# Volume One

# Major Research Project

# An exploration of the Psychological Well-Being and relationship quality of partners and spouses after acquired brain injury

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# Contents

Page

**Abstract**

**Abbreviations guide**

**Acknowledgements**

**Dedication**

**INTRODUCTION**

**1.1 Overview and background to the study....................................1**

**1.2 What is Acquired Brain Injury? ..............................................4**

Terminology........................................................................... ....4

Causes or aetiologies of ABI.........................................................4

Sequelae of ABI for the individual...................................................7

*Physical*.................................................................... 7

*Cognitive*....................................................................8

*Emotional*...................................................................9

*Personality and behaviour*..............................................10

*Social and Vocational outcomes*.......................................10

**1.3 Impaired awareness of deficit after acquired brain injury............11**

Terminology of impaired awareness of deficit......................................11

The heterogeneity of the phenomenon...............................................12

Models of impaired awareness of deficit.............................................12

Measuring impaired awareness of deficit............................................15

The relationship between severity and impaired

awareness of deficit....................................................17
The relationship between time lapsed since injury and impaired
awareness of deficit ....................................................18
Implications of impaired awareness of deficit.....................................19
Summary...........................................................................20
**1.4 The effects of brain injury on partners and spouses.................21**
Family members after brain injury – theoretical models...........................21
Spouse and partner outcomes after ABI.............................................22
Factors that influence partner outcomes............................................26
*Severity*.........................................................................*27*
*Time since injury*................................................................*28*
*The functional abilities of the patient*...........................................*29*
*Awareness of deficit*.............................................................*31*
Summary...........................................................................32
**1.5 The effect of brain injury on relationships..............................34**
Change in family dynamics after ABI................................................34
Change in nature of the marital/partner relationship after ABI....................34

Factors that impact on the nature of relationships after brain injury

*Severity of the injury*..........................................................*37*
*Time since injury*................................................................*38*
*Personality change & functional ability of the injured person*...................*39*
*Awareness of deficit*.............................................................*40*
*Other factors*....................................................................*40*
Summary...........................................................................41
**1.6 Psychological well-being.................................................43**

Introducing the concept of well being........................................ .......43

Well being, growth and flourishing in significant others after ABI...............45

Summary...............................................................................48

**1.7 Overall summary and research questions...............................49**

Overall Summary...................................................................50

Research Questions...............................................................51

## METHOD

**2.1 Design.................................................................. 51**

**2.2 Statistical Power.................................................... 52**

**2.3 Ethical Approval.................................................... 53**

**2.4 Measures.............................................................. 54**

*'Level of awareness of deficit'..................................................53*

*Partner subjective rating of current neurobehavioral function...................55*

*Personality change..............................................................56*

*Current patient level of functioning..........................................57*

*Severity...............................................................................58*

*Partner psychological well-being..............................................58*

*Quality of Current Relationship...............................................59*

*Relationship satisfaction preinjury and change in relationship satisfaction since injury.......60*

*Financial Strain.....................................................................60*

*Socio-Economic Classification..................................................60*

**2.5 Procedure..............................................................61**

*Couples contacted through a brain injury rehabilitation unit........................61*

*Couples contacted through Headway charity*......................................62

**2.6 Recruitment**..........................................................................62

*Inclusion and exclusion criteria*.........................................................62

*Brain injury unit participants*............................................................64

*Headway participants*......................................................................65

## RESULTS

**3.1 Describing the sample**...........................................................67

*Demographic characteristics of couples*.......................................67

*Relationship characteristics*.........................................................70

*Brain injury related characteristics*..............................................70

*Scores on important measures*....................................................71

Preliminary exploration and preparation of data.....................................73

Comparing TBI couples with couples where the brain injury was from other causes or aetiologies.......................................................74

**3.2 Main hypotheses testing**.........................................................78

Exploring the Psychological Well Being of partners..............................78

Exploring the quality of the relationship between the partner and the injured person as perceived by the partner..................................80

*Premorbid relationship*..................................................................80

*Current relationship*.......................................................................81

Exploration and preparation of data prior to regression analyses........ ......83

Which, if any, brain injury related factors are associated with dimensions of partner Psychological Well-Being?....................... ....87

Which brain injury related factors are associated with the quality of the relationship between the partner and the person with ABI as perceived by the partner?..............................91

**3.3 Subsidiary hypotheses testing................................................94**

Exploring whether other factors are associated with partner PWB and relationship quality between the injured person and the partner......................................................................95

*Gender and marital status*..........................................................*95*

*Length of relationship preinjury*................................................ *95*

*Presence of children/adolescents at home*..................................*96*

Exploring awareness of deficit........................................................97

Do *patients rate themselves as having fewer deficits and changes than partners rate patients as having?*..................... *98*

*Do patients show different levels of awareness for different functional deficits?*..................................................................*98*

*Do levels of awareness of deficit in the patient show any change over time after injury?*..............................................*100*

*Are levels of awareness of deficit linked with the initial severity of the injury?*..........................................................*101*

## DISCUSSION

**4.1 Overview of aims, methods and findings of the study.............102**

**4.2 Interpreting findings..........................................................105**

Main hypotheses..........................................................................105

Exploring the Psychological Well-Being of partners of individuals with ABI...................................................105

Exploring the quality of the relationship between the partner and the person with ABI as perceived by the partner...........107

Which, if any, brain injury related factors are associated with dimensions of partner Psychological Well-Being?................111

Which brain injury related factors are associated with the quality of the relationship between the partner and the person with ABI as perceived by the partner?................115

Subsidiary hypotheses

Exploring whether other factors are associated with the Psychological Well Being of the partner and relationship quality between the injured person and the partner.............119

Exploring awareness of deficit................................................121

**4.3 Strengths and limitations...................................................123**

Generalisability of the findings......................................................123

Design........................................................................................124

Measurement issues.......................................................................125

**4.4 Future Research..............................................................129**

**4.5 Implications.....................................................................132**

Theoretical, scientific and research implications...................... .........132

Clinical and professional implications..............................................134

**REFERENCES.............................................................................137**

**APPENDICES.................................................................. ..........163**

A Letters of ethical approval...................................................164

B Rough protocol for initial telephone conversation with partner/spouse .......... 166
C Information sheets and consent forms .......... 167
D Awareness Questionnaire – patient and partner forms .......... 171
E Neurobehavioural Rating Scale .......... 175
F Partner rating of personality change .......... 176
G Patient Competency Rating Scale – Partner version .......... 177
H Measures of Severity .......... 179
I Ryff Scales of Psychological Well Being .......... 180
J Details of Psychological Well Being scales chosen for the study .......... 183
K Dyadic Adjustment Scale .......... 184
L Rating of preinjury relationship satisfaction and change in relationship satisfaction since injury .......... 187
M Rating of financial strain .......... 188
N Classifying Social Class .......... 189
O Letter and Personal details forms .......... 190
P Missing data management .......... 194

## Content of tables

Page

Method

**Table 1** – Frequencies of distribution of questionnaire packs and exclusions in phase two of brain injury unit recruitment................. 64

**Table 2** – The distribution of responses for questionnaire packs sent out to brain injury unit participants......................................65

Results

**Table 3** – Distribution of ethnicity of partners and patients........................69

**Table 4** – Distribution of religious affiliations of partners and patients in the sample............................................................69

**Table 5** – The distribution of number of children aged 18 years or below living at home...............................................................70

**Table 6** – Distribution of cause or aetiology of brain injury in the sample.........................................................................71

**Table 7** – Means and standard deviations for major measures of patient functioning...........................................................72

**Table 8** – Means and standard deviations for measures of
partner PWB and relationship quality....................................................72

**Table 9** – Means and standard deviations of demographic and
injury related variables in the TBI and 'other injuries' groups......................75

**Table 10** – Means and standard deviations on major measures
in the TBI and 'other injuries' groups....................................................77

**Table 11** – Comparison of PWB scores for individuals in the current
sample with the individuals in the 'Life Histories and
Health in Midlife' study.....................................................................79

**Table 12** – Characteristics of the sample in the original scale development
study (Spanier, 1976) compared with partners in the current sample.........82

**Table 13** - Comparison of scores of the current sample with
those of the original sample (Spanier, 1976) ................................. .......82

**Table 14** - The inter-correlations of potential independent variables............84

**Table 15** – The inter-correlations between continuous
independent and dependant variables...................................................86

**Table 16** – Inter-correlations of Psychological Well Being and

relationship quality measures........................................................87

**Table 17** - Hierarchical regression analyses for the three dimensions of PWB in partners: Environmental Mastery, Personal Growth and Positive Relations with Others..............................................89

**Table 18** – Intercorrelations of PCRS subscales with regression controlling variables and Environmental Mastery...................................90

**Table 19** – Regression analysis to investigate which subscales of the PCRS predict Environmental Mastery...............................................91

**Table 20** – Hierarchical regression analyses predicting relationship quality (DAS total score)........................................................92

**Table 21** – Intercorrelations of NRS subscales with regression controlling variables and relationship adjustment scores.......................93

**Table 22** - Hierarchical regression analyses for relationship quality using subscales of the NRS as predictors (after controlling for demographics)...................................................94

**Table 23** – The descriptive data on well-being and relationship adjustment for those in shorter and longer relationships prior to injury .......................96

**Table 24** - Descriptive data for PWB and relationship quality measures for those with and without children aged 18 years and younger living at home........................................................................97

**Table 25** – Means and standard deviations for partner ratings, patient ratings and for 'awareness' discrepancy scores on the AQ...................................................................98

**Table 26** – Correlations showing the link between awareness of deficit and length of time since injury...................................................100

**Table 27** – Results of comparisons of levels of 'awareness' between different severity groups..................................................101

# Content of figures

Page

## Method

**Figure 1** – Flow chart of recruitment ....................................................66

## Results

**Figure 2** – Distribution of social class of couples based on highest level of occupation achieved by patient or partner ........................ 67

**Figure 3** – Distribution of partner perceived financial strain in couples ..........................................................................................67

**Figure 4** - Partner ratings of personality change in the patient as a result of the injury ............................................................. ......72

**Figure 5** – The distribution of retrospective ratings of satisfaction with the relationship prior to injury ............................................. ......79

**Figure 6** - Partner ratings of change of satisfaction with relationship now compared to before the injury .............................. ......80

**Figure 7** - Average discrepancy per item on Awareness Questionnaire subscales measuring cognitive, behavioural and physical (motor/sensory) domains of function ......................... ...98

# Abstract

Historically, the acquired brain injury (ABI) literature has tended to address the negative outcomes of spouses and caregivers. As a result, the area of positive functioning, or 'flourishing', has been neglected. The field has also tended to focus on psychological outcomes to the exclusion of understanding relationships, particularly between spouses or partners, after ABI. The effect of 'awareness of deficit', a common consequence of ABI, on partners or spouses is also relatively unexplored. This study was intended to bridge these gaps. It aimed to explore the positive Psychological Well-Being (PWB) of partners of persons with ABI; the nature of the couple relationship; and what factors affect these outcomes. The sample consisted of 46 partners of patients with acquired non-progressive brain injury (traumatic brain injury, 50%; cerebrovascular accident, 37%; anoxia, 7%; infection, 4%; other, 2%) in the chronic phase of injury. Contacted through a neurorehabilitation unit and a charity, couples were required to complete postal questionnaires and partners, a follow up semi-structured telephone interview.

Using three scales of Psychological Well-Being (e.g. Ryff, 1989), partners appeared able to achieve PWB in certain dimensions ('Personal Growth', PG; 'Positive Relations with Others', PR) but not others ('Environmental Mastery', EM). On the Dyadic Adjustment Scale (DAS; Spanier, 1976), certain relationship dynamics were also found to be preserved (cohesion, expression of affection) whilst others suffered (overall adjustment, consensus, satisfaction). About a third of the couple relationships were considered

'poorly adjusted' by commonly used cut-offs. The trend was for partners to be less satisfied with their relationship with the injured person now compared to before the injury, although a minority was more satisfied.

Lower patient current functioning (particularly in activities of daily living; Patient Competency Rating Scale, PCRS) emerged as predictive of better partner PWB in one dimension (EM) although no brain injury factor was predictive of other dimensions (PG, PR). Similarly, more severe patient neurobehavioural symptoms (Neurobehavioural Rating Scale, NRS; Levin et al, 1979; particularly 'somatic/anxiety' symptoms) and lower satisfaction with preinjury relationship were predictive of poorer current relationship quality. Awareness of deficit, length of time since injury and injury severity were predictive neither of PWB nor relationship quality. Those with children/adolescents at home had greater relationship cohesion but were no different in other aspects of the relationship and partner PWB. Length of time in relationship preinjury had no association with outcomes.

In exploring impaired awareness of deficit, patients rated themselves as having significantly fewer deficits than partners rated them, and 'awareness' was more impaired for cognitive and behavioural than physical deficits. Awareness was not associated with time since injury or severity. The strengths and limitations of the study and the implications for theory, research, professional and clinical practice are discussed.

## Abbreviations Guide

| | |
|---|---|
| **ABI** | *Acquired brain injury* |
| **AQ** | *Awareness Questionnaire* |
| **BSI** | *Brief Symptom Inventory* |
| **CVA** | *Cerebrovascular accident* |
| **EM** | *Environmental Mastery* (a dimension of Psychological Well-Being) |
| **FAD** | Family Assessment Device; measures family functioning |
| **GCS** | *Glasgow Coma Scale*; measures depth of coma or unconsciousness |
| **GHQ** | *General Health Questionnaire* |
| **NRS** | *Neurobehavioural Rating Scale* |
| **PCRS** | *Patient Competency Rating Scale* |
| **PG** | *Personal Growth* (a dimension of Psychological Well-Being) |
| **PR** | *Positive Relations with Others* (a dimension of Psychological Well-Being) |
| **PTA** | Length of *Post-Traumatic Amnesia* following brain injury |
| **PWB** | *Psychological Well-Being* |
| **SCL-90** | *Symptom Checklist-90* |
| **SCI** | *Spinal cord injury* |
| **TBI** | *Traumatic brain injury* |

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Most of all, thank you to all brain injured patients and their partners and spouses who took part, for their generosity and touching honesty in allowing me insight into life after brain injury.

# **Dedication**

I would like to dedicate this thesis to my parents, Margaret and Dave Whelan. I want to say thank you for all the support you have shown to me, financially, practically and emotionally; for always being there when I have needed you; and for your great humour, intelligence and compassion. Thank you.

# Introduction

## 1.1 Overview and background to the study

> *"There are places in man's heart which do not yet exist, and*
> *into them enters suffering, so that they may have existence"*
>
> (Boly, cited in Adams, 1996)

Acquired brain injury (ABI) can be an unexpected and devastating condition which has long term consequences not only for the injured person but also for their family. The deficits left with the injured person depend on the nature, extent and location of damage to the brain and the emotional reaction of the person to his/her changes (Lishman, 1998) and can include cognitive, behavioural, physical and emotional impairments and handicaps (Wilson and Powell, 1994). A common consequence of ABI is impaired self awareness or the inability to accurately perceive the brain injury-related deficits and changes (Prigatano and Schachter, 1991). This can have implications for the patient's rehabilitation, employment and, importantly, interpersonal relationships (e.g. Lezak, 1988).

Family members often take responsibility for the care of the injured person after acute care and rehabilitation have subsided (Anderson, 1992; Bishop and Evans, 1995; Frank, 1994), leaving them struggling with demands of the caregiving role, change in life situation and their personal journey of loss of the preinjury person (Lezak, 1988). This struggle may be particularly acute for the partner or spouse, as the brain injured person may no longer be able to fulfill roles in the marital/partner relationship they once could: companion, source of emotional support, lover, co-parent, financial manager and breadwinner (Lezak, 1988). Partners can experience high levels of stress, depression and psychopathology (Livingston, Brooks and Bond, 1985a; Williams, 1993) and negative changes in their relationship with the injured person (Peters, Stambrook, Moore, Zubek, Dubo and Blumenstein, 1992). The severity of the injury, time since injury, patient personality changes and functional disabilities have been associated with family negative psychological and relationship outcomes (e.g. Koskinen, 1998; Peters, Stambrook, Moore and Esses, 1990; Livingston, Brooks and Bond, 1985a; Minnes et al., 2000; Linn et al., 1994) although few studies address the spousal relationship alone. In addition, there is little research into how 'impaired awareness of deficit' in the patient affects partners and their relationship with the injured person (Wallace and Bogner, 2000).

The quote at the start of the introduction suggests that suffering and difficult experiences can actually encourage personal development and 'flourishing'. Indeed, research also shows that individuals can not only recover or show resilience following traumatic events (Bonanno, 2004) but grow and develop as a result (Ryff and Singer, 1995). Despite the acknowledgement that many families manage well and report positive outcomes after brain injury (e.g. Adams, 1995; Perlescz, Kinsella and Crowe, 1999) there are few systematic studies addressing flourishing, growth and positive psychological functioning in partners after ABI. As a result, we have little understanding of factors that influence positive functioning in these individuals.

The main aims of the current study are three-fold: first, to explore the nature of positive Psychological Well-Being (PWB) in partners of individuals with ABI and the nature of the relationship between partners and patients in the chronic phase of injury; second, is to explore which factors are most associated with partner PWB and the quality or 'adjustment' of the couple relationship; third to explore the nature of impaired awareness of deficit in light of conflicting literature.

The introduction is divided into five main sections. The *first section* introduces terms, common causes and long term outcomes of ABI, including impaired awareness of deficit. The *second section* presents theory and research examining the psychological functioning of partners and spouses after ABI and a review of factors that appears to influence outcomes. The *third section* reviews the literature on family relationships after brain injury, with particular reference to the partner or spousal relationship, and explores the kinds of factors that influence relationship outcomes. The *fourth section* introduces the concept of Psychological Well-Being and explores this in relation to the literature on partner/spousal outcomes after ABI. The *fifth and final section* presents the rationale for the study and research questions.

## 1.2 What is Acquired Brain Injury?

### Terminology

The term '*Acquired Brain Injury*' (ABI) refers to brain damage that is not congenital and attained during the life span. This can be caused by traumatic brain injury, cerebrovascular accidents, anoxia, infections and tumours, for example. '*Traumatic Brain Injury*' (TBI), used interchangeably with '*head injury*' or '*closed head injury*', .refers to injury arising from an external force being applied to the head and it's contents. ABI can be sub-classified according to progressiveness of the condition: *degenerative disorders* (e.g. dementias, normal pressure hydrocephalus, multiple sclerosis) are conditions where there is progressive deterioration over time (Lezak, 1983). The brain injuries dealt with in this thesis are acquired and non-progressive. Therefore an overview of some kinds of brain injury that fall into this category and are seen in rehabilitation units will now be provided (for a comprehensive review including of degenerative disorders, see Lishman, 1998, and Lezak, 1983).

