understand that you are free to withdraw from the study:
At any time?
Without having to give a reason for withdrawing?
And Without affecting your future medical care?
Yes [ ] No [ ]

Do you agree to take part in this study?
Yes [ ] No [ ]

Signed...
Date.......................................

Name in block letters..
....

Signed (Researcher)..............................
Date.......................................

Pennaeth yr Adran · Professor David Oborne · Head of Department
Tel 01792 295278 Fax 01792 295679 Email psychology@swansea.ac.uk

Appendix I

Personal Information Sheet

We would be grateful if you could fill this in this sheet so that we can compare your information more accurately with the clinical group.

1.) Age? ☐

2.) **Gender?** Male ☐ Female ☐

3.) Education: *Please tick all that apply*

Secondary School ☐ Further Education/ A-levels ☐ Higher Education/ Degree ☐

4.) Occupation of chief income earner? ☐

5.) Weight? (In stones and pounds) ☐

6.) Height? (In feet and inches) ☐

7.) Have you ever had: *Please tick all that apply*

A head injury? ☐

A stroke? ☐

A prior history of epilepsy? ☐

Any other neurological illness? ☐

A prior history of psychiatric illness? ☐

A prior history of drug/ alcohol dependency? ☐

7.) **Could you please leave your contact details**, e.g., address for questionnaires to be sent

…………………………………………………………………………………

…………………………………………………………………………………

…………………………………………………………………………………

…………………………………………………………………………………

Thank you very much for your time

Appendix II

Please read the following statements and rate them using a number from the scale to indicate what comes closest to your opinion.

1. I eat sweets and carbohydrates without feeling nervous.

Always	Usually	Often	Sometimes	Rarely	Never
1	2	3	4	5	6

2. I think my stomach is too big.

Always	Usually	Often	Sometimes	Rarely	Never
1	2	3	4	5	6

3. I think about dieting.

Always	Usually	Often	Sometimes	Rarely	Never
1	2	3	4	5	6

4. I think my thighs are too large.

Always	Usually	Often	Sometimes	Rarely	Never
1	2	3	4	5	6

5. I feel extremely guilty about overeating.

Always	Usually	Often	Sometimes	Rarely	Never
1	2	3	4	5	6

6. I think my stomach is just the right size.

Always	Usually	Often	Sometimes	Rarely	Never
1	2	3	4	5	6

7. I am terrified about gaining weight.

Always	Usually	Often	Sometimes	Rarely	Never
1	2	3	4	5	6

8. I feel satisfied with the shape of my body.

Always	Usually	Often	Sometimes	Rarely	Never
1	2	3	4	5	6

9. I exaggerate or magnify the importance of weight.

Always	Usually	Often	Sometimes	Rarely	Never
1	2	3	4	5	6

10. I like the shape of my buttocks.

Always	Usually	Often	Sometimes	Rarely	Never
1	2	3	4	5	6

11. I think my hips are too big.

Always	Usually	Often	Sometimes	Rarely	Never
1	2	3	4	5	6

12. I am preoccupied with the desire to be thinner.

Always	Usually	Often	Sometimes	Rarely	Never
1	2	3	4	5	6

13. I think my thighs are just the right size.

Always	Usually	Often	Sometimes	Rarely	Never
1	2	3	4	5	6

14. If I gain a pound I worry that I will keep gaining.

Always	Usually	Often	Sometimes	Rarely	Never
1	2	3	4	5	6

15. I think that my buttocks are too large.

Always	Usually	Often	Sometimes	Rarely	Never
1	2	3	4	5	6

16. I think my hips are just the right size.

Always	Usually	Often	Sometimes	Rarely	Never
1	2	3	4	5	6

Please read the following statements and rate them using a number from the scale to indicate what comes closest to your opinion. Please answer as honestly as possible.

1. On the whole I am satisfied with myself.

Strongly Agree	Agree	Disagree	Strongly Disagree
1	2	3	4

2. At times I Think I am no good at all.

Strongly Agree	Agree	Disagree	Strongly Disagree
1	2	3	4

3. I feel that I have a number of good qualities.

Strongly Agree	Agree	Disagree	Strongly Disagree
1	2	3	4

4. I am able to do things as well as most other people.

Strongly Agree	Agree	Disagree	Strongly Disagree
1	2	3	4

5. I feel that I do not have much to be proud of.

Strongly Agree	Agree	Disagree	Strongly Disagree
1	2	3	4

6. I certainly feel useless at times.

Strongly Agree	Agree	Disagree	Strongly Disagree
1	2	3	4

7. I feel that I'm a person of worth, at least on an equal plane with others.

Strongly Agree	Agree	Disagree	Strongly Disagree
1	2	3	4

8. I wish I could have more respect for myself.

Strongly Agree	Agree	Disagree	Strongly Disagree
1	2	3	4

9. All in all, I am inclined to feel that I am a failure.

Strongly Agree	Agree	Disagree	Strongly Disagree
1	2	3	4

10. I take a positive attitude towards myself.

Strongly Agree	Agree	Disagree	Strongly Disagree
1	2	3	4

HAD Scale

Tick only one box in each section

el tense or 'wound up':
- ost of the time ☐ ▨
- lot of the time ☐ ▨
- ime to time, Occasionally ☐ ▨
- ot at all ☐ ▨