### Causes or aetiologies of ABI

TBI tends to be the most commonly seen brain injury in adult rehabilitation settings, followed by haemorrhage, infection, anoxia and cerebrovascular accident (e.g. Bajo, Hazan, Fleminger and Taylor, 1999; Lazaro, Butler and Fleminger, 2000).

#### ***Traumatic brain injury and head injury***

Head injury or TBI can be closed or open (Richardson, 2000). A '*closed head* *injury'* is one that does not expose the contents of the skull whereas, in *'open head injury'*, the contents are exposed as the dura mater membrane (lining the interior of the skull) is torn. Both can produce similar neuropsychological effects, requiring similar management. A *'blunt head injury'* refers to damage that results from *blunt* impact (e.g. acceleration from contact with a moving blunt object/surface or deceleration, with a blunt immovable object). In *'Penetrating head injury'*, caused by sharp objects or propelled missiles, the dura mater is commonly damaged and the contents of the skull is exposed, which can leave the brain open to secondary infection. Blunt and penetrating head injuries differ: the former is more likely to bring about impairment of consciousness and diffuse cerebral damage (Richardson, 2000); and the latter, to cause severe focal lesions with little disturbance of consciousness (Salazar et al 1986). Both may bring about primary injuries (relating to damage the insult itself) and secondary injuries (subsequent neuropathological damage e.g. increased pressure, haematomas, hypoxia). The most common causes of TBI are road traffic accidents, falls, assault and sports/recreational activities (Wilson and Powell, 1994). Males are more likely to sustain a head injury (Willer, Abosch and Dahmer, 1990) and these tend to be more severe (Levin, Grossman, Rose and Teasdale, 1979, cited in Richardson, 2000).

### *Cerebrovascular disorders*

Cerebrovascular Disease or Disorder refers to pathological processes involving blood vessels of the brain (Lishman, 1998) the most common of which is cerebrovascular accident (CVA) or 'stroke'. Brain tissue starvation in cerebrovascular disorders can result from *obstruction* of blood vessels (e.g. through thrombosis, embolism) or from *haemorrhage*, artery rupture and bleeding into the brain (e.g. abnormal/weak blood vessels, aneurysm, subarachnoid haemorrhage). Obstructive strokes tend to cause diffuse and bilateral damage in the acute phase with an increasing degree of lateralization with time depending on location of injury (Lezak, 1983). Haemorrhagic strokes tend to show more widespread effects than obstructive stroke (Lezak, 1983). The incidence of stroke is estimated at 200 per 100, 000 annually (Wade, 1994) and risk increases with age although certain disorders (e.g. subarachnoid haemorrhage) are commonly seen among younger people (Lezak, 1983).

### *Cerebral Infection*

Infectious processes that can have an impact on the central nervous system include HIV, syphilis, encephalitis (produced by influenza, herpes simplex virus, measles), cerebral abscess; and meningitis (Lishman, 1998). Lishman acknowledges, in the case of encephalitis, that the course and effects can vary greatly form person to person even with the same causative organism. Patients with infectious brain damage formed 1% of admissions to a brain injury unit in one study (Lazaro et al, 2000).

### *Metabolic and endocrine disorders*

Metabolic disorders can have an impact on cerebral function (e.g. hyper- and hypothyroidism, diabetes related syndromes, anoxia; Lishman 1998). Anoxia (complete lack of oxygen to the brain) or hypoxia (insufficient supply of oxygen to the brain) can follow cardiac arrest, carbon monxoxide poisoning, surgery under general anesthetic and pulmonary diseases; Lezak, 1983). Anoxia patients formed 24% of rehabilitation unit admissions in one study (Lazaro et al, 2000)

## Sequelae of ABI for the individual

The behavioural expression of brain injury depends on the severity, extent and location of damage (Lezak, 1983). Clinicians tend to define severity on the basis of neurological and neuropsychological impairment in the period just after injury (Richardson, 2000) using three methods: length of coma or loss of consciousness (Williamson, Scott and Adams, 1996), score on the Glasgow Coma Scale (GCS; Teasdale and Jennett, 1974) and length of Post-Traumatic Amnesia (PTA; Kraus and McArthur, 1996). Studies have shown that duration of PTA can be a better assessment of severity of brain damage than either depth or duration of coma especially where there is little loss of consciousness (Wilson, Teasdale, Hadley, Wiedmann and Lang, 1994 cited in Richardson, 2000). The following section provides a brief overview of the kinds of long term sequelae of brain injury, with reference to several of the more commonly seen disorders in neurorehabilitation units (Bajo et al, 1999). Much of the literature concerns more severe injuries.

### *Physical*

Moderate to severe TBI can leave a person with physical difficulties such as impairment of vision and balance, epilepsy, difficulties with taste and smell, headaches, tiredness, slowness, intolerance of noise, restlessness

(McKinlay, Brooks, Bond, Martinage, and Marshall, 1981; Brooks, Campsie, Symington, Beattie and McKinlay, 1986; Brooks, Campsie, Symington, Beattie, and McKinlay, 1987). Physical problems following CVA can include hemiplegia and hemiparesis, visual problems, problems with coughing and swallowing and incontinence (Anderson, 1992). In anoxic conditions, a variety of physical sequelae may also be observed including hemiplegia, blindness and sensory loss (Lishman, 1998).

### *Cognitive*

Neurological damage can lead to deficits in 'executive functions' including ineffective planning, performing and monitoring steps of goal directed tasks; reduced initiation and motivation; problem with attention; cognitive rigidity; and impulsivity (Lezak, 1983). Impairments in learning, retaining information and memory are also commonly reported after TBI and can persist over time (e.g. Richardson, 2000; Oddy, Coughlan, Tyerman and Jenkins, 1985; Oddy, Humphrey and Uttley 1978b; McKinlay et al., 1981; Brooks et al., 1986; Brooks et al., 1987). TBI patients can be left with diagnosable language disorders such as dysphasia and dysarthria (McKinlay, et al., 1981; Brooks et al., 1986) as well as subclinical difficulties with comprehension and expression (Richardson, 2000). In anoxic conditions, disturbances in memory, attention, affective dulling, disinhibition; tendency to concrete thinking; problems with goal directed tasks; visuo-spatial difficulties; and generalised intellectual impairment can occur (Caine and Watson, 2000; Lezak, 1983). In the case of metabolic disorders, neuropsychological impairments include deficits in attention, memory, reasoning and judgement

(Lishman, 1998; Whelan, Schteingart, Starkman and Smith, 1980; cited in Lezak, 1983) as well as lethargy, sluggishness and disorientation (Lezak, 1983).

### *Emotional*

Lezak (1988) suggests the emotional consequences of brain injury can be *direct* (the effects of actual organic damage) and/or *indirect* (the person's emotional reactions to their deficits and changes). Neurological damage, especially to the frontal areas of the brain, can impair the individual's ability to regulate moods and emotions (Lezak, 1983). This can results in increased irritability, excitability, frustration, emotional lability or flattening, lowered tolerance and loss of temper (Coughlan and Humphrey, 1982, cited in Anderson, 1992; Lezak, 1983; McKinlay et al., 1981; Brooks et al., 1986; Brooks et al., 1987; Oddy, Coughlan, Tyerman and Jenkins, 1985; Oddy et al., 1978b). Lezak (1988) acknowledges how difficult it can be to tease apart "the emotional expressions that arise directly from the dysfunctional brain; and those that reflect patient's reactions to their plight" (Lezak, 1988; p 113). Indeed, authors acknowledge the frustrations and failures experienced by brain injured individuals as they try to reintegrate into society and the patient's raised levels of anxiety and depression (e.g. Linn, Allen and Willer, 1990; McKinlay et al., 1981; Brooks et al., 1986; Brooks et al., 1987).

### *Personality and behaviour*

Personality and behavioural changes are common after ABI (e.g. Lezak, 1988). Patients may exhibit excessive talkativeness, childishness (McKinlay et al., 1981; Lezak, 1988), suspiciousness, bossiness, socially inappropriate behaviour, withdrawal from social interaction (Brooks et al., 1987), depressive mood, poor insight, somatic concern, guilt feelings, unusual thought content (Groom, Shaw, O'Connor, Howard and Pickens, 1998) and can become readily upset by small changes in routine (Brooks et al., 1986). Studies have noted that 'disturbed behaviours' and personality changes can increase with time or fluctuate, whilst other deficits (e.g. dependence, physical, language) can decline in the 12 months after injury (McKinlay et al., 1981; Brooks et al., 1986).

### ***Social and Vocational outcomes***

People with ABI will often not return to the same level in their original profession, if at all, after injury (Oddy et al., 1985). Those with severe injuries have a slower rate of return to work, report reduced interest and poorer performance (Oddy et al., 1978b; Oddy and Humphrey, 1980). In addition, brain injured patients show markedly reduced leisure activities, social encounters and experience feelings of boredom, loneliness and social isolation (Anderson, 1992; Oddy, Coughlan, Tyerman and Jenkins, 1985; Oddy and Humphrey, 1980; Oddy et al., 1978b). In a study of very severely head injured persons 10 years after injury, individuals rated least life satisfaction in the domains of contact with friends and leisure activities (Koskinen, 1998).

## 1.3 Impaired awareness of deficit after acquired brain injury

Another important consequence is that patients are frequently less aware than others of their difficulties. Unawareness of deficit has been observed in a wide variety of neurological and psychiatric syndromes such as TBI, dementia, schizophrenia and stroke (Prigatano, 1991, McGlynn and Kasniak, 1991). The following section will be devoted to understanding this phenomenon: the terminology used; clinical and theoretical models; issues around measurement, the link between time since injury and severity and unawareness; and the implications of impaired awareness of deficit for the patient.

### Terminology of impaired awareness of deficit

The literature on self awareness and awareness of deficit uses a variety of terms (Clare, in press). Babinski (1914) introduced the term *anosagnosia* to describe the lack of verbally expressed knowledge of deficit in two patients with left hemiplegia. The term has since been used to describe unawareness of other deficits (Prigatano and Schacter, 1991). *Insight* is the term commonly used in psychiatric literature to suggest awareness of the symptoms and implications of mental illness (Markova and Berrios, 1992) used interchangeably with the term *imperception of disease. Denial* can be used interchangeably with *anosagnosia* (e.g. Weinstein, 1991) but psychodynamic theorists tend to reserve *denial, defensive denial or motivated denial* to refer to an active coping mechanism whereby the mind keeps painful or upsetting information out of conscious awareness to prevent distress (Lewis, 1991). Anosagnosia can be differentiated from *anosodiaphoria:* lack of concern with, or emotional indifference to, neurological impairment (Heilman, 1991).

## The heterogeneity of the phenomenon

Disturbances in self awareness after ABI are heterogeneous: individuals may be aware of some aspects of their deficits and unaware of others (Schacter and Prigatano, 1991). For example an aphasic individual may acknowledge the existence of a language problem, but show little awareness of making the mistake as it happens (Rubens and Garrett, 1991). In addition, patients may show differential levels of awareness for different functions. Prigatano, Altman and O'Brien (1990) showed that patients tended to overestimate their abilities in social and emotional domains, in relation to ratings by relatives of patient dysfunction, but show similar ratings in domains related to activities of daily living. Other studies have also found that there tends to be higher agreement among TBI patients and relatives in sensory and motor domains and less agreement of emotional and behavioural changes (McKinlay et al, 1981). Port, Wilmott and Charleston (2002) observed that TBI patients showed unawareness for executive functions but preserved awareness in other domains (e.g. physical, cognitive, memory, emotional and behavioural functions). Clinical and theoretical models have been developed to attempt to account for the heterogeneity of impaired awareness of deficit in ABI.

## Models of impaired awareness of deficit

The aim of ***clinical models*** is to describe phenomena seen in the clinic. Crosson, Barco, Velozo et al., (1989), in their 'Pyramid Model', identify three levels of (un)awareness: *intellectual awareness or* the ability to understand that an impairment exists (knowledge of deficit); *emergent awareness,* the ability to recognise deficits as they occur; and *anticipatory awareness,* the ability to anticipate the problem will occur in future. These three are constructed as a hierarchy with intellectual awareness as the cornerstone for the other two. Authors recognise the role of psychological denial in the patient's presentation. Similarly, Fleming and Strong (1995) suggesting that lack of awareness can exist on three levels. The first is a reduced awareness of brain injury deficits themselves (e.g. memory or concentration problems). The second is unawareness of the impact of their deficits on daily life tasks (e.g. driving, leisure activities). The third is the altered ability to set realistic goals in light of their difficulties.

***Neuroanatomical models*** implicate different brain regions involved in producing unawareness of deficit. These include the frontal lobes (particularly the right; e.g. Damasio and Anderson, 1993; Stuss, 1991), the right hemisphere in general (e.g. Heilman et al, 1993; Ranseen, Bohaska, and Schmidt, 1990) and the right parietal lobe (McGlynn and Schacter, 1989). Prigatano (1991) advocates a model where damage to functional areas known collectively as the 'heteromodal cortex' (Mesualm, 1985, cited in Prigatano, 1991), important in the maintenance of normal self awareness, can lead to impaired awareness of deficit in specific domains.

***Neuropsychological models*** seek to explain the complex neuropsychological processes involved in unawareness of deficit. An example of this is Schacter's (1989; cited in Schacter, 1991) 'Dissociable Interactions and Conscious Experience' (DICE) model. Initially developed to explain the dissociation between implicit and explicit memory in amnesia, it has been usefully applied to describe mechanisms of impaired awareness after ABI. This postulates that the 'Conscious Awareness System' (CAS) gives to and receives information from lower level modules representing specific cognitive functions (e.g. language, motor function, memory) and passes input into the executive system which syntheses the information, needed for higher cognitive functions to take place. Damage to the connections between individual modules and the CAS presents in the patient as *unawareness of specific functions* (e.g. memory, language); damage to the CAS, as *global unawareness of deficit*; and damage to the executive system or the connections between this and the CAS, as *unawareness of more complex deficits* (difficulties with problem solving, or social interaction).

***Psychodynamic and psychogenic models*** have sought to explore the overlap between unawareness of deficit and the coping mechanism of denial. Weinstein (1991) suggests that the patient's awareness presentation after brain injury is determined not only by the type, severity, rate of onset, location and extent of damage, but also by the nature of the disability, the patient's perception of the meaning of the disability based on past experience, their values and personality, and the context in which the behaviour is elicited and observed (Weinstein, 1991). Psychogenic and psychodynamic models thus emphasise the role of emotion, personality and context in limited awareness, suggesting that unawareness may not be purely organic in nature but act as a coping mechanism or a means of presenting oneself favorably to avoid distress. Indeed, some studies have shown that greater expressed awareness of deficit is linked to a higher depression, anxiety and emotional distress in the in the brain injured patient (e.g. Fleming and Strong, 1998; Linn, Allen and Willer, 1994; Godfrey, Partridge, Knight, Bishara, 1993) lending support to this theory. However this is controversial, as other studies have found no such link (Malec and Moessner, 2000).

## Measuring impaired awareness of deficit

The problems in defining and understanding awareness of deficit has meant controversy surrounding how best it is measured. Available measures used tap awareness of different functions: awareness of global functions (e.g. *Awareness Questionnaire*; Sherer, Bergloff, Boake, High Jr., and Levin, 1998) or of specific functions: self care abilities (e.g. *Mayo-Portland Adaptability Inventory*; Malec, Machulda & Moessner, 1997), memory functions (e.g. *Memory Awareness Rating Scale;* Clare, Wilson, Carter, Roth and Hodges, 2002), neurobehavioural symptoms (e.g. *Head Injury Behaviour Scale*; Godfrey, Partridge, Knight & Bishara, 1993) or psychosocial adjustment (e.g. *Katz Adjustment Scale*; Katz and Lyerly, 1963).

Four main approaches to measurement have been operationalised (Sherer, Boake, Levin, Silver, Ringholz and High Jr, 1998). Three of these involve comparing the patient's own ratings of his/her deficits to an 'objective' benchmark measure of his/her deficits namely a) ratings of a 'significant other' or b) ratings of a clinician or c) neuropsychological test performance. The discrepancy between the patient's rating and the 'objective' measure are taken as a measure of level of 'awareness' in the patient. The last method is to obtain an overall clinician rating of the client's awareness (Sherer et al., 1998). Each method has advantages and disadvantages.

Measuring awareness of deficit via **clinician ratings** or **comparing clinician with patient ratings** has been used in several studies (e.g. Sherer, Hart, Whyte, Nick, Thompson and Yablon, 2003; Prigatano & Klonoff, 1998). Although considered a more 'objective' measure, some authors suggest that clinician's ratings may be subject to bias from their attitude to, and expectations of, the patient (Ponsford, 1988): they may overestimate pathology in clients, especially in those who are 'resistant' to therapy (Fordyce and Roueche, 1986). In addition, the rehabilitation clinician is unlikely to have known the patient premorbidly so may not be able to judge accurately the injury-related change in personality and behaviour (Fleming, Strong and Ashton, 1996).

Studies have compared the patient's own evaluation of their deficits with his/her performance on **neuropsychological tests** (e.g. Allen and Ruff, 1990). Although this eliminates the 'subjective' element of relative or clinician ratings, the process itself can be time consuming and there is debate about whether test performance is a valid reflection of daily life functional performance (Ponsford, 1988).

The validation of patient reports with those of a **'significant other'**, such as a spouse or relative, is recommended in routine clinical practice (e.g. Fleming, Strong and Ashton, 1996). Many studies have used comparisons between patient self-ratings and relative ratings of patient's competencies to determine degree of self awareness (e.g. Sherer, Hart and Nick, 2003; Prigatano, Bruna, Mataro, Munoz, Fernandez and Junque, 1998). An advantage of a relative's perceptions is that they have extensive knowledge of the person prior to injury and may be able to detect subtle changes in functioning, through observation of the patient in the unstructured family environment (e.g. Sbordone, Seyranian and Ruff, 1998). Disadvantages include potential bias through: denial (particularly in the early stages; Lezak, 1986); levels of stress and fatigue; and personality style (e.g. neuroticism; McKinlay and Brooks, 1984). Certain studies have used a variety of 'significant others', with varying degrees of knowing the patient to measure patient awareness (Wallace and Bogner, 2000). It is likely that the partner of the person with brain injury, owing to the intimate nature of the relationship and the frequency of contact with the patient, will be more aware of changes than other individuals (e.g. grandparents, in-laws, friends).

### The relationship between severity and impaired awareness of deficit

Although clinical experience suggests that there seems to be a greater disturbance of awareness of deficit with a greater severity of injury (Sherer, et al, 1998), at present there is no conclusive support for the link between the initial severity of the injury and the degree of unawareness of deficit, despite some positive results. Allen and Ruff (1990; cited in Crisp, 1991), for example, found that mild to moderately injured individuals are more accurate in their ratings of their abilities than those with more severe injuries and Prigatano et al. (1998) found that increased severity (GCS score, PTA) was linked to greater unawareness. Levin, High, Goethe, Sisson, Overall, Rhoades, Eisenberg, Kalisky, and Gary (1987) found that self appraisal was poorer in patients with more severe injuries. However, other studies have found no consistent associations between measures of severity and impaired awareness (e.g. Brooks and McKinlay, 1983; McKinlay and Brooks, 1984; Prigatano, Altman and O'Brien, 1990; Lanham, Weissenburger, Schwab and Rosner, 2000).

## The relationship between time lapsed since injury and impaired awareness of deficit

Some results suggest that individuals with recent injuries are less likely to show awareness of their disabilities than those who have lived with them for a long time (e.g. Crisp, 1991). The phenomenon appears to be more pronounced immediately after injury - presenting, in extreme cases, as a lack of realisation of having had a brain injury at all (Sherer, Boake, Levin, et al., (1998). In some cases of stroke, unawareness of deficit can be transient lasting for only a few days (Weinstein, 1991): however, in other cases, the phenomenon has been observed seven years on (Oddy et al, 1985). Several studies have provided support for the hypothesis that awareness of deficit improves over time (e.g. Godfrey et al, 1993; Allen and Ruff, 1990). Other studies have found that level of awareness has no link to the length of time since injury. Bechtold Korte, Wegener and Chwalisz (2003), for example, found no correlation between either Anosagnosia or denial and time since injury in their sample of mixed brain injured individuals (stroke, TBI, anoxia, tumour resection). Yet other studies have observed *fluctuations* of insight (e.g. Krefting, 1989; cited in Crisp, 1991) and even *decreases* in awareness of over time after injury (e.g. Wallace and Bognor, 2000). Thus the picture of how awareness changes over time remains unclear.

## Implications of impaired awareness of deficit

The inability of a patient to accurately appraise their deficits has implications for their rehabilitation and employment. Individuals with reduced awareness are more likely to refuse therapy, show less motivation in rehabilitative tasks and are less likely to benefit from rehabilitation (Diller and Gordon, 1981; Nockleby and Deaton, 1987; Lam, Mahon, Priddy, Gehred-Schultz, 1988; cited in Fleming and Strong, 1995). They may take on tasks with demands beyond their current abilities, leading to failures, problems with safety, and loss of employment (Adamovich et al, 1985). In a prospective study of TBI patients, awareness of deficit was strongly predictive of employment outcome in the post acute phase of brain injury: those with accurate self awareness were over twice as likely to be employed than those without (Sherer, Bergloff, Levin et al., 1998). Lack of awareness of deficit also has implications for the relationships the individual holds with others. The following section considers the impact of acquired brain injury on families, with particular reference to the partner or spouse.

## Summary

The deficits resulting from acquired brain injuries (e.g. traumatic brain injury, cerebrovascular disorders, cerebral Infection, metabolic and endocrine disorders) can manifest themselves in various domains of function. The severity of the initial injury is generally measured via length of loss of consciousness, Glasgow Coma Scale score or length of Post-Traumatic Amnesia.

A common consequence of brain damage is an impaired awareness of deficit or self awareness, which can have implications for rehabilitation and vocational outcomes for the patient. Awareness of deficit can be impaired for some domains or aspects of function and preserved for others, and there is no conclusive link between severity or time since injury and impaired awareness of deficit. Methods of measurement vary in their functional focus (e.g. global functions, psychosocial function, physical abilities). They also vary in the approach adopted (e.g. comparison of 'objective' clinician or significant other or neuropsychological test results to 'subjective' patient ratings), each approach having certain inherent difficulties. However, it is commonly believed that the rating of a 'significant other', who knows the patient well, is the most ecologically valid.

## 1.4 The effects of brain injury on partners and spouses

This section briefly presents models that have been developed to understand and explain the reactions of family members to brain injury, describes the impact of brain injury on partners and spouses and the factors which seem to be particularly associated with partner outcomes.

### Family members after brain injury – theoretical models

Lezak (1986), in her ***model of loss and bereavement***, outlines of a series of stages that family members pass though as they adjust to the changes in the head injured person and life after ABI: initially they feel happiness and relief that the patient is home and alive; this is followed by anxious bewilderment, discouragement, guilt and depression as they realize things have not returned to normal in the patient; they may then experience despair and as they start to contemplate that many of the deficits and personality changes may be permanent; a mourning phase may follow, where family members grieve the loss of the premorbid person and the old life; and finally, they reach 'reorganization', or adjustment to the new situation. ***Models of caregiver burden*** are borrowed from studies of families of those discharged from long term psychiatric care (Oddy and Herbert, 2003) and have tended to dominate research on outcomes of relatives after ABI (Chawalsz, 1992; Perlescz et al, 1999; Low, Payne and Roderick, 1999). The premise is that the responsibility for caring for the brain injured person commonly lies with the family after discharge from acute-care and rehabilitation settings (Oddy and Humphrey, 1999; Anderson, 1992). It makes a distinction between *objective burden* (the measurable severity of the patient's disabilities) and *subjective burden* (the carers perception of it's extent). However, there can be a lack of consensus on definitions: subjective burden is sometimes operationalised as the distress experienced by carers as a result of the 'objective' brain injury impairments (Chawalsz, 1992). ***Stress and coping models*** (based on Lazarus and Folkman's, 1984, Coping Theory), on the other hand, place more emphasis on the personal coping resources of family members and the appraisals and attributions they make (e.g. about the daily 'hassles' in caring for the patient; Oddy and Herbert, 2003). Finally, ***family systems models*** highlight the relationship difficulties in families after ABI and draw attention to concepts of role strain, cohesion, conflict, overinvolvement and power struggles. Emphasis is placed upon circular, not linear, causality: difficulties experienced in one part of the system (e.g. marital relationship) can reverberate through others (Oddy and Herbert, 2003).

## Spouse and partner outcomes after ABI

Lezak describes spouses as "living in a social limbo, unable to mourn decently, unable to separate or divorce without recrimination or guilt" (Lezak, 1978) and they "loose their chief companion and source of emotional support and affection at a time when it is most needed" (Lezak, 1988). In addition to adjusting to the 'loss' of their preinjury partner, the brain injury can have implications for their life more widely: becoming carer of the injured person (e.g. Lezak, 1988); having to reduce working hours outside the home (Wallace, Bognor, Corrigan, Clinchot, Mysiw and Fugate, 1998); increased responsibilities and roles in household and financial management (Leathem, Heath and Wooley, 1996); increased or sole parenting responsibilities (e.g. Lezak, 1988; Perlescz et al., 1999); and having to make decisions alone (e.g. Gosling and Oddy 1999). Kozloff (1987; cited in Kosciulek, 1994) showed that as the social network of brain injured people decreases over time, family members served more functions for the injured person in the absence of non-relatives which leads to social isolation of families from the community. Spouses have been shown to utilize less social support than is available (Leathem, Heath and Wooley, 1996), participate less in leisure activities (Wallace et al., 1998) and, by consequence, experience feelings of isolation and loneliness (e.g. Rosenbaum and Najenson, 1976; Lezak, 1988).

A wealth of the brain injury literature has focused on attempting to explore and quantify levels of psychopathology, psychiatric symptoms and negative outcomes in relatives. The kinds of instruments commonly used include the General Health Questionnaire (GHQ; Goldberg D, 1972), the Brief Symptom Inventory (BSI; Derogatis et al., 1983), Leeds Anxiety and Depression Scales (Snaith, Bridge and Hamilton, 1976), the Symptom Checklist-90 (SCL-90; Derogatis, L. R., 1983) and specifically designed scales to measure burden and perceived stress (e.g. Koskinen, 1998). Livingston, Brooks and Bond (1985a) in their study of relatives (wives, mothers and daughters) of 42 severely head injured men 3 months after injury, found that over 57% of relatives showed caseness on the GHQ; 45% on the Leeds anxiety scale; and 21% on the Leeds Depression scale. Their later study (Livingston, Brooks and Bond, 1985b) with 57 relatives 3, 6, and 12 months after injury, found persistently high scores on the GHQ and the Leeds Anxiety scale over time. Kreutzer, Gervasio and Camplair (1994a), in their study exploring carers (parents and spouses) of 62 traumatically injured males found that 47% exceeded caseness for 'clinically significant' levels of emotional distress using the BSI. Seventy three percent of spouses of brain injured persons in another study (Linn et al., 1994) acknowledged significantly elevated levels of depression and 55%, elevated anxiety. Gervasio and Kreutzer (1997), in their American sample of 116 caregivers of patients with TBI, found that 44% met "caseness" on the BSI. A large proportion of caregivers showed distress in many areas (39% showed elevations on three or more subscales of the BSI). Rosenbaum and Najenson (1976) showed that wives of head injured males showed higher levels of depression than wives of men with spinal cord injury and non-injured controls. High rates of psychological difficulties have been found in carers of stoke patients: 45% of carers scored above cut-off points for anxiety and depression (Williams, 1993); rates in carers of 2.5 to 3.5 times higher than age matched samples (Schultz, Tompkins and Rau, 1988); 40-50% of caregivers were depressed compared to 2% in community samples (Lichtenberg and Gibbons, 1993; cited in Bishop and Evans, 1995).

When addressing studies that look at levels of caseness, it is equally important to note that many *do not* meet criteria for caseness or show low levels of distress. For example, in the Livingston et al. (1985a) study, 43% of relatives scores fell in the non-caseness range on the GHQ, 55% on the Leeds anxiety scale and 79% on the Leeds Depression scale. In the Linn et al. (1994) study, 72% of spouses showed no or only mild elevations in depressive symptoms and 78%, no or mild elevations of anxiety. In the Gervasio and Kreutzer (1997) study 39% of their sample showed no elevations on any BSI subscale.

Although many studies use a mixed sample of caregivers, certain studies allow unique interpretation of the experience of the partner or spouse. In terms of burden, Minnes, Graffi, Nolte, Carlson and Harrick (2000) found that partners reported significantly more personal burden than parent caregivers, and Allen, Linn, Gutierrez and Willer (1994) showed that spouses report significantly less personal reward in caring than parents. Levels of psychopathology have been seen to be higher in spouses. Evans, Noonan, Bishop and Hendricks (1989 cited in Bishop and Evans, 1995) found that spouses experience more anxiety than sibling and children caregivers of stroke patients. Kreutzer, Gervasio and Camplair (1994a) found that spouses achieved significantly higher depression, anxiety, general symptoms and psychoticism (on the BSI; Derogatis et al., 1983) than parent caregivers of traumatically head injured males. In another study by the same group (Kreutzer et al., 1994b) kinship showed itself to be a significant predictor of depression: spouses reported higher levels than parents. Similarly, Gervasio and Kreutzer (1997), in their sample of caregivers of TBI patients, showed that spouses were more likely than parents to fall into the caseness category on the BSI and showed significantly more distress on 7 subscales. Literature has also looked at the differential social impact on spouses. Livingston et al. (1985a) found no significant differences between wives and mothers of 42 different head injured males on measures of anxiety, depression and general psychopathology but wives were more vulnerable than mothers to being more handicapped socially. In terms of life changes, Leathem et al, (1996) found that spouses reported significantly greater degree of role change than parents in financial and household areas but the trend was for greater changes for spouses in *all* areas. Both spouses and parents indicted their greatest perceived changes were in their relationship with the injured person and in social areas, which included going out together socially and spending leisure time together. Qualitative data from partners highlighted several themes: less contact with other people outside the household; others tending not to involve the couple socially; avoidance of certain social occasions (owing to the patient's difficulty handling noise or crowded settings); and tending to see only a few friends at a time (Leathem et al., 1996). There may be an active avoidance of social occasions by partners on account of the patient's unusual or socially embarrassing behaviours (e.g. hostility or irritability) and difficulties understanding and interpreting social cues in complex interpersonal situations (e.g. Lezak, 1988).

## Factors that influence partner outcomes

Research has focused not only on the types and levels of distress in relatives and carers, but on which brain injury related factors are of key importance to these outcomes. These have included the time lapsed since the injury, the severity of the injury, the functional abilities of the patient, the personality changes in the patient and, although relatively unexplored, the patient's impaired awareness of his/her deficits.

### *Severity*

The picture is mixed as to whether the initial severity of the injury has significant impact on partner outcomes in and of itself. Livingston et al. (1985a) compared relatives of severely head injured men (wives, mothers and daughters) with a control group of relatives of mildly head injured men: relatives of the severely injured showed significantly greater levels of psychopathology (anxiety/insomnia and social dysfunction on the GHQ-90) and had significantly higher burden. In looking at wives alone, in comparison to controls, this group showed significantly higher GHQ and Leeds Anxiety scores and significantly poorer difficulties with social roles at home. Similarly, McKinlay et al. (1981) interviewed relatives 3, 6 and 12 months after head injury and found that there was a tendency for a greater link between severity of injury (measured by length of PTA) and carer's degree of subjective burden but only *earlier after the injury*. Wallace et al. (1998) found, in their sample of caregivers one year after injury, that there was a nonsignificant trend for increased experience of negative life change for the carer with greater severity of injury (GCS score). However, in a predictive equation of carer life change, the *perceived* deficits of the injured person accounted for a significant amount of variance whereas severity did not. Further studies have found no association between the severity of initial injury and spousal or caregiver ratings of their anxiety, depression and other symptoms of psychopathology (Linn et al., 1994; Gervasio and Kreutzer, 1997; Groom et al., 1998; Rosenbaum and Najenson, 1976). Kreutzer et al. (1994b) in their sample of 62 family member caregivers of TBI patients including spouses, found no significant correlations between measures of initial injury severity (e.g. GCS score, length of unconsciousness) and BSI subscale and total scores. In sum, the association between the severity of the initial injury and the outcome in partners, spouses and carers is not conclusive.

### *Time since injury*

A mixed picture also emerges as to whether the passage of time has an effect on the distress experienced by partners and carers. Some studies have found that psychopathology in spouses and carers decreases over time. For example, Groom et al. (1998), using a mixed sample of caregivers of head injured persons (including spouses), found that the greater the time since injury the lower the perceived stress of the caregiver. Other studies have found that difficulties increase over time after injury. Macnamara, Gummow, Goka and Gregg (1990; cited in Low, Payne and Roderick, 1999) found that carers anxiety increased with time since stroke. Minnes et al. (2000) found that the longer the time since injury the lower the sense of personal reward inherent in caregiving by carers (including spouses). Yet other studies have found that levels of distress develop early and remain high. Livingston et al. (1985b) followed up relatives of 57 severely head injured men 3, 6, and 12 months after injury and found the mean GHQ score at 6 months was in the caseness range; and mean Leeds anxiety scores at all 3 time intervals fell in the caseness range and did not significantly decline over time. The number of relatives within the caseness range on the GHQ and Leeds anxiety scales showed no significant changes over the year and burden measured on a 25 item scale also showed no statistically significantly differences between time points. Yet other studies have found a variation with time after injury. Koskinen (1998), using retrospective reports, found that close relatives of severely head injured individuals (including spouses) experienced most strain the year following injury with a decrease at 5 years but no further decrease at 10 years (remained at a high level). Further studies have found an absence of a link between time since injury and spousal/carer outcomes: that time since injury was not predictive of spousal self ratings of anxiety and depression (Linn et al, 1994) or caregiver psychological distress and perceived stress (Kreutzer et al., 1994b; Gervasio and Kreutzer, 1997). Therefore the link between time since injury and psychological difficulties experienced by spouses or carers is not a straightforward one.

### *The functional abilities of the patient*

The functional ability of the patient has been explored in relation to the experience of the spouse or caregiver after brain injury. Some studies have shown a link between the neuropsychological function of the patient, as measured by neuropsychological tests, and spouse/carer outcomes such as depression (e.g. Kreutzer, Gervasio and Camplair, 1994b). However, in general, there is agreement that outcomes in spouses or carers are mediated by the *subjective perception* of the changes and deficits and less so by the patient's actual ('objective') levels of disability (Oddy, Humphrey and Uttley, 1978a; Livingston and Brooks, 1988; Knight, Devereux and Godfrey, 1998). Therefore many studies have asked spouses and carers about their perception of deficits and have found that lower patient functioning is associated with poorer outcomes. For example, Minnes, et al.,

(2000) found that carer-perceived patient functioning (cognitive, behavioural, interpersonal function, activities of daily living) predicted 44% of the variance in overall caregiver burden, much more so than the amount and types of coping strategies employed. In addition, patient functioning emerged as a significant predictor in more specific types of burden (e.g. limits on family opportunities, personal burden). Koskinen (1998) found that strain in the relative 10 years after injury was highly correlated with the overall perceived functioning of the patient in cognitive, psychological and communication domains, as well as with particular symptoms of depression, insight, learning potential, self esteem and ability to manage money. Therefore it appears that when patient functions at a lower level the spouse or carer fares worse, possibly through having to provide increased care giving duties to the patient, and take on more responsibilities and roles in the home.