ill enjoy the things I used to enjoy:
- Definitely as much ▨ ☐
- Not quite so much ▨ ☐
- Only a little ▨ ☐
- Hardly at all ▨ ☐

et a sort of frightened feeling as if mething awful is about to happen:
- Very definitely and quite badly ☐ ▨
- Yes, but not too badly ☐ ▨
- A little, but it doesn't worry me ☐ ▨
- Not at all ☐ ▨

an laugh and see the funny side of ings:
- As much as I always could ▨ ☐
- Not quite so much now ▨ ☐
- Definitely not so much now ▨ ☐
- Not at all ▨ ☐

orrying thoughts go through my ind:
- A great deal of the time ☐ ▨
- A lot of the time ☐ ▨
- From time to time but not too often ☐ ▨
- Only occasionally ☐ ▨

feel cheerful:
- Not at all ▨ ☐
- Not often ▨ ☐
- Sometimes ▨ ☐
- Most of the time ▨ ☐

can sit at ease and feel relaxed:
- Definitely ☐ ▨
- Usually ☐ ▨
- Not often ☐ ▨
- Not at all ☐ ▨

I feel as if I am slowed down:
- Nearly all the time ▨ ☐
- Very often ▨ ☐
- Sometimes ▨ ☐
- Not at all ▨ ☐

I get a sort of frightened feeling like 'butterflies' in the stomach:
- Not at all ☐ ▨
- Occasionally ☐ ▨
- Quite often ☐ ▨
- Very often ☐ ▨

I have lost interest in my appearance:
- Definitely ▨ ☐
- I don't take so much care as I should ▨ ☐
- I may not take quite as much care ▨ ☐
- I take just as much care as ever ▨ ☐

I feel restless as if I have to be on the move:
- Very much indeed ☐ ▨
- Quite a lot ☐ ▨
- Not very much ☐ ▨
- Not at all ☐ ▨

I look forward with enjoyment to things:
- As much as ever I did ▨ ☐
- Rather less than I used to ▨ ☐
- Definitely less than I used to ▨ ☐
- Hardly at all ▨ ☐

I get sudden feelings of panic:
- Very often indeed ☐ ▨
- Quite often ☐ ▨
- Not very often ☐ ▨
- Not at all ☐ ▨

I can enjoy a good book or radio or TV programme:
- Often ▨ ☐
- Sometimes ▨ ☐
- Not often ▨ ☐
- Very seldom ▨ ☐

Do not write below this line

Please respond to each statement by indicating how much you agree or disagree with each statement. For example, if you agree with Question 1. You will circle number 5.

1. My Body weight has made me think of going on a diet.

1	2	3	4	5	6	7
Definitely Disagree						Definitely Agree

2. I worry that I look thin and skinny.

1	2	3	4	5	6	7
Definitely Disagree						Definitely Agree

3. Men should be of a bigger build than females.

1	2	3	4	5	6	7
Definitely Disagree						Definitely Agree

4. If my build was bigger I would feel more confident.

1	2	3	4	5	6	7
Definitely Disagree						Definitely Agree

5. If I lost weight I would be more outgoing.

1	2	3	4	5	6	7
Definitely Disagree						Definitely Agree

6. I would like to gain a bigger build.

1	2	3	4	5	6	7
Definitely Disagree						Definitely Agree

7. Losing weight is a goal I am aiming for.

1	2	3	4	5	6	7
Definitely Disagree						Definitely Agree

8. It's more acceptable for males to be muscular than it is for females.

1	2	3	4	5	6	7
Definitely Disagree						Definitely Agree

9. I would feel happier if I weighed more.

1	2	3	4	5	6	7
Definitely Disagree						Definitely Agree

10. I am concerned that I might have put on weight.

1	2	3	4	5	6	7
Definitely						Definitely
Disagree						Agree

11. On the whole, it is accepted that females diet but men work out.

1	2	3	4	5	6	7
Definitely						Definitely
Disagree						Agree

12. I believe that females seek males that are thinner than me.

1	2	3	4	5	6	7
Definitely						Definitely
Disagree						Agree

13. It's less desirable for males to be thin than for females

1	2	3	4	5	6	7
Definitely						Definitely
Disagree						Agree

14. I find myself wanting to have a bigger build.

1	2	3	4	5	6	7
Definitely						Definitely
Disagree						Agree

15. Losing weight would make me a happier person.

1	2	3	4	5	6	7
Definitely						Definitely
Disagree						Agree

16. I associate losing weight with being skinny, which I would view as undesirable.

1	2	3	4	5	6	7
Definitely						Definitely
Disagree						Agree

17. I think people think of me as weak because of my size.

1	2	3	4	5	6	7
Definitely						Definitely
Disagree						Agree

18. Small builds are more suited to females than males.

1	2	3	4	5	6	7
Definitely						Definitely
Disagree						Agree

Listed below are areas of the body. Please indicate how you feel about each part of your body using the scale below.