Personality changes after injury can manifest themselves in cognitive, behavioural and emotional domains of function and have been shown to be particularly problematic for spouses or carers of injured persons (Perlescz, et al. 1999; Low et al., 1999). Wallace et al. (1998) found that the cognitive functioning of the injured person, as perceived by the primary caregiver (36% spouses), was significantly predictive of the degree of negative life change felt by the carer one year after injury. Anderson (1995) showed that behavioural abnormalities in stroke patients were better predictive of carers' (59% of which were spouses) poor physical and mental health than the patient's physical disabilities. Similarly, in spouses of TBI persons, personality changes and behavioural problems in the patient were more associated with high levels of carer stress than initial severity of injury (Oddy et al, 1978a). Kreutzer et al., (1994b), in their sample of 62 family member caregivers of TBI patients, found that higher neurobehavioural dysfunction in the patient was associated with greater distress in caregivers on all subscales of the BSI. In addition, the subscale measuring behavioural deficits and changes, out of all five subscales of the neurobehavioural problem checklist (physical, cognitive, behavioural, communication, social), was the best predictor of the majority of BSI subscales. Koskinen (1998) found that neurobehavioral symptoms were highly positively correlated with the strain felt by relative's 10 years after severe TBI of which patient depression, motor retardation, decreased initiative, fatigue and emotional withdrawal were most highly correlated. McKinlay et al. (1981), in their sample of relatives of head injured persons, found that when relatives were grouped according to 'high', 'medium' and 'low' stress, the 'low stress' group tended to report the patient as having fewer emotional changes than those in the 'medium' and 'high' stress groups. Although it is often not possible to draw causal relationships, it does seem that the functioning of the patient is closely associated with spousal or caregiver psychological functioning.

### ***Awareness of deficit***

The implication of impaired self awareness in the patient for spouses and partners is a largely unexplored area (e.g. Ergh, Rapport, Coleman and Hanks, 2002). In a qualitative study of spouses of head injury persons, wives (but not the husbands) felt one of their own major concerns was their husbands' lack of insight and acceptance of disabilities (Willer, Allen, Liss and Zicht, 1991; cited in Perlescz et al, 1999). In a quantitative study, Groom et al. (1998) found that the greater the level of 'Indifference' in head injured patients (an operational definition for impaired awareness), the higher the perceived stress of 'significant others' (largely spouses and parents). Indeed, out of all subscales on a neurobehavioural checklist, 'indifference' was the best predictor of perceived stress. Similarly, Koskinen (1998) found that the level of unawareness of deficit in severely head injured individuals 10 years after injury was highly positively correlated with the strain felt by the close relative. However, other studies have found no, or simply a modest, association between awareness of deficit and partner or spouse outcomes. Wallace and Bognor (2000) found no significant association between level of awareness in 50 TBI patients and the depression and anxiety experienced by 'significant others' (including spouses). Ergh et al. (2002) found that a model comprising awareness of deficit, time since injury, neurobehavioral and neuropsychological functioning and social support accounted for 39% of the variance in caregiver psychological distress, although awareness accounted for only 1%. Certainly this area deserves more investigation as both spouses (e.g. Willer et al., 1991) and clinicians (e.g. Lezak, 1988) report that a lack of self awareness and low awareness of deficit can be a problematic consequence of brain injury for family members.

## Summary

The literature on negative psychological outcomes for relatives and carers after brain injury has been extensively studied. This has included looking at levels of depression, anxiety, burden and other symptoms of psychopathology. This attention to negative outcomes is unsurprising as professionals have needed to know the kinds of psychological difficulties experienced by partners after brain injury in order to consider appropriate interventions. Certain brain injury factors have been shown to have a potentially important link to negative outcomes for carers and relatives. The link between severity of injury and time since injury have been shown to be influential but this is by no means conclusive (Livingston et al., 1985a; McKinlay et al., 1981; Wallace et al., 1998, Linn et al, 1994; Gervasio and Kreutzer, 1997; Groom et al, 1998; McKinlay et al, 1991; Rosenbaum and Najenson, 1976; Kreutzer et al., 1994b; Koskinen, 1998; Macnamara et al. 1990; Minnes et al., 2000). There is more consistent evidence to suggest that the functional disabilities of the patient and personality changes, particularly as perceived by the spouse/'significant other', are most strongly associated with spouse/'significant other' negative outcomes (e.g. Oddy et al, 1978a; Minnes et al., 2000; Koskinen, 1998).

Understanding the unique experiences of the partners or spouse has been complicated by a number of factors in research including the use of a mixed samples of spouses and other relatives and carers (e.g. Livingston et al., 1985a; 1985b); the tendency to use married couples to the exclusion long-term committed partners (e.g. Linn et al., 1994); and the selection of participants from self help groups who may initially be more distressed and therefore less representative (e.g. Lezak, 1988; Linn et al., 1994). In addition, many studies overemphasize the high levels of distress in some individuals whilst neglecting to discuss how many are functioning adequately.

## 1.5 The effect of brain injury on relationships

As we have seen, brain injury has consequences not only for the patient but for the psychological functioning and health of the partner and other family members. What, then, is the impact of ABI on family relationships and the marital or partner relationship in particular?

### Change in family dynamics after ABI

The nature of relationships between the injured person and family members has started to be explored. Kreutzer et al., (1994a), for example, found that over half of their American sample of 62 caregivers of male TBI patients reported unhealthy levels of family functioning on the General Functioning subscale of the Family Assessment Device (FAD; Epstein, Baldwin and Bishop, 1983) at levels similar to those reported for psychiatric patients. On closer inspection of subscales of the FAD, family communication problems (74%); difficulties with affective involvement (60%) and with roles (46%) were common. Similarly, Groom et al. (1998) also found that family functioning on the FAD as rated by caregivers was significantly worse than normal controls. Although studies on family functioning give us a useful picture of overall functioning in the family unit, they tend not to allow us a good understanding of the dynamics of particular relationships (e.g. the marital relationship) within the family unit.

### Change in nature of the marital/partner relationship after ABI

A few studies have aimed to identify how the spousal relationship may be affected after ABI. Gosling and Oddy (1999) explored the dynamics of the marital relationship in 18 heterosexual married couples where the male had sustained a head injury. They found that wives rated their satisfaction with the current marital relationship as significantly lower compared to before the injury and tended to report more dissatisfaction than their injured husbands. Wives were interviewed and certain themes emerged: the loss of an equal sharing relationship; feeling more like a parent than a wife; the tendency for the injured person to show 'gratitude' but little physical or emotional affection which made them uncertain about the patient's feelings for them. In an earlier study by the same group (Oddy and Humphrey, 1980) researchers found that spouses of severely injured patients reported feeling much less affectionate towards their partner. Peters et al. (1992) compared couples where the patient had a severe head injury with those with moderate injury or a spinal cord injury (SCI). Spouses of the severed head injured males had lower levels of expressed affection, poorer marital satisfaction, poorer marital cohesion, and lower overall marital adjustment than spouses in the SCI group. Spouses of the moderately head injured males had significantly lower dyadic satisfaction than the SCI spouses. Flanagan (1998) explored the communication patterns between relatives and head injured males, coding them according to level of Expressed Emotion in relatives, a communication pattern characterized by high levels of criticism, over-involvement, and hostility and low levels of warmth and positive comments, (closely linked to relapse in psychiatric patients; Kavanagh, 1992). A significant majority of wives fell in the high EE group with only a few in the low EE group. In comparison, relatives with a different relationship with the injured person (mothers, husbands, fathers) fell mostly in the low EE group or were equally balanced between the two groups (siblings). The implication is that wives may be particularly vulnerable to dysfunctional communication patterns with the brain inured individual.

Research has noted significant changes in the sexual functioning of the injured person and in the sexual relationship between the injured person and their partner. The percentage of ABI patients reporting sexual dysfunction has been said to vary between 4 and 51% (Sandel, Williams, Dellapietra and Derogatis, 1996; Chandler and Brown, 1998). Difficulties include inability to maintain an erection, decreased sex drive and ability to orgasm, decreased self perceived sex appeal and confidence (Kreutzer and Zasler, 1989; Sandel et al., 1996). Spouses of TBI patients have described their sexual relationship as non-existent and significantly poorer compared to before the injury; their encounters as being “boring, flat, or feeling wrong”; and perceive their partner’s sexual advances coercive at least some of the time (Gosling and Oddy, 1999; p 790).

## Factors that impact on the nature of relationships after brain injury

This section will discuss factors found to affect relationships between the injured person and family members. This will include reference to studies on marital relationship but, as these are few, will include research on wider family relationships.

### *Severity of the injury*

The severity of the injury has been found to be a significant predictor of relationship functioning and adjustment in some studies. Douglas and Spellacy (1996) looked at family functioning in a sample of thirty adults (male and female) with severe TBI and an adult cohabiting family member, 57% of whom were spouses. They found that greater severity of injury, as measured by length of PTA, was a reliable and significant predictor of difficulties in family functioning and relationships. Livingston et al., (1985a) found that relatives of severely head injured men in their sample, showed significantly worse self-reported marital functioning and family unit functioning than relatives of mildly head injured males. Peters, Stambrook, Moore and Esses (1990) compared marital adjustment in the wives of 55 mild, moderate and severely head injured males up to eight years after injury. They found that wives of 'severely' injured males reported significantly lower overall marital adjustment and dyadic consensus than wives of patients in the 'moderate' group, and lower levels of affectional expression than wives of both moderately and mildly injured patients. Using stepwise multiple regression analyses, the researchers found severity of injury to be a significant predicator of expressed affection and overall marital adjustment.

### *Time since injury*

It is not uncommon for spousal or partner relationships to degenerate or breakdown completely after injury. Gosling and Oddy (1999) cite the separation rates of marital couples after TBI in various samples: 40%, higher than spinal cord injured controls (Panting and Merry, 1972); 40% at seven years post-injury (Oddy, et al, 1985); a 55% divorce rate by 6 years after injury (Tate et al., 1989); 7 out of 9 couples had separated by 15 years after injury (Thomsen, 1984); 49% during a 5-8 year period after injury (Wood and Yurdakul; 1997). These high rates suggest that the quality of the relationship may either remain impaired or worsen over time after injury. Wood and Yurdakul (1997) found that a greater time since injury amongst other factors (increased severity, shorter length of relationship prior to head injury) to be predictive of eventual relationship breakdown (separation or divorce). The age of the patient, the sex of partner and the number of children aged 15 or below at home were not predictive of separation.

However, many couples do remain together after injury and some authors even report that family difficulties may alleviate over time. Bishop and Evans (1995) in their review of the literature of families after stroke conclude that affective dimensions of family life, namely the communication of appropriate feelings and emotional investment in one other, improve over time. Similarly, Kreutzer et al. (1994b), in their sample of caregivers of 62 TBI males, found that healthier functioning in roles, affective responsiveness, affective involvement and general functioning (FAD; Epstein et al., 1983) were associated with greater time since injury. However, other studies have found no relationship between the time lapsed since the injury and the functioning of relationships in the family (e.g. Groom et al., 1998)

### ***Personality change and functional ability of the injured person***

The presence of personality changes, neurobehavioural symptoms and the level of functioning of the patient has been found to influence the nature and dynamics of family relationships after ABI. Peters et al. (1990) found that high psychosocial maladjustment in the patient and increased physical restrictiveness in the patients day-to-day functioning were significantly related to relationship difficulties between spouses and their head injured husbands, particularly the ability of the couple to reach agreement over everyday matters (dyadic consensus). Douglas and Spellacy (1996) found that increased neurobehavioural dysfunction was a significant predictor of family dysfunction in their sample of thirty adults with severe TBI and an adult cohabiting family member, 57% of which were spouses. Relatives' perception of the patient's ability to perform various everyday tasks was also a significant predictor of family functioning, providing 9% unique variance. Kreutzer et al. (1994b), in their sample of caregivers of 62 TBI males, found that a greater severity of neurobehavioural problems predicted poorer general functioning, communication and roles (FAD; Epstein et al., 1983). The behaviour subscale proved to be the best predictor: family member's perceptions of increased patient behaviour problems had the greatest link to family dysfunction. They also found that out of all predictors (injury severity, total neurobehavioural checklist score, neuropsychological test scores and kinship), neurobehavioural scores were the best predictor of FAD scores. Similarly, Groom et al. (1998) in their mixed sample of caregivers of head injured patients found that the neurobehavioural checklist subscales of 'Depression' and 'Inappropriateness' were most predictive of overall family dysfunction.

### ***Awareness of deficit***

Once again, few studies have addressed the impact of impaired awareness on the relationships the injured person has with important others. Ergh et al (2002), in their study of 60 brain injured patients and their caregivers, found that a model including awareness of deficit, time since injury, neurobehavioural and neuropsychological functioning of the patient and social support accounted for 52% of the variance in *family* dysfunction. The sample was mixed, including predominantly parents (52%) but also spouses/partners (20%) amongst other types of caregiver (siblings, children, friends) and the data did not allow analysis of the impact of awareness of deficit on outcome for spouses alone for their perception of family functioning.

### ***Other factors***

Other factors have been linked with the quality of the relationship between spouses or long terms partners. Studies have noted that certain demographic characteristics, such as age, can impact on marital satisfaction in the general population. Gagnon, Herson, Kabakoff and Van Hasselt (1999), in their review of the literature on ageing and martial satisfaction, suggest that marital satisfaction is low in middle age and improves in later life after child rearing years and work role demands have subsided and there is an increase in shared leisure activities and experiences. Less conflict is reported in older adults over childrearing, finances and leisure time spent together but greater distress in their sexual relationship (Norris, Snyder and Rice, 1997). Satisfaction with one's financial situation has been related to better marital satisfaction in the general population (Koutstaal, Stanley-Wellington, 1998). Brain injury can often impose financial hardship on the family, especially in the early days after injury (Gosling and Oddy, 1999). Peters et al, (1990) found that financial strain was significantly related to problems reaching consensus in the marital relationship, lower expressed affection and lower overall marital adjustment.

## Summary

The literature on the nature of *relationships* between the injured person and their significant others after ABI is much more limited than that addressing personal psychological outcomes for significant others (i.e. spouses, caregivers, relatives). In addition, it has proved difficult to understand how the unique nature of the relationship between the partner or spouse and the injured person is affected by ABI as many studies address 'family functioning' using a mixed sample of individuals with a variety of kinships with the injured person (e.g. Douglas and Spellacy, 1996). A few studies have focused on the marital relationship alone. These have identified difficulties in the areas of communication patterns, sexual and marital relationship satisfaction, expressed affection, cohesion and general adjustment; and some positive changes such as continued companionship, mutual affection and commitment (Gosling and Oddy, 1999). These studies tend not to include long term committed partner relationships in their explorations. Factors such as severity of the injury (e.g. Peters et al., 1990), the patient's current functional abilities (Douglas and Spellacy, 1996), the presence of neurobehavioral symptoms and personality changes (e.g. Peters et al., 1990), the length of time lapsed since injury (e.g. Wood and Yurdakul, 1997; Bishop and Evans, 1995), perceived financial strain (Peters et al., 1990) and age (e.g. Gagnon et al., 1999) have been linked to marital adjustment. However, awareness of deficit has received little attention in this context. Intuitively, difficulties and strains are likely to be present in a partner/spousal relationship where the injured person has a reduced capacity to be self aware and to be aware of their deficits and changes.

The current study will therefore aim to explore the unique nature of the partner/spousal relationship and to investigate which brain injury factors, including lack of awareness of deficit, are mostly strongly associated with the relationship adjustment between the partner and the injured person. From now on, the term partner will be used to denote both married *and* unmarried long-term partners unless otherwise specified.

## 1.6 Psychological well-being

### Introducing the concept of well-being

There has been a general tendency in the medical and psychological literature to focus on disease, illness and negative states when addressing aspects of human functioning, including psychological functioning (Ryff and Singer, 1996). Myers and Diener (1995), in their review of psychological literature, found an overwhelming focus of research on the negative aspects of individuals lives compared to positives: a ratio of 17:1. However, the World Health Organisation's definition of health as 'a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity' (WHO 1948; cited in Ryff and Singer, 1998) supports the notion that health is more than the absence of negative states. Similarly, research in the field of well-being has long acknowledged that the presence of well-being and positive experience is not simply the opposite of low distress and the absence of negative experience and that these are distinct (Conway and MacLeod, 2002; Ryan and Deci, 2001). With the recent growth of the Positive Psychology movement in the USA (e.g. Seligman and Csikszentmihalyi, 2000), there has been a shift to wanting to understand, conceptualize and foster positive states and qualities such as happiness, morale, life satisfaction and wellness (e.g. Cowen, 1991). This includes an interest in how people can survive and flourish both in adverse circumstances and in more benign situations with the occurrence of environmental stressors (Seligman and Csikszentmihalyi, 2000).

There exists two main schools in the field of well-being (Ryan and Deci, 2001). The hedonic view suggests that well-being consists of subjective happiness and the balance between pleasurable and displeasurable experience. This is commonly operationalised as Subjective Well-Being (SWB) consisting of three components: life satisfaction; the presence of positive mood; and the absence of negative mood (Deiner, Suh, Lucas and Smith, 1999). The eudaimonic movement, on the other hand, proposes that well-being is not just the pursuit of happiness or drive fulfillment but in growth, development and fulfillment of potential. Ryff has been important to this movement, in developing a comprehensive life span formulation of Psychological Well-Being (PWB) or human flourishing where well-being represents the actualization of one's true potential. Drawing on other respected theories (e.g. Maslow's 1968 conception of 'self actualization'; Roger's 1961 idea of the 'fully functioning person'; Jung's 1933 concept of 'individuation'; Allport's 1961 conception of 'maturity'; Erikson's 1959 psychosocial stage model of life span development), researchers identified six distinct dimensions of PWB - autonomy, personal growth, self-acceptance, life purpose, mastery and positive relatedness with others. They went on to operationalise these constructs and used an empirical approach to test the validity of self report measures (Ryff, 1989). A clear advantage of this approach is it's grounding in theory and empirical evidence. However, debates continue about which model (SWB or PWB) constitutes true well-being with each possessing strengths and weaknesses, the debate being beyond the scope of this thesis (see Ryan and Deci, 2001; Ryff and Singer, 1998).

## Well-being, growth and flourishing in significant others after ABI

Literature on human functioning after one-off traumatic events suggests that individuals responses can follow four major trajectories or patterns of disruption (Bonanno, 2004): *chronic*, where functioning remains below normal levels long after the event; *delayed*, where functioning is normal at the start and decreases later on; *recovery*, a transient reduction in normal functioning followed by a return to normal levels; and *resilience*, where the individual is able to maintain normal levels of functioning over time. As we have seen, the brain injury literature has provided overwhelming evidence for negative psychosocial outcomes in families and family members after ABI (Kosciulek, 1994) including *relationship dysfunction and breakdown* (e.g. Wood and Yurdakul, 1997; Peters et al. 1990; Gosling and Oddy, 1999; Peters et al., 1992), *loss and grief* (e.g. Lezak, 1986) and *stress, burden and psychopathology* (e.g. Linn et al., 1994; Kreutzer et al., 1994a; Livingston et al., 1985a; 1985b). However, several authors note the absence of distress and burden in some family members after ABI (Perlescz et al., 1999) and the ability of many families to function well after stroke (Bishop and Evans, 1995) and TBI (Perlescz et al., 1999). Kosciulek, McCubbin and McCubbin (1993) emphasis the importance of addressing strengths and positive adaptation processes in their *'Resiliency Model of Family Stress, Adjustment and Adaptation'* after head injury. They suggest that families *can* adjust to their 'new life' and identify important factors in adjustment. The model posits that the initial *'adjustment'* phase (when families attempt existing patterns of family functioning to deal with the stresses and strains of head injury) can lead to 'crisis' in the family unit: the family system becomes disrupted, disorganized or incapacitated as result of head injury and other piled-up stressors (i.e. existing strains on the family from life cycle challenges and transitions, for example). The *'adaptation'* phase follows, requiring the family to make changes to bring about balance, harmony and satisfactory functioning. They suggest that positive adaptation depends on a number of different factors including the family type, family strengths, appraisal of the situation and the head injured persons difficulties; beliefs about the world, social support and ability to problem-solve and cope. Families who possess strengths such as a *sense of mastery and control* over the environment; *cohesion*; and a family tendency to focus on *together time and established routines* ('rhythmic' families) are said to be more predisposed to positive adaptation after head injury (Kosciulek et al., 1993; Kosciulek, 1994; Kosciulek, 1996).

Furthermore, authors in the general literature note that the process of adaptation to major life events, in addition to negative outcomes, can also actually bring about enhanced positive functioning such as growth and increased personal development (Ryff and Singer, 1998). This concept of growth and development in the face of adversity is no less applicable to relatives facing the major life event of brain injury and the life changes that follow (Adams, 1996). For example, spouses and carers of brain injured patients have reported a strengthening of the family unit, a deepened sense of faith and maturity, a reevaluation of priorities and growth through the adversity of ABI (Sachs, 1985; Perlescz et al, 1989; cited in Adams, 1996).

In respect of positive relationship outcomes, Gosling and Oddy (1999), found that wives were able to cite ongoing positive facets of their relationship with their brain injured husbands, including companionship, mutual affection, mutual commitment and feeling stronger and more in control in their relationship since the injury. Similarly, Leathem et al., (1996) reported that one spouse in their qualitative study on life change after head injury felt that they had grown closer to their husband since the injury, and that they relied on each other and needed each other more.

Researchers in the field of brain injury are therefore beginning to look beyond traditional psychiatric and 'mental ill health' outcomes in family member after ABI. These have including addressing life change (Wallace et al., 1998), role change (Leatham et al., 1996), life satisfaction (Ergh, Hanks, Rapport and Coleman, 2003) and quality of life (White, Mayo, Hanley and Wood-Dauphinee, 2003). Occasionally, the literature has made erroneous statements about degree of *psychological well-being* of significant others through the use of inappropriate measures for these conclusions. For example, Williams (1993) made conclusions about the 'psychological well-being' of their carers of stoke patients based on carers scores on the Symptom Questionnaire (Kellner, 1983), a measure of psychopathology and distress. Similarly, Sander, High, Hannay and Sherer (1997) made conclusions about the 'psychological health' of caregivers of TBI patients on the basis of scores on the General Health Questionnaire (Goldberg, 1972), measuring psychological *ill*-health. Authors in the field of Psychological Well-Being argue that a lack of or low levels of disease or distress in only part of the picture of positive psychological well-being or health (Ryff and Singer, 1998) and one cannot make conclusions about an individual's Psychological Well-Being purely on the basis of presence or absence of these sorts of symptoms.

## Summary

There has been an overwhelming devotion to negative outcomes, both in the general psychological literature and in literature devoted to spousal and family outcomes after acquired brain injury (e.g. Wood and Yurdakul, 1997; Peters et al., 1990; Gosling and Oddy, 1999; Lezak, 1986; Linn et al., 1994; Kreutzer et al., 1994a and 1985b). However, there is some suggestion that many family members are able to function well, to adjust over time and even to experience enhanced personal growth and development (Sachs, 1985; Perlescz et al, 1989; cited in Adams, 1996; Perlescz et al., 1999; Kosciulek et al. 1993). To the best of the knowledge of the researcher, few studies have been designed exclusively to explore the positive psychological outcomes of partners and spouses after ABI and none looking at positive Psychological Well-Being (as defined by Ryff and her colleagues) in partners/spouses.

## 1.7 Overall summary and research questions

### Overall Summary

The field of positive outcomes for spouses and partners after ABI is relatively uninvestigated. An aim of this study will therefore be to explore positive psychological outcomes in partners, in the form of Psychological Well-Being (PWB) as defined by Ryff and colleagues (e.g. 1989). It will aim to identify which, if any, brain injury factors are associated with partner PWB. The brain injury factors chosen will be based on those identified as salient to partner and family outcomes in previous research, namely severity, patient functioning, presence of neurobehavioural symptoms/personality changes and time since injury. In addition, awareness of deficit will be included, as little research has been devoted to the impact of this on partners.

As few studies have addressed how the relationship between the partner and injured person changes after injury, this will be explored. Similarly, the association between certain brain injury factors (e.g. severity, presence of neurobehavioural symptoms/personality change, time since injury) and the nature of the relationship between the partner and the injured person will be investigated. Again, owing to lack of research, awareness of deficit will be included in this regard to examine how this particular symptom is linked with the quality or adjustment of the partner relationship.

The phenomenon of impaired awareness of deficit will also be examined, particularly in respect of conflicting literature.

## Research Questions

**The main aims of the current study are as follows:**

- To explore the Psychological Well-Being of partners of individuals with acquired brain injury.
- To explore the quality of the relationship between the partner and the injured person as perceived by the partner.
- Which, if any, brain injury related factors are associated with dimensions of partner Psychological Well-Being?
- Which brain injury related factors are associated with the quality of the relationship between the partner and the person with ABI as perceived by the partner?

**In addition, subsidiary aims are:**

To explore whether other factors are associated with the Psychological Well-Being of the partner and relationship quality between the injured person and the partner.

To explore the construct of awareness of deficit after ABI, namely:

- Do patients show lower awareness of their deficits than do partners?
- Do patients show different levels of awareness for different deficits?
- Do levels of awareness of deficit in the patient show any change over time after injury?
- Are levels of awareness of deficit linked with the severity of the injury?

# Method

## 2.1 Design

The study used a quantitative cross sectional correlational design with a mixed sample of brain injured patients and their partners from a variety of sources.

Research questions were tackled by measuring: discrepancy between partner and patient view's on patient's current functioning ('level of awareness of deficit', 'awareness' for specific functions), severity of injury, time since injury, age and number of years of education of partner, financial strain, presence of children aged 18 or below at home, length of time in relationship preinjury. The following measures, rated by partners, were also used: patient current functioning (and subscales), severity of neurobehavioural symptoms (and subscales), perceived personality change, quality of the current marital relationship (and specific dynamics), retrospective rating of satisfaction with preinjury relationship, change of relationship satisfaction since the injury, partner Psychological Well-Being (three dimensions).

As discussed in the introduction, the field of measurement of awareness after neurological damage is fraught with difficulties. A widely used method is to compare patient reports of his/her difficulties with the reports of a significant other who knows the patient well, where a discrepancy in viewpoints is taken to represent 'impaired awareness' in the patient (e.g.

Fleming et al, 1996). An advantage to taking the partners view as the 'benchmark' or 'objective' measure is that partners are likely to have a high level of contact with the patient and knowledge of patient functioning now compared to before the injury. In addition, in the context of the present study, it may be more clinically valid to examine how discrepant interpretations between the person with brain injury and his/her partner is linked to the well-being and marital satisfaction in the partner, rather than using other debatably more 'objective' but less relevant measures (e.g. clinician/patient discrepancies or neuropsychological test/patient discrepancies, or clinician ratings of awareness). Practical issues also confirmed the decision to use this method: many clients were no longer in regular contact with clinicians (therefore clinician ratings could not be uniformly collected) and the time-scale meant it would not be feasible to collect neuropsychological test results for all patients. However, the limitations of this approach were borne in mind and will be further considered in the discussion.

## 2.2 Statistical Power

The power of a study refers to the probability of successfully finding a true effect and not a spurious one due to chance or random error: this increases with greater sample size. Cohen (1992) recommends that for a multiple regression using four predictor variables and a significance level of $\alpha = 0.05$, a sample size of 38 participants is needed to demonstrate a large effect size with a power of 80%. Were five variables to be used in the present study a minimum sample size of 42 is suggested and, for six, 45, using the same criteria. These were used to provide a rough lower-bound estimate.

## 2.3 Ethical Approval

Ethical Approval was sought and attained from the Barnet, Enfield and Haringey Research Ethics committee (see Appendix A).

Consideration was given to the language used in information sheets to improve understanding by the patients, with likely compromised cognitive functioning. As the emphasis of the study was on partner outcomes, involvement by the patient was minimised to a single questionnaire, the Awareness Questionnaire, chosen partly for simplicity of language. Within the initial telephone conversation with partners and the consent form enclosed with the information pack, emphasis was placed on freedom to participate or not, and their right to withdraw at any time they wished (see Appendix B for the protocol for the initial conversation with partners and Appendix C for information sheets and consent forms).

## 2.4 Measures

### *'Level of awareness of deficit' (Appendix D)*

The Awareness Questionnaire (Sherer, Bergloff, Boake, High and Levin, 1998) is a 17 item scale designed to measure awareness of deficit after acquired brain injury. Equivalent versions exist for the patient and the significant other to fill out (there is also a clinician rated version). Individuals rate how well the patient performs in particular functions now compared to before the injury on a 5 point likert scale from 'much worse' (1) to 'much better' (5). Level of awareness is calculated by subtracting the significant other's total score from the patient total score. Factors analysis of the scale has yielded three domains or subscales (Sherer, Bergloff, Boake et al., 1998):

motor/sensory (items 6, 7, 8, 9)
cognitive (items 1, 4, 10, 11, 12, 13, 15)
behavioural/affective (items 2, 3, 5, 14, 16, 17)

Level of awareness of a domain of function is calculated by subtracting the significant other score from the patient's score in that domain/subscale. A discrepancy score of zero indicates good agreement between patient and significant other and is said to represent good awareness of deficit in the patient. A positive discrepancy score suggests that the patient rated him/herself as more capable than does the significant other, indicating impaired awareness of deficit in the patient. A negative discrepancy score, where the patient rates himself/herself as functioning at a lower level than the partner does, suggests hyperawareness of deficit in the patient.

Internal consistency as measured by Cronbach's Alpha coefficient has been shown to be acceptable for patient (0.88) and significant other (0.88) versions of the scale (Sherer, Bergloff, Boake et al., 1998) and sensitivity has been supported through patients tending to rate themselves as less impaired than do family members and clinicians (Sherer, Hart and Nick, 1998). Criterion validity has been demonstrated through discrepancies being predictive of eventual productivity outcome for persons with brain injury (Sherer, Bergloff, Levin et al., 1998).

This questionnaire was chosen for being user-friendly - it employs simple wording and, at 17 items, is shorter than other commonly used measures (e.g. PCRS, Prigatano, Fordyce and Zeiner, 1986; SADI, Simmond and Fleming, 2003) yet compares favourably in respect of psychometric properties (e.g. Sherer, Hart and Nick, 2003). Another strength is that it gives raters the opportunity to disclose perceived improvements in functioning as a result of the injury.

*Partner subjective rating of current neurobehavioral function (Appendix E)*

The Neurobehavioral Rating Scale (NRS; Levin, High, Goethe, Sisson, Overall, Rhoades, Eisenberg, Kalisky, and Gary, 1987) was designed to measure presence and severity of various neurobehavioural symptoms after brain injury. It consists of 27 items on a 7-point likert scale (from 'not present' to 'extremely severe'). Factor analysis has yielded four factors:

Cognition/Energy (items 3, 6, 7, 10, 17, 19, 21)
Metacognition (items 8, 11, 12, 20, 22, 23)
Somatic/Anxiety (items 2, 4, 13, 14, 16, 25)
Language (items 5, 26)

The measure has been shown to have good inter-rater reliability (0.90, 0.88) and validity, through links between the scale and severity of injury and recovery. The NRS has featured in research with patients with traumatic brain injuries (e.g. Lanham, Weissenburger, Schwab and Rosner, 2000) and other neurological disorders (e.g. Sultzer, Berisford and Gunay, 1995). More specifically, it has been used in a study looking at family functioning after traumatic brain injury (Douglas and Spellacy; 1996).

Contact with the authors of the scale clarified that there was no published manual available for use of the scale. However the original paper (Levin, High, Goethe, et al., 1987) gave a semi-structured interview guide, which was used with partners by way of telephone interview. This use of partner ratings of neurobehavioural symptoms echoes earlier research into the sequelae of brain injury (e.g. McKinlay, Brooks, Bond, Martinage, and Marshall, 1985; Brooks, Campsie, Symington, Beattie and McKinlay, 1986; Brooks, Campsie, Symington, Beattie, and McKinlay, 1987) and examining partner and family outcomes after brain injury (Ergh, Rapport, Coleman and Hanks, 2002; Groom, Shaw, O'Connor, Howard, and Pickens, 1998) owing to partner's in depth knowledge of the patient in everyday life situations. Therefore, the scale was used more as *a checklist of partner perceived ratings of severity of neurobehavioural symptoms* and not, as originally developed, a clinician rated scale based on information gained from observation and interview with the patient coupled with information from other sources (e.g. partners perceptions, documented evidence) (Levin et al., 1987)

### *Personality change (Appendix F)*

In addition to the NRS measuring the presence of symptoms indicating change in personality, a one item measure was developed to assess subjective rating of difference in personality now compared to before the injury on a 5 point likert scale from 'the same' (rating of 1) to 'completely different' (rating of 5).

*Current patient level of functioning (Appendix G)*

The Patient Competency Rating Scale (PCRS; Prigatano, Fordyce and Zeiner, 1986) is a 30 item self-report measure which assesses patient functioning in everyday life. Responses indicate the ease to which various everyday tasks can be carried out by the patient on a 5 item likert scale from 'can do with ease' (5) to 'can't do' (1). Items are devoted to four main functions in the patient:

activities of daily living, (items 1-6, 14, 26)
cognitive functions (items 7, 9-13, 24, 25)
interpersonal functioning (items 8, 15, 17, 20, 22, 23)
emotional functioning (items 16, 18, 19, 27, 28, 29, 30)

It was developed as a measure of awareness of deficit after brain injury however studies have used relatives' ratings on the 'significant other' version of the scale as a measure of patient functioning after brain injury (e.g. Minnes, Graffi, Nolte, Carlson and Harrick, 2000). Therefore, the 'significant other' version was used in this study for partners to rate the patient's current level of functioning. It was chosen because it is short, easy to fill out, the language is simple and easy to understand and is designed specially to be filled out by a 'significant other'. The scale has shown good test-retest reliability for relatives (r = .92; Prigatano, Altman & O'Brien, 1990) and for a control group of uninjured college students (r = .82; Heilbronner et al., 1993). Internal consistency has also been shown to be strong for relatives' ratings of patients (Cronbach's alpha = .93) (Fleming, Strong and Ashton, 1998).

*Severity (Appendix H)*

The severity of injury was classified as mild, moderate or severe according to at least one of the following:

length of coma/loss of consciousness (Williamson, Scott and Adams, 1996)
lowest Glasgow Coma Scale score (GCS; Teasdale and Jennett, 1974)
length of Post-Traumatic Amnesia (PTA; Kraus and McArthur, 1996).

For participants obtained through the neurorehabilitation unit, severity data was obtained from files where possible. For Headway participants, as there was no access to file information, partners were asked to supply information related to severity either from a rehabilitation or medico-legal report they had been given or, as a last resort, on the basis of retrospective analysis of length of coma or memory of GCS score or length of PTA given by a clinician at time of injury.

*Partner psychological well-being (Appendix I)*

Ryff's scales of psychological well-being are theoretically driven, self-report scales designed to measure dimensions of psychological well-being. The six domains of well-being are measured by six subscales, each of 20 items. 14-item scales have been derived from the parent scales. Owing to the demands being placed on participants, three short-form scales (environmental mastery, personal growth and positive relations with others) were selected for use in the current study to measure specific dimensions of well-being based on consideration of the literature and clinical experience (see Appendix J). The scales have good internal consistency (Environmental Mastery - alpha = 0.86; Personal Growth - alpha = .85; Positive relations with others – alpha = .88) and the 14 item versions correlate well with the 20-item parent scales (EM = .98; PG = .97; PO = .98; Ryff, 1989).

*Quality of Current Relationship (Appendix K)*

The Dyadic Adjustment Scale (DAS; Spanier, 1976) is a widely used measure of adjustment or quality of an intimate relationship. It consists of 32 items and a higher score indicates greater adjustment. Factor analysis has yielded four subscales:

dyadic satisfaction (items16-23; 31, 32)
dyadic cohesion (items 24-28)
dyadic consensus (items 1-3; 5; 7-15)
affectional expression (items 4, 6, 29, 30).

Criterion related validity was established through statistically significant discrimination between married and divorced couples and construct validity, through good correlation with the Marital Adjustment Scale (Locke and Wallace, 1959) for married (.86) and divorced (.88) couples. Good reliability was found for the total scale (r = .96) (Spanier, 1976). The DAS has been used in other studies to assess relationship quality after brain injury (Peters, Stambrook, Moore and Esses, 1990; Moore, Stambrook, Peters and Lubusko, 1991).

### *Relationship satisfaction preinjury and change in relationship satisfaction since injury (Appendix L)*

Single item measures were developed for these purposes. For retrospective rating of relationship satisfaction prior to injury, a 5 point likert scale was used where 5 represented 'extremely satisfied' and 1, 'extremely unsatisfied'. Change in relationship satisfaction was also measured via a 5 point likert scale where 1 was 'much less satisfied' and 5, 'much more satisfied'.

### *Financial Strain (Appendix M)*

Financial strain was operationalised via household net monthly income and a 5 point likert scale where 1 was 'not at all' and 5 was 'all of the time'.

### *Socio-Economic Classification (Appendix N)*

A scale was used to classify social class based on the OPCS Occupational Classification (1980) criteria (see Appendix M). Initially, two raters made independent ratings of social class by highest held profession for patients and for partners. A high level of agreement was achieved. For disagreements, the raters discussed each case until agreement was reached. Patients' occupation was frequently based on that prior to injury (as many were no longer in their original profession owing to injury related difficulties). Social class of couple/family was then rated by taking the highest held social class rating out of patient and partner classifications for each couple.