1. Nose

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

2. Appetite

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

3. Physical Stamina

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

4. Reflexes

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

5. Lips

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

6. Muscular Strength

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

7. Waist

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

8. Body Scent

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

9. Energy Level

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

10. Thighs

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

11. Ears

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

12. Biceps

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

13. Chin

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

14. Body Build

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

15. Physical Co-ordination

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

16. Buttocks

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

17. Agility

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

18. Width of Shoulders

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

19. Arms

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

20. Chest or Breasts

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

21. Appearance of eyes

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

22. Cheeks/Cheekbones

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

23. Hips

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

24. Legs

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

25. Figure or Physique

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

26. Sex Drive

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

27. Feet

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

28. Sex Organs

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

29. Appearance of Stomach

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

30. Health

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

31. Sex Activities

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

32. Body Hair

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

33. Physical Condition

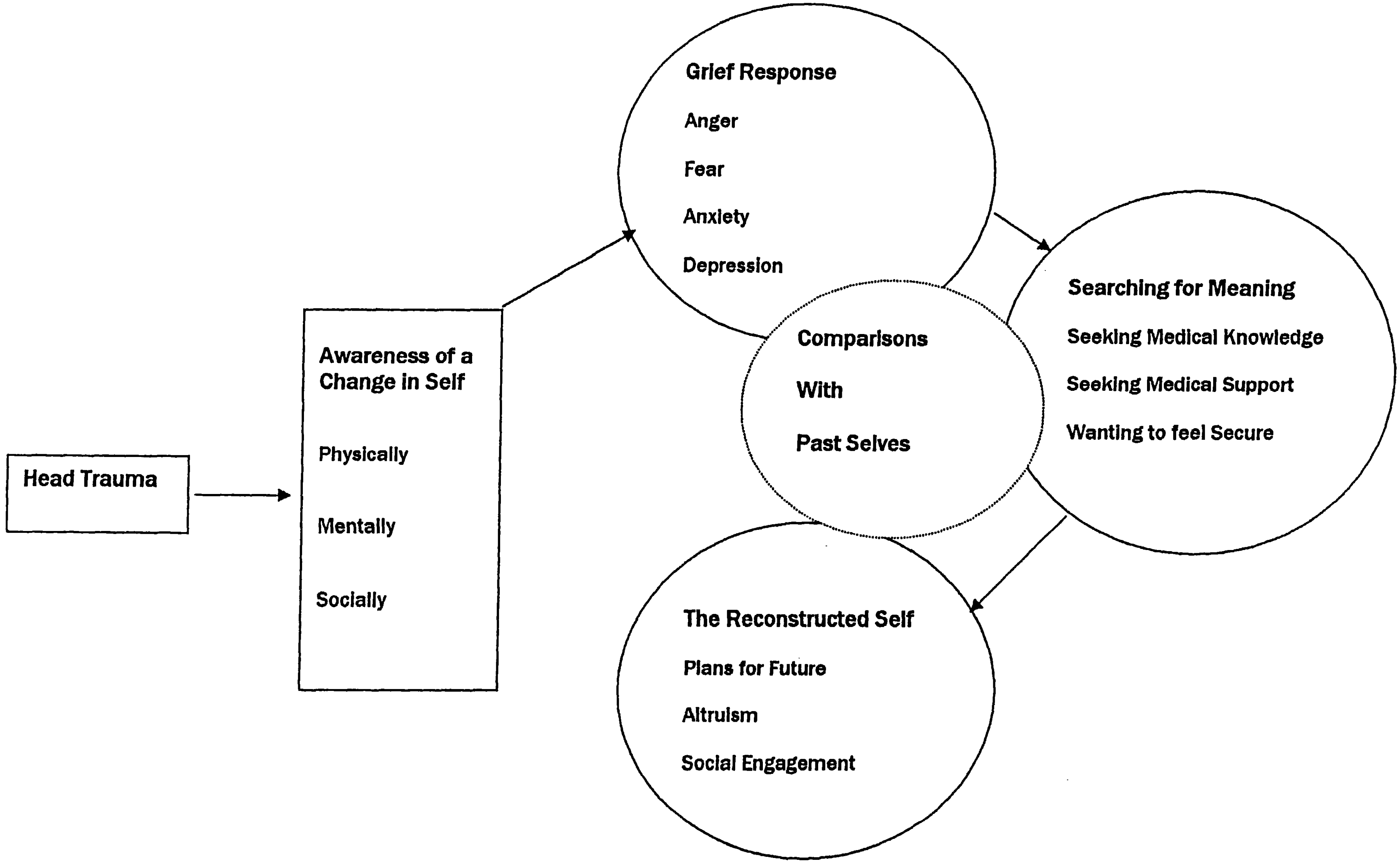
1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

34. Face

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings

35. Weight

1	2	3	4	5
Have strong negative feelings	Have moderate negative feelings	Have no feelings either way	Have moderate positive feelings	Have strong positive feelings



Appendix III. A model of the loss of self and development of new self in females with acquired brain injury.