## 2.5 Procedure

*Couples contacted through a brain injury rehabilitation unit*

Couple's details were obtained through the database of clients at a neurorehabilitation unit. Contact was made with the partner/spouse of the couple by telephone where possible. A protocol was developed to guide the conversation (see Appendix B). If partners felt they and the patient may be interested in taking part, a questionnaire pack was sent to them to look over with the patient and decide whether they wanted to participate (see Appendix O for letter and personal details form). If couples did not return their pack within a few weeks, the partner was telephoned to check whether they had decided to take part. If either the patient or the partner expressed a desire not to take part, they were thanked for their time and not contacted again. If couples were interested, they were offered help to fill them out at a mutually convenient time. If they had lost the questionnaires but were still interested, they were sent another pack and given a follow up telephone call a few weeks later.

When couples returned completed questionnaires, the partner was contacted for a follow up telephone interview to collect the last set of data (Neurobehavioral Rating Scale; years of education; occupational history of patient and partner; occurrence of other brain injuries in the patient and brain surgery). Brain injury unit files were consulted to get information about initial severity of injury and to confirm and extend information given by partners (e.g. history of other neurological diagnoses/impairments; brain surgery).

*Couples contacted through Headway charity*

Headway London consists of two Day Centres and four local Branches. The researcher attended monthly meetings at two local branches, where details of the research were presented verbally and packs given out to interested couples and managers to distribute. The manager of another branch presented details of the study at their monthly branch meeting and gave out contact details. A further branch was contacted but they had no-one suitable at the present time. The managers of both Day Centres agreed to distribute packs to couples that showed an interest and met criteria. In addition, research and contact details were posted in the monthly newsletter that goes out to members and staff of all London Headway establishments.

On receipt of completed questionnaires, the researcher contacted partners by telephone to collect the final data (e.g. Neurobehavioral Rating Scale; years of education; occupational history of patient and partner; occurrence of other brain injuries in the patient and brain surgery; data regarding initial severity of injury, preferably from previous rehabilitation or medico-legal reports).

## 2.6 Recruitment

### *Inclusion and exclusion criteria*

*Inclusion*

- Although initial criteria included only cases of one-off traumatic brain injury, shortage of participants resulted in an inclusion of all cases where the brain injury was of an acquired and non-progressive nature at the time of the study. This population is broadly representative of community brain injury rehabilitation units (e.g. Bajo, Hazan, Fleminger and Taylor (1999).

- Injury sustained no longer than approximately 10 years prior to contact.
- Self-identified as in a heterosexual relationship with an adult partner for least one year prior to injury.
- Currently self-identified as 'together'. This included being married or cohabiting or living separately but in a long-term 'partner' relationship with regular contact.

*Exclusion*

- There was little convincing evidence that the patient's ongoing difficulties were largely as a result of the brain injury (e.g. difficulties as a result of severe mental health problems, continued heavy drinking/drug abuse).
- The brain injury was progressive at the time of the study (e.g. dementia, tumour).
- The couple considered themselves no longer 'together' or the relationship had changed radically since the injury such that most of the 'care' of the patient was not with the partner at the time of the study (e.g. brain injured person in a nursing home, residential care or inpatient rehabilitation).
- Either the patient or the partner were not fluent in English
- The patient had severe communication difficulties which would prevent him/her understanding information or filling out questionnaires accurately.

### Brain injury unit participants

#### *Phase one – identifying participants*

At the rehabilitation unit, 320 patients were identified as potentially having been with a partner/spouse at the time of referral via the database of referrals and liaison with unit staff.

#### *Phase two – screening participants*

Through mainly telephone conversations with partners and some consultation with staff, 85 couples were sent a questionnaire pack and 235 were not. Table 1 shows the frequencies of distribution of questionnaire packs and reasons for exclusions in phase two.

Table 1 – Frequencies of distribution of questionnaire packs and exclusions in phase two of brain injury unit recruitment.

| | | **Number of couples** | **Percentage of couples** |
|---|---|---|---|
| Questionnaire packs sent (seemed to meet inclusion criteria) | | 85 | 26.56 |
| Questionnaire packs not sent | | | |
| Excluded | Couple separated/divorced/not 'together' | 16 | 5.00 |
| | Patient died since referral | 19 | 5.94 |
| | Partner died since referral | 1 | 0.03 |
| | Patient had other complicating problems (e.g. severe mental health problems, alcohol related injury) | 11 | 3.44 |
| | Patient or partner not fluent in English | 8 | 2.50 |
| | Patient had severe communication problems | 8 | 2.50 |
| | Severe relationship difficulties at time of study (advised not to contact by rehabilitation staff) | 2 | 0.63 |
| | Patient diagnosed with progressive neurological disorder | 4 | 1.25 |
| | Homosexual couple | 2 | 0.63 |
| | Patient in hospital | 4 | 1.25 |
| | Patient in residential care/nursing home | 6 | 1.88 |
| | Patient in inpatient rehabilitation | 5 | 1.56 |
| Contact attempted but could not be made (moved away, contact details wrong on file, did not respond to telephone messages) | | 129 | 40.31 |
| Partner and/or patient not interested | | 20 | 6.25 |
| Total | | 320 | 100 |

*Phase three – questionnaire pack sending*

Of the 85 partners contacted, agreeing to take part and sent questionnaires, 39 completed packs were returned and deemed suitable for inclusion. Therefore the overall rehabilitation unit response rate was 45.88%. Table 2 shows the distribution of responses for questionnaire packs sent out.

Table 2 – The distribution of responses for questionnaire packs sent out to brain injury unit participants

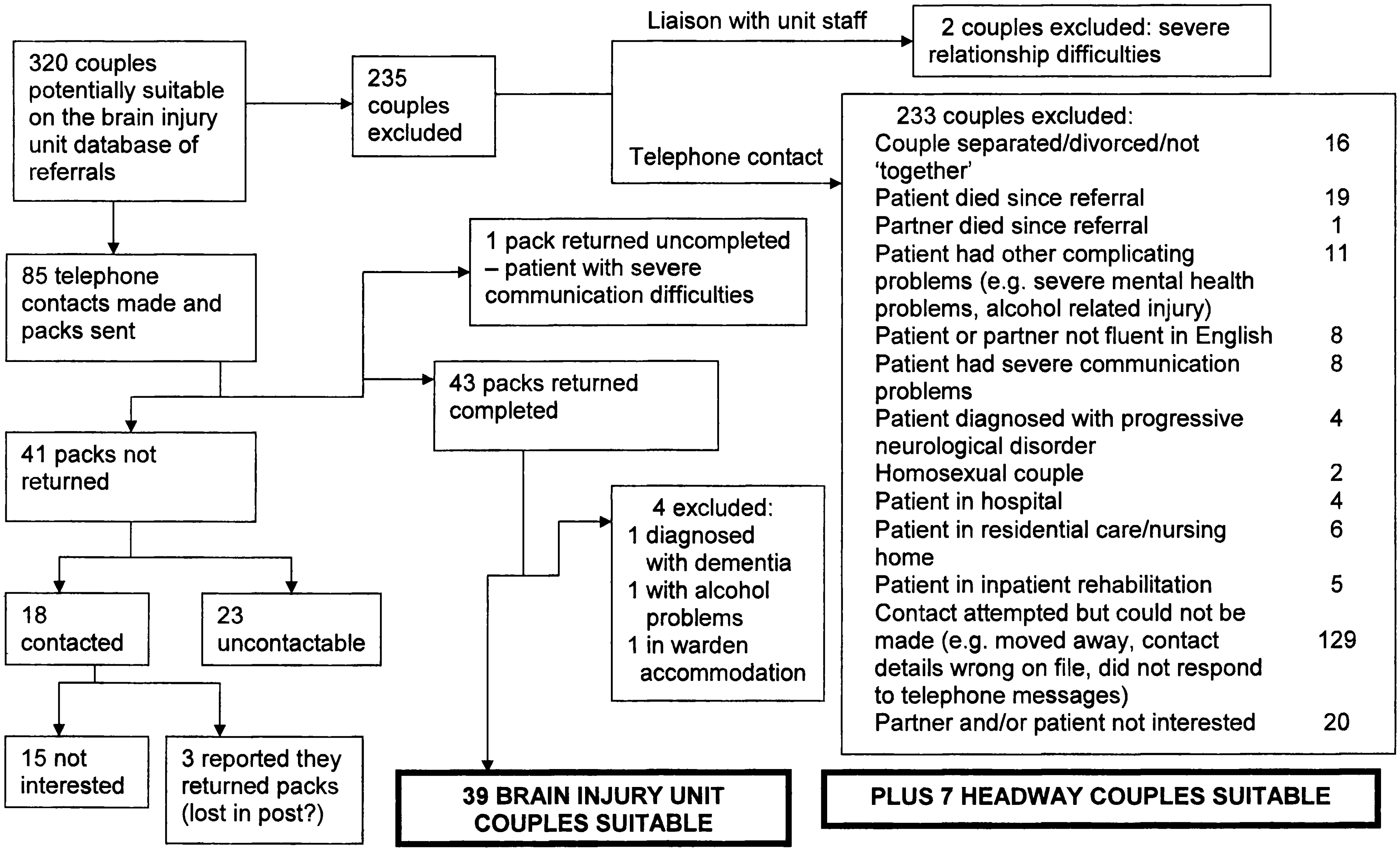
| | | **Number of couples** | **Percentage of couples** |
|---|---|---|---|
| Suitable couples who returned packs and packs were received | | 39 | 45.88 |
| Couples returned packs but packs lost in post | | 3 | 0.53 |
| Couple did not return their questionnaires | | | |
| | Reported they were not interested in taking part | 15 | 17.65 |
| | No reason available | 23 | 27.06 |
| Further exclusions | Patient had severe communication problems | 1 | 1.18 |
| | Patient diagnosed with dementia | 1 | 1.18 |
| | Patient brain injury mainly related to alcohol | 1 | 1.18 |
| | Patient in nursing home / warden controlled accommodation | 2 | 2.35 |
| Total | | 85 | 100 |

*Headway participants*

Twenty two packs were distributed through Headway, directly to participants or through managers. Eight couples from Headway returned completed packs, of which one couple was excluded as they had met after the injury, giving an overall Headway response rate of 31.82%.

Figure 1 shows a flow chart of recruitment including numbers of couples at each stage of the process.

**Figure 1 - Flow Chart of Recruitment**



233 couples excluded:

| | |
|---|---|
| Couple separated/divorced/not 'together' | 16 |
| Patient died since referral | 19 |
| Partner died since referral | 1 |
| Patient had other complicating problems (e.g. severe mental health problems, alcohol related injury) | 11 |
| Patient or partner not fluent in English | 8 |
| Patient had severe communication problems | 8 |
| Patient diagnosed with progressive neurological disorder | 4 |
| Homosexual couple | 2 |
| Patient in hospital | 4 |
| Patient in residential care/nursing home | 6 |
| Patient in inpatient rehabilitation | 5 |
| Contact attempted but could not be made (e.g. moved away, contact details wrong on file, did not respond to telephone messages) | 129 |
| Partner and/or patient not interested | 20 |

# Results

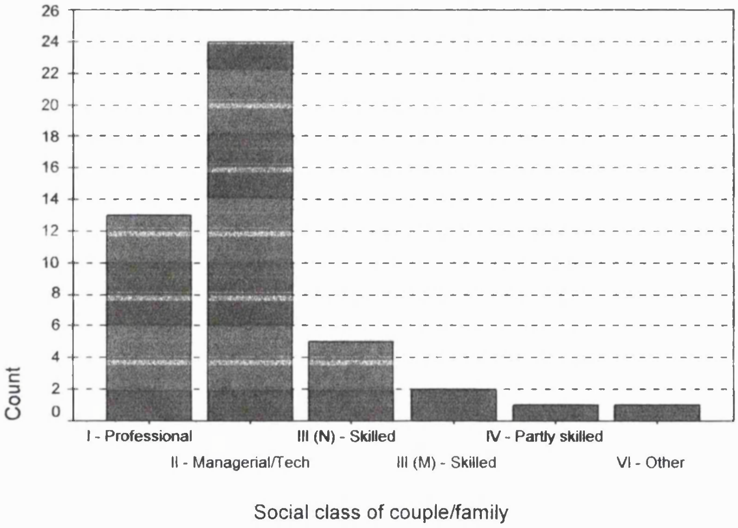
The results are contained in three main sections (sections 3.1 – 3.3). The first (section 3.1) describes the sample, compares TBI couples with couples where injury was from other sources and gives data preparation relevant for analyses. In the second section (3.2), the main hypotheses are examined and preliminary statistical data checking and preparation presented. The third and final section explores the subsidiary hypotheses (section 3.3) concerning partner well-being, relationship quality and awareness of deficit.

## 3.1 Describing the sample

### Demographic characteristics of couples

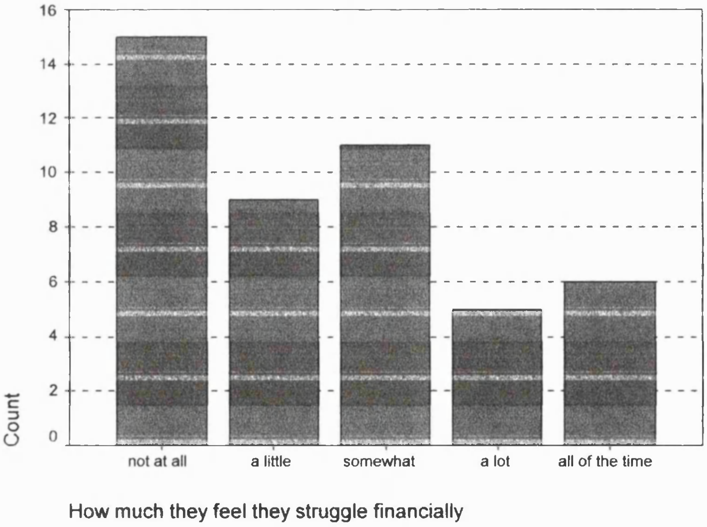
Forty six couples took part: 40 (85%) of the partners were female and 6 (15%) were male. The mean age of the partner was 53.41 years (SD = 10.29; Range = 30 to 72) and the patient, 55.30 years (SD = 10.74; Range = 27 to 67). The partners had received 13.30 years of education on average (SD = 2.80; Range = 10 to 23) and patients, 13.67 years (SD = 3.46; Range = 9 to 24). Figure 2 shows the social class distribution of couples.

Figure 2 – Distribution of social class of couples based on highest level of occupation achieved by patient or partner



Around half are described as possessing 'Managerial and Technical' occupations (n=24; 52.17%). The mean household monthly income for couples was £1,652.33 (SD = £1,164.26; Range = £388.00 - £7,500.00) with data for four couples missing. Figure 3 shows ratings of financial strain in couples.

Figure 3 – Distribution of partner perceived financial strain in couples.



While the most frequently endorsed response was no financial strain at all, the mean was 2.52 (SD = 1.39; Range 1 to 5) falling between 'a little' and 'somewhat'. Significant financial distress was reported by a minority (11 or 23.91% endorsed 'a lot' or 'all of the time').

Table 3 shows the distribution of ethnic background and table 4, the religious affiliation, of patients and partners in the sample.

Table 3 – Distribution of ethnicity of partners and patients

| | Frequency of Partners | Percentage of Partners | Frequency of Patients | Percentage of Patients |
|---|---|---|---|---|
| White UK | 33 | 71.74 | 35 | 76.09 |
| White Irish | 5 | 10.87 | 3 | 6.52 |
| Black Afro-Caribbean | 2 | 4.35 | 3 | 6.52 |
| Indian | 2 | 4.35 | 3 | 6.52 |
| White European | 1 | 2.17 | 1 | 2.17 |
| Black African | 1 | 2.17 | 1 | 2.17 |
| Anglo-Indian | 1 | 2.17 | 0 | 0.00 |
| Israeli | 1 | 0.00 | 0 | 0.00 |
| Total | 46 | 100 | 46 | 100 |

Table 4 – Distribution of religious affiliations of partners and patients in the sample.

| | Frequency of partners | Percentage of partners | Frequency of patients | Percentage of patients |
|---|---|---|---|---|
| Christian (non Roman Catholic) | 22 | 47.83 | 23 | 50.00 |
| Roman Catholic | 13 | 28.26 | 11 | 23.91 |
| No religion / atheist / agnostic | 6 | 13.04 | 5 | 10.87 |
| Spiritualist | 2 | 4.35 | 1 | 2.17 |
| Jewish | 2 | 4.35 | 3 | 6.52 |
| Muslim | 1 | 2.17 | 1 | 2.17 |
| Rastafarian | 0 | 0.00 | 1 | 2.17 |
| Hindu | 0 | 0.00 | 1 | 2.17 |
| Total | 46 | 100 | 46 | 100 |

Partners and patients were predominantly 'white UK' and were mostly Christian/non-catholic and Roman Catholic.

## Relationship characteristics

Most couples were married (89.13%); 10.87% were unmarried, cohabiting partners. The spouses of one married couple were not living together (2.17% of the sample) but still considered themselves 'together'.

The mean length of time in relationship before the injury was 23.33 years (SD = 10.96; Range = 1 to 43). Thirty nine (84.78%) partners indicated there had been no difficulties in the premorbid relationship, 7 (15.22%) indicated there had been difficulties. The mean number of children of couples was 2.37 (SD = 1.29; Range = 0 to 5); the majority had 2 children (41.30%), 23.91% had three, 10.87% had none or 4 children, and 6.52% had one or five children. Table 5 shows the frequency of number of children aged 18 years or below living at home.

Table 5 – The distribution of number of children aged 18 years or below living at home.

| Number of children aged 18 or below living at home | Frequency | Percentage |
|---|---|---|
| 0 | 32 | 69.57 |
| 1 | 4 | 8.70 |
| 2 | 8 | 17.39 |
| 3 | 1 | 2.17 |
| 4 | 1 | 2.17 |
| Total | 46 | 100 |

## Brain injury related characteristics

The mean length of time since injury was 54.29 months (SD = 35.23; Range = 6.90 to 133.06). Thirteen partners (28.26%) were classified as being in a relationship with a patient with a mild injury, 2 (4.35%) moderate and 28 (60.87%), severe. Data relating to severity were missing for 3 (6.52%) patients. Table 6 shows the distribution of causes of brain injury in the sample.

Table 6 – Distribution of cause or aetiology of brain injury in the sample.

| | | Frequency | Percentage |
|---|---|---|---|
| Traumatic Brain Injury | Road traffic Accident | 13 | 28.26 |
| | Fall | 7 | 15.22 |
| | Assault | 1 | 2.17 |
| | Sporting/leisure accident | 1 | 2.17 |
| | Work accident | 1 | 2.17 |
| Cardiovascular accident (CVA) | | 17 | 36.96 |
| Infection | | 2 | 4.35 |
| Anoxia | | 2 | 4.35 |
| Epileptic fit and anoxia from respiratory distress | | 1 | 2.17 |
| Benign brain cyst removal and subsequent meningitis | | 1 | 2.17 |
| Total | | 46 | 100 |

Seventeen (36.96%) patients had undergone brain surgery. Two CVA patients had evidence of another brain injury prior to the index injury. One had had a stoke from which, according files, he had “made a full recovery” and had not been diagnosed with a deteriorating condition. The other had had a benign brain cyst removed prior to her haemorrhage, the latter being the index injury for which she was referred for rehabilitation.

Scores on important measures

For reference in relation to later analyses, table 7 shows data on measures relating to patient functioning and table 8, data on partner measures of Psychological Well-Being and relationship quality.

Table 7 – Means and standard deviations for major measures of patient functioning

| | **Mean** | **SD** | **Range** | | **Possible Range** | |
|---|---|---|---|---|---|---|
| | | | Min | Max | Min | Max |
| Awareness Questionnaire (AQ) | | | | | | |
| Patient total score | 37.55 | 10.98 | 20.00 | 64.00 | 17.00 | 85.00 |
| Partner total score | 32.12 | 8.08 | 19.00 | 49.00 | 17.00 | 85.00 |
| Overall Discrepancy score | 5.44 | 8.08 | -8.00 | 26.00 | -68.00 | 68.00 |
| Cognitive discrepancy | 2.55 | 3.84 | -8.00 | 11.00 | -35.00 | 35.00 |
| Behavioural/affective discrepancy | 2.28 | 3.56 | -6.00 | 12.00 | -30.00 | 30.00 |
| Motor/sensory discrepancy | 0.60 | 2.08 | -4.00 | 9.00 | -20.00 | 20.00 |
| Patient Competency Rating Scale (PCRS) * | 93.71 | 23.50 | 52.00 | 143.00 | 30.00 | 150.00 |
| Activities of daily living | 25.92 | 7.75 | 11.00 | 39.00 | 8.00 | 40.00 |
| Cognitive functioning | 23.91 | 7.52 | 10.00 | 39.00 | 8.00 | 40.00 |
| Interpersonal functioning | 22.03 | 8.16 | 9.00 | 34.00 | 7.00 | 35.00 |
| Emotional functioning | 21.92 | 5.59 | 10.00 | 34.00 | 7.00 | 35.00 |
| Neurobehavioural Rating Scale (NRS) * | 53.52 | 27.28 | 9.00 | 125.00 | 0.00 | 162.00 |
| Cognition/Energy | 17.43 | 7.82 | 2.00 | 33.00 | 0.00 | 42.00 |
| Metacognition | 9.48 | 6.64 | 0.00 | 31.00 | 0.00 | 36.00 |
| Somatic/anxiety | 11.93 | 8.61 | 0.00 | 30.00 | 0.00 | 36.00 |
| Language | 4.09 | 3.06 | 0.00 | 12.00 | 0.00 | 12.00 |

Table 8 – Means and standard deviations for measures of partner PWB and relationship quality

| | **Mean** | **SD** | **Range** | | **Possible Range** | |
|---|---|---|---|---|---|---|
| Dyadic Adjustment Scale (DAS) * | 105.59 | 18.59 | 45.00 | 140.00 | 0.00 | 151.00 |
| Dyadic satisfaction subscale | 37.15 | 6.06 | 21.00 | 47.00 | 0.00 | 50.00 |
| Dyadic cohesion subscale | 13.61 | 4.91 | 2.00 | 22.00 | 0.00 | 24.00 |
| Dyadic consensus subscale | 46.43 | 10.27 | 12.00 | 65.00 | 0.00 | 65.00 |
| Affectional expression subscale | 8.39 | 2.96 | 0.00 | 12.00 | 0.00 | 12.00 |
| Psychological Well-Being (PWB) * | | | | | | |
| Environmental Mastery | 56.80 | 12.15 | 33.00 | 84.00 | 14.00 | 84.00 |
| Personal Growth | 67.17 | 11.68 | 37.00 | 84.00 | 14.00 | 84.00 |
| Positive Relations with Others | 67.39 | 12.86 | 37.00 | 84.00 | 14.00 | 84.00 |

Table 7 shows that partners rate patients as lower in function now since before the injury than patients rate themselves. Tables 7 and 8 show the means on overall scales and subscales (PWB, DAS, NRS, PCRS, AQ) tend not to fall at the extreme ends of the achieved range or the possible range of scores, suggesting some variability. Figure 4 shows the partners ratings of personality change.

Figure 4 - Partner ratings of personality change in the patient as a result of the injury.

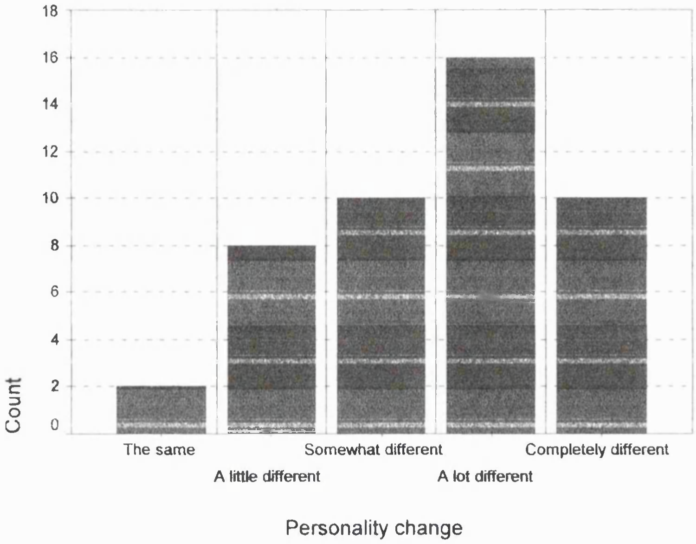


Figure 3 shows that the modal response of how the personality of the patient has changed since injury was ‘a lot different’ (n = 16; 35%) followed by ‘somewhat’ or ‘completely different’ (both n = 10; 22%). Only a few (n = 10; 22%) indicated only little or no change in personality of their injured partner. Therefore the majority (95.65%) rated at least some personality change in the patient.

### Preliminary exploration and preparation of data

Data were entered and analyzed using SPSS: very few data were missing and were mean substituted (see Appendix P for more details). Data was inspected visually, and by examining skewness and kurtosis (by dividing standard scores by their standard error, with a threshold of +/- 2.5). Transformations were performed as necessary: square root transformations for positively skewed data and, for negative skew, scores were inversed, a number added to make values positive and a subsequent square root function performed. Z-scores were also derived in order to assess for outlying cases (+/- 3 SD from the mean), which were excluded as necessary.

The number of years of education of partner was positively skewed with an outlier. Transformation and exclusion of the outlying case brought the variable within normal limits. Satisfaction with preinjury relationship was negatively skewed: appropriate transformation lead to normality of distribution. For DAS total score, with close checking, an outlier was excluded for some analyses and transformations were used for others as appropriate. In addition, one outlying case was excluded from each of the following variables to bring them within limits of normality: the 'Metacognition' subscale of the NRS; the Dyadic Consensus subscale of the DAS; average levels of awareness of Motor/Sensory deficits per item; and mean net household monthly income. In terms of initial severity of injury, as only two cases were considered 'moderate', cases were recoded into two severity groups– 'mild/moderate' and 'severe' – for analyses.

### Comparing TBI couples with couples where the brain injury was from other causes or aetiologies

As a mixed sample was used (TBI vs other one off non progressive conditions), the data was examined for differences between these groups on demographic and brain injury related variables. Table 9 shows the means and standard deviations of certain demographic and injury related variables in the TBI group and the 'other injuries' group.

Table 9 – means and standard deviations of demographic and injury related variables in the TBI and 'other injuries' groups.

| Characteristics | | TBI (n = 23) | | Other (n = 23) | |
|---|---|---|---|---|---|
| | | Mean | SD | Mean | SD |
| Patients | Mean age (years) | 53.17 | 11.67 | 57.43 | 9.52 |
| | Mean years of education | 12.83 | 2.86 | 14.52 | 3.86 |
| Partners | Mean age (years) | 52.39 | 9.67 | 54.43 | 11.00 |
| | Mean years of education | 12.74 | 2.34 | 13.9 | 3.1 |
| Mean number of children | | 2.48 | 1.62 | 2.26 | 0.86 |
| Mean net monthly household income | | 1451.45 | 771.81 | 1873.30 * | 1472.59 |
| Mean rating of financial strain [1] | | 2.83 | 1.58 | 2.22 | 1.12 |
| Mean years in relationship prior to injury | | 21.23 | 11.72 | 25.43 | 9.96 |
| Preinjury relationship satisfaction [2] | | 4.26 | 1.10 | 4.09 | 1.20 |
| Change in relationship satisfaction since injury [3] | | 2.26 | 1.10 | 2.70 | 1.36 |
| Mean length of time since injury (months) | | 49.98 | 33.78 | 58.59 | 36.86 |

[1] Financial strain - a 5 point scale - 1 (not at all) to 5 (all the time).
[2] Preinjury relationship satisfaction – 5 point scale - 5 (extremely satisfied) to 1 (extremely unsatisfied)
[3] Change in relationship satisfaction – 5 point scale - 1 (much less satisfied) to 5 (much more satisfied)
* Data missing for 3 couples

In order to test for differences between groups in these variables, independent samples t-tests were performed: no significant differences emerged between the groups for age of patients (t(44) = -1.111, p = .272) and partners (t(44) = -.420, p = .676); years of education of patients (t(44) = -1.694, p = .097) and partners (t(43) = -1.023, p = 0.312); mean number of children (t(44) = .568, p = .574), income (t(43) = .071, p = .944), financial strain (t(39.70) = 1.501, p = .141), length of relationship prior to injury (t(44) = -1.312, p = .196), preinjury relationship satisfaction (t(44) = -.448, p = .656), change in relationship satisfaction (t(44) = -1.249, p = .218) and time since injury (t(44) = .413, p = .673).

Groups were also largely similar on visual inspection of other variables. All partners of TBI patients were female as were most in the 'other injuries' group (n = 17; 73.91%; 6 were male, 26.09%). The modal ethnic background for patients in both groups was white UK (TBI patients n=19, 82.61%; patients with other injuries n=16, 69.57%). This was also true of partners in both groups (TBI partners n=20, 86.96%; partners of people with other injuries n=13, 56.52%). The modal social class for TBI couples was social class II, 'managerial and technical' (n = 14; 60.87%). For couples in the 'other injuries' group, the joint modal social classes were I ('professional'; n = 10, 43.48%) and II ('managerial and technical'; n = 10, 43.48%). Most of the TBI couples were married (married, n = 18, 78.26%; unmarried, n = 5, 21.74%) and all in the 'other injuries' group were married. A small proportion of both groups (5 partners in the TBI group, 21.74%; 2 in the 'other injuries' group, 8.70%) mentioned having experienced relationship difficulties prior to the injury. Seven (30.43%) couples in each group had at least one child aged 18 or younger living at home.

A visual inspection of severity highlighted differences between the groups: most of the TBI patients' injuries were classified as severe (n = 20, 86.96%) with few moderate (n = 2; 8.70%) and mild (n = 1, 4.35%) injuries. On the other hand, injuries in the 'other injuries' group were predominantly mild (n = 12, 52.17%) with some severe injuries (n = 8, 34.78%), with data missing for three 'other injuries' couples. With 'moderate' and 'mild' injuries grouped into one category (mild/moderate), a chi square test showed that there were significantly higher rates of 'severe' injuries in the TBI group ($\chi^2(1) = 10.384$, $p = .002$).

Table 10 shows the means and standard deviations of each group on major measures used in the study.

Table 10 – Means and standard deviations on major measures in the TBI and 'other injuries' groups.

| | TBI (n=23) | | Other (n=23) | |
|---|---|---|---|---|
| | Mean | SD | Mean | SD |
| **Scores on Measures** | | | | |
| Global level of awareness of deficit | 6.54 | 8.56 | 4.33 | 7.37 |
| Awareness of cognitive deficits | 2.80 | 3.72 | 2.30 | 4.03 |
| Awareness of behavioural/affective Deficits | 3.02 | 3.71 | 1.54 | 3.33 |
| Awareness of motor/sensory deficits | 0.71 | 2.52 | 0.48 | 1.56 |
| Personality change * | 3.48 | 1.24 | 3.57 | 1.08 |
| Severity of neurobehavioural symptoms | 56.78 | 25.97 | 50.26 | 28.72 |
| Cognition/Energy | 18.43 | 7.83 | 16.43 | 7.85 |
| Metacognition | 9.87 | 6.03 | 9.09 | 7.32 |
| Somatic/anxiety | 12.83 | 7.95 | 11.04 | 9.33 |
| Language | 4.74 | 3.05 | 3.43 | 3.00 |
| Patient current functioning | 91.09 | 22.23 | 96.33 | 24.93 |
| Activities of daily living | 26.61 | 6.63 | 25.24 | 8.83 |
| Cognitive functioning | 23.50 | 7.54 | 24.33 | 7.66 |
| Interpersonal functioning | 20.70 | 6.01 | 23.37 | 6.14 |
| Emotional functioning | 20.28 | 5.59 | 23.57 | 5.19 |
| Overall dyadic adjustment | 104.57 | 16.38 | 106.61 | 20.89 |
| Dyadic satisfaction subscale | 36.57 | 5.90 | 37.74 | 6.28 |
| Dyadic cohesion subscale | 14.30 | 4.72 | 12.91 | 5.10 |
| Dyadic consensus subscale | 44.96 | 7.51 | 47.91 | 12.43 |
| Affectional expression subscale | 8.74 | 2.58 | 8.84 | 3.32 |
| Well-being – environmental mastery | 53.74 | 9.98 | 60.0 | 13.5 |
| Well-being – personal growth | 67.78 | 10.45 | 66.6 | 13.0 |
| Well-being – positive relations with others | 63.57 | 12.06 | 71.2 | 12.7 |

* Personality change – rated on a 5 point scale from 1 (the same) to 5 (completely different)

In order to test for differences between groups on these measures, independent samples t-tests were conducted. The only significant differences were that the well-being dimension of Positive Relations with Others (t(44) = -2.092, p = .042) and PCRS emotional functioning (t(44) = -2.064, p = .045) were significantly higher in the 'other injuries' group, but not after Bonferroni correction for the number of comparisons made (p = 0.05 / 23 = 0.002). There were no significant differences between groups for global awareness of deficit (t(44) = .942, p = .351), cognitive awareness (t(44) =

.942, p = .664), behavioural/affective awareness (t(44) = 1.423, p = .162), motor/sensory awareness (t(43) = -.274, p = .785), personality change (t(44) = -.254, p = .801), overall neurobehavioural symptoms on the NRS (t(44) = .808, p = .404), NRS cognition/energy (t(44) = .865, p = .342), NRS metacognition (t(43) = 1.108, p = .314), NRS somatic/anxiety (t(44) = .698, p = .489), NRS language (t(44) = 1.463, p = .141), overall patient current functioning on the PCRS (t(44) = -.752, p = .456), PCRS activities of daily living (t(44) = .595, p = .555), PCRS cognitive functioning (t(44) = -.369, p = .794), PCRS interpersonal functioning (t(44) = -1.492, p = .143), transformed DAS total score (t(44) = .668, p = .507), dyadic satisfaction (t(44) = -.653, p = .517), dyadic cohesion (t(43.75) = .960, p = .342), dyadic consensus (t(44) = -.976, p = .334), DAS affectional expression (t(44) = .793, p = .432), PWB Environmental Mastery (t(44) = - 1.750, p = .087) and PWB personal growth (t(44) = .350, p = .728).

## 3.2 Main hypotheses testing

### Exploring the Psychological Well-Being of partners

Owing to the lack of published studies containing descriptive data for a normative sample using the 14 items scales of PWB (used in the current study), contact was made with the authors of the scales (Dr. Carol Ryff, Gayle Love) who sent the researcher unpublished descriptive data on the 'Life Histories and Health in Midlife' study. This was carried out by Ryff and colleagues as part of the wider 'Wisconsin Longitudinal Study' (WLS). The full WLS study is a 40-year study of a random sample of 10,317 men and women who graduated from Wisconsin high schools in 1957 and of their randomly selected brothers and sisters, of which 8,493 were followed up in 1992/1993. A subsample (n=202) took part in the 'Life Histories and Health in Midlife' study in 1996. Most of these were aged 57 (range = 56-58), only slightly older than the current sample (mean age of partners = 53.41 years; patients, 55.30 years). Ninety eight percent were white American; the current sample were also largely white UK (partners = 71.74%; patients = 76.09%). In terms of marital status, most were married (76.7%), about a sixth (15.3%) were divorced, and small proportions were widowed (4.5%), had never married (3.0%) or had separated (<1%). Similarly, most in the current sample were married (89.13%); although *all* were in a long term relationship by the nature of the study. The mean number of children was 3 (including biological, adopted, foster and stepchildren): the majority had either two or three children, approximately one-third had four or more children, 8% had none and 7% had one child. The current sample mean number of children was 2.37 and the majority had either 2 (41.30%) or 3 (23.91%) children so in this way, too, samples were comparative. No data was collected on financial situation or social class. Data from the current sample are compared to the normative sample in table 11.

Table 11 – Comparison of PWB scores for individuals in the current sample with the individuals in the 'Life Histories and Health in Midlife' study.

| **PWB scale** | **Current sample (n = 46)** | | **Reference sample (n = 202)** | |
|---|---|---|---|---|
| | **Mean** | **SD** | **Mean** | **SD** |
| Environmental mastery | 56.8 | 12.1 | 65.4 | 10.6 |
| Personal growth | 67.1 | 11.7 | 69.0 | 10.0 |
| Positive relations with others | 67.4 | 12.9 | 67.3 | 10.7 |

Results are displayed to 1 decimal place as this was the case in reference sample data

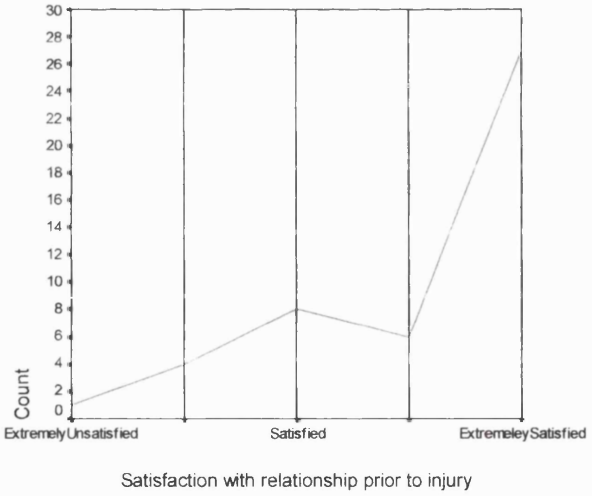
In order to compare the current sample with Ryff's sample, one sample t-tests were performed which showed that Environmental Mastery was significantly lower in the current sample than the normative sample (t(45) = -4.904, p <0.001). There were no differences in Personal Growth (t(45) = -1.060, p = .295) and Positive Relations with Others (t(45) = .048, p = .962) between groups.

## Exploring the quality of the relationship between the partner and the injured person as perceived by the partner

### Premorbid relationship

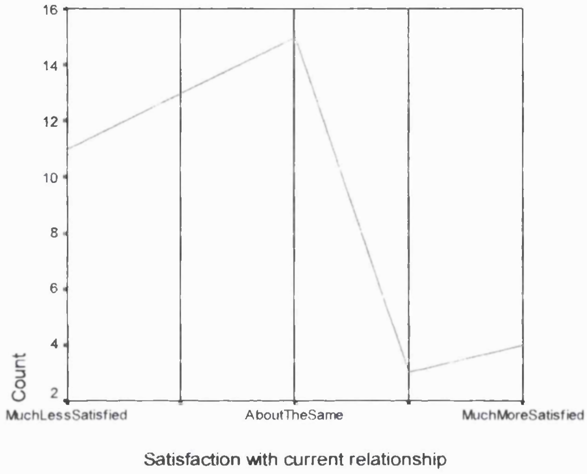
Figure 5 shows the distribution of partner retrospective ratings of satisfaction with the relationship prior to injury

Figure 5 - The distribution of retrospective ratings of satisfaction with the relationship prior to injury.



Most partners (89.13%) retrospectively rated themselves satisfied to extremely satisfied with their relationship with the injured person prior to injury. A few (10.87%) were less than satisfied. Figure 5 shows partner ratings of change of satisfaction with relationship now compared to before the injury.

Figure 6 - Partner ratings of change of satisfaction with relationship now compared to before the injury.



Twenty four partners (52.17%) rated their current relationship satisfaction as less now than before the injury, 15 (32.61%) as the same and 7 (15.22%) felt they were more satisfied now. Out of the 7 partners with improved relationship satisfaction, 2 (28.57%) had mentioned the presence of relationship difficulties prior to injury on the ‘personal details form’ of the questionnaire.

*Current relationship*

In order to see how partners of people with ABI compared with the normal population, the current sample was compared to a normative sample from the original Dyadic Adjustment Scale development paper (Spanier, 1976). Table 12 shows the relevant characteristics of the normative sample compared with the current sample.

Table 12 – Characteristics of the sample in the original scale development study (Spanier, 1976) compared with the current sample

| Characteristics of the samples | | Spanier (1976) sample | Partners in the current sample |
|---|---|---|---|
| Sex | Number of males | 109 | 6 |
| | Number of females | 109 | 40 |
| Mean age | | 35.1 years | 53.4 years (SD 10.3) |
| Mean no of years of education | | 13.0 years | 13.3 years (SD 2.8) |
| Mean no of children | | 2.0 | 2.4 (SD 1.3) |

Table 12 shows that the current sample is somewhat older and contains a greater proportion of females in comparison to the Spanier (1976) sample. Data on income was not compared as Spanier's sample was American and the current one was largely British.

Table 13 shows the comparison of scores of the current sample on the Dyadic Adjustment Scale and Subscales in comparison to the norms from the Spanier study (1976).

Table 13 - comparison of scores of the current sample with those of the original sample (Spanier, 1976)

| | Current sample | | Spanier (1976) sample | |
|---|---|---|---|---|
| | Mean | St. Dev. | Mean | St. Dev. |
| Dyadic Consensus Subscale | 46.4 | 10.3 | 57.9 | 8.5 |
| Dyadic Satisfaction Subscale | 37.2 | 6.1 | 40.5 | 7.2 |
| Dyadic Cohesion Subscale | 13.6 | 4.9 | 13.4 | 4.2 |
| Affectional Expression Subscale | 8.4 | 3.0 | 9.0 | 2.3 |
| DYADIC ADJUSTMENT SCALE | 105.6 | 18.6 | 114.8 | 17.8 |

In order to test for differences between samples, one sample t-tests were performed. Dyadic Consensus (t(44) = -8.015, $p < .001$), Satisfaction (t(45) = -3.750, p = .001) and overall Dyadic Adjustment (t(44) = -3.222, p = .002) were significantly lower in the current sample. No significant differences were found for Cohesion (t(45) = .288, p = .774) and Affectional Expression (t(45) = -1.394, p = .170) subscales. A cut off point of 100 is commonly used in the literature, below which a couple is considered to have poor relationship adjustment or quality (e.g. Pistrang and Barker, 1998). Fourteen partners in the current sample (30%) scored below this cut-off.

### Exploration and preparation of data prior to regression analyses

Before regression analyses, several checks were made: inspection of errors of prediction residuals (to see if they were normally distributed with a mean around zero); visual inspection of homogeneity of variance of arrays (via a plot of the residuals against the predicted values); and checks for multivariate outliers using Cook's distance values (where an outlier would be indicated by a score above 1). There were no regression problems indicated by these checks.

As the social class of couples was predominantly I and II (little variability) and as it was significantly skewed with an outlying case, this variable was not used in the regression. Similarly, the single item measure of financial strain was judged as a more valid measure of perceived strain than net monthly household income, especially as brain injured couples may get little in the way of regular income but may have received a compensation settlement (e.g. after a road traffic accident, accident at work), complicating the validity of monthly income as a genuine indicator. Moreover, it is the perception of financial hardship that is arguably more important to outcome.

The first stage of preliminary analysis of data was an exploration of the inter-relationships between all independent variables. Table 14 shows the inter-correlations of all continuous independent variables with Bonferroni corrections for the number of correlations carried out (p = 0.05/36 = 0.00139).

Table 14 - The inter-correlations of potential independent variables

| Variable | 1. | 2. | 3. | 4. | 5. | 6. | 7. | 8. | 9 |
|---|---|---|---|---|---|---|---|---|---|
| 1. Age of partner | --- | | | | | | | | |
| 2. Partner years of education ♦ | .153 | — | | | | | | | |
| 3. Financial strain | -.368 | -.407 | --- | | | | | | |
| 4. Time since injury | .252 | .153 | -.250 | --- | | | | | |
| 5. Preinjury relationship satisfaction ♦ | -.233 | -.011 | .267 | .036 | --- | | | | |
| 6. Personality change | -.005 | -.280 | .076 | .036 | .101 | — | | | |
| 7. AQ | .292 | -.072 | .169 | .201 | -.069 | -.074 | --- | | |
| 8. PCRS | -.271 | .212 | -.015 | -.092 | -.197 | -.646* | -.113 | — | |
| 9. NRS | -.066 | .052 | .111 | .112 | .114 | .543* | .058 | -.790* | --- |

p < 0.00139 – Bonferroni correction as 36 correlations were performed
♦ Transformations and/or exclusions of outlier

Table 14 shows that the single item measure of personality change was significantly negatively correlated with measures of patient current functioning (PCRS) and, positively, with severity of neurobehavioural symptoms in the patient (NRS), where patients with higher degree of personality change had greater severity of neurobehavioural symptoms and a lower degree of competency/functioning in everyday life. In addition, the Neurobehavioural Rating Scale scores were significantly negatively correlated with PCRS score, suggesting that patients with more neurobehavioural symptoms tend to be less capable of performing everyday life activities independently.

As severity was categorical (mild/moderate vs severe) independent samples t-tests were performed to look at differences between severity groups on continuous independent variables. There were found to be no differences between groups for age of partner (t(41) = -.635, p = .529), years of education (t(41) = -.599, p = .553), financial strain (t(41) = .674, p = .504), preinjury relationship satisfaction (t(41) = -.589, p = .559), time since injury (t(41) = -.948, p = .349), personality change (t(41) = -.817, p = .419), neurobehavioural function (t(41) = -1.507, p = .140), patient competency (t(41) = 1.107, p = .345), awareness (t(41) = .019, p = .985).

The next stage in the preliminary analysis of data was to explore relationships between the independent and dependant variables. Correlations between the independent continuous variables and outcome measures (PWB and relationship quality) are shown in table 15.

Table 15 – The inter-correlations between continuous independent and dependant variables

| Measure | Well-being – Environmental mastery | Well-being – Personal growth | Well-being – Positive relations with others | Dyadic Adjustment Scale – Total score [1] |
|---|---|---|---|---|
| Age of partner | .231 | -.108 | .237 | -.147 |
| Partner years of education | .235 | .171 | .229 | .183 |
| Financial strain | -.108 | .125 | -.035 | -.101 |
| Time since injury | .240 | .087 | .046 | -.173 |
| Satisfaction with relationship preinjury [2] | -.044 | .157 | .325 | .467* |
| Personality change | -.284 | -.250 | -.204 | -.398 |
| AQ | .087 | .233 | .161 | -.049 |
| PCRS | .344 | .195 | .221 | .366 |
| NRS | -.253 | -.141 | -.313 | -.433 |

* $p < 0.00139$ – Bonferroni correction used as 36 correlations performed ($p = 0.05/36 = 0.00139$)

[1] Outlying case excluded

[2] Transformed data

After Bonferroni correction ($p = 0.05/36 = 0.00139$), the only correlation that reached significance was the positive relationship between the retrospective rating of preinjury relationship satisfaction and current relationship satisfaction: the more satisfied partners were with their relationship before the injury, the more satisfied they tended to be nowadays. In order to see whether there were differences in the dependant variables between couples where the injury was mild/moderate or severe, independent samples t-tests were performed, which showed no differences between groups.

The final stage of the preliminary analyses was to look at the relationships between all dependant variables, in order to see whether PWB was associated with relationship satisfaction and should be entered into mutual regression equations. Table 16 shows the inter-correlations between dimensions of PWB and relationship satisfaction in partners.

Table 16 – Inter-correlations of Psychological Well-Being and relationship quality measures.

| | Well-being – EM | Well-being – PG | Well-being – PR | Dyadic Adjustment [1] |
|---|---|---|---|---|
| Well-being – environmental mastery | —— | .268 | .579*** | .044 |
| Well-being – personal growth | ----- | ----- | .453** | .143 |
| Well-being – positive relations with others | ----- | ----- | ----- | .275 |
| Dyadic Adjustment [1] | —— | —— | —— | —— |

** p<0.01 *** p < 0.001

[1] Outlier excluded

After Bonferroni correction (p = 0.05 / 6 = 0.0083), Positive Relations with Others was significantly correlated with Environmental Mastery (Pearson correlation = .579, p = 0.000) and Personal Growth (Pearson correlation = .453, p = 0.002). However, dimensions of Psychological Well-Being were not significantly related to relationship adjustment (EM: Pearson = .44, p = .775; PG: Pearson = .143, p = .350; PR: Pearson = .275, p = .068), suggesting these were not needed to be controlled for the in the regression analyses.

### Which, if any, brain injury related factors are associated with dimensions of partner Psychological Well-Being?

In order to explore which brain injury variables impact most on the partner's ability to achieve positive Psychological Well-Being (PWB), hierarchical stepwise regressions were carried for each of the three dimensions of PWB. With 46 participants and some missing data, consideration was given to which brain injury variables should be given priority for use in the regressions given limited power. Since the single-item personality change scores were significantly intercorrelated with scores on the neurobehavioural rating scale (NRS) and patient competency rating scale (PCRS), these more substantial measures were used. In addition, as NRS and PCRS scores were also significantly inter-correlated, *either* the PCRS *or* the NRS was chosen as a dependant variable in regressions. The PCRS was chosen for the regression predicting the well-being dimensions of Environmental Mastery (EM) and Personal Growth (PG), as it was thought that living with a person less capable in daily life activities may have a greater impact on these than would neurobehavioural symptoms. The NRS was chosen to predict Positive Relations with Others (PR), as it was thought that neurobehavioural symptoms may have greater impact on the relationship the partner has not only with the injured person but with others in her/his network (the presence of these kinds of symptoms may be experienced as 'socially embarrassing' and lead to less contact or worse quality relationships with others).

For the first step of the three regressions (predicting each of the three dimensions of PWB) age of partner, partner number of years of education and financial strain was controlled for on the basis on previous research that suggests these are associated with PWB (e.g. Kwan, Love, Ryff and Essex, 2003; Ryff and Keyes, 1995). For the second step, a stepwise procedure was adopted as no specific brain injury variable has been linked with Ryff's conceptualization of PWB in partners of brain injured people owing to lack of previous research. Variables entered as predictors for EM and PG were: level of awareness (AQ discrepancy), patient competency (PCRS), initial severity of injury and time since injury. For PR, the same model was used but replacing the PCRS with the NRS variable, measuring neurobehavioural symptoms. Table 17 shows the results of the hierarchical regression analyses for the dimensions of partner PWB.

Table 17 - Hierarchical regression analyses for the three dimensions of PWB in partners: Environmental Mastery, Personal Growth and Positive Relations with Others.

| | R2 | R2 Change | F value for R2 change | P value for R2 change | Beta | P value for Beta |
|---|---|---|---|---|---|---|
| **Well-being – Environmental mastery** | | | | | | |
| *Model 1* | 0.15 | 0.15 | 2.25 | 0.10 | | |
| Age of partner | | | | | 0.25 | 0.12 |
| Partner years of education | | | | | 0.29 | 0.09 |
| Financial strain | | | | | 0.05 | 0.79 |
| *Model 2* | 0.29 | 0.14 | 3.93* | 0.01 | | |
| Age of partner | | | | | 0.40* | 0.01 |
| Partner years of education | | | | | 0.14 | 0.37 |
| Financial strain | | | | | 0.05 | 0.75 |
| Patient competency | | | | | 0.43* | 0.01 |
| **Well-being – Personal growth** | | | | | | |
| *Model 1* | 0.07 | 0.07 | 0.91 | .044 | | |
| Age of partner | | | | | -0.05 | 0.78 |
| Partner years of education | | | | | 0.27 | 0.12 |
| Financial strain | | | | | 0.14 | 0.45 |
| **Well-being – Positive relations with others** | | | | | | |
| *Model 1* | 0.17 | 0.17 | 2.68 | 0.06 | | |
| Age of partner | | | | | 0.29 | 0.07 |
| Partner years of education | | | | | 0.31 | 0.06 |
| Financial strain | | | | | .067 | 0.51 |

* $p < 0.05$

In the cases of PG and PR, no brain injury variables emerged as significant predictors in the equations although the control variables together were significantly predictive. Patient competency, however, emerged as predictor of EM, the overall equation accounting for 29% of the variance in the dependant variable. Patient competency accounted for 14% unique variance in the equation after controlling for demographic variables (age, education, financial strain of partner).

In order to investigate *which* aspects of patient functioning was most predictive of Environmental Mastery in the partner, a further stepwise hierarchical regression was carried out. Initially, inter-correlations between PCRS subscales and correlations of PCRS subscales with controlling variables (age, years of education of partner, financial strain) and EM were examined, shown in table 18.

Table 18 – Intercorrelations of PCRS subscales with regression controlling variables and Environmental Mastery

| | **Activities of daily living** | **Cognitive functioning** | **Interpersonal functioning** | **Emotional functioning** |
|---|---|---|---|---|
| PCRS subscales | | | | |
| Activities of daily living | —— | .77*** | .62*** | .53*** |
| Cognitive functioning | ----- | ----- | .68*** | .63*** |
| Interpersonal functioning | ----- | ----- | ----- | .73*** |
| Emotional functioning | —— | —— | —— | —— |
| Well-being – | | | | |
| Environmental Mastery | .30* | .31* | .26 | .34* |
| Age of partner | -.26 | -.16 | -.36* | -.15 |
| Years of education | .17 | .29 | .11 | .13 |
| Financial strain | -.03 | -.04 | .11 | -.08 |

Bonferroni correction: $p = 0.05 / 32 = 0.0016$
* $p < 0.05$ *** $p < 0.001$

Table 18 shows that all subscales of the PCRS are highly inter-correlated. Subscales concerned with activities of daily living, cognitive and emotional functioning were significantly positively correlated with partner EM (although not after Bonferroni correction: $p = 0.0016$) suggesting that with greater patient competency in these areas, partner environmental mastery tends to be higher. In the regression analysis, age of partner, years of education and financial strain were entered in the first step following by the 4 PCRS subscales in the second step (stepwise). Table 19 show the results of the regression analysis.

Table 19 – Regression analysis to investigate which subscales of the PCRS predict environmental mastery

| | R2 | R2 Change | F value for R2 change | P value for R2 change | Partial correlation | Beta | P value for Beta |
|---|---|---|---|---|---|---|---|
| **Well-being – Environmental mastery** | | | | | | | |
| *Model 1* | 0.11 | 0.11 | 1.75 | 0.171 | | | |
| Age of partner | | | | | 0.10 | 0.11 | 0.50 |
| Partner years of education | | | | | 0.30 | 0.31* | 0.046 |
| Financial Strain | | | | | 0.01 | 0.01 | 0.95 |
| *Model 2* | 0.23 | 0.12 | 3.11* | 0.025 | | | |
| Age of partner | | | | | 0.24 | 0.26 | 0.12 |
| Partner years of education | | | | | 0.31 | 0.29* | 0.043 |
| Financial Strain | | | | | 0.08 | 0.08 | 0.62 |
| PCRS – Activities of daily living | | | | | 0.37 | 0.38* | 0.015 |

$P < 0.05$

In the second step of the regression, the PCRS subscale concerned with the ability of the patient to carry out activities of daily living emerged as a significant predictor after controlling for demographics (partner years of education), accounting for 12% unique variance in the equation, similar to using the whole PCRS.

### Which brain injury related factors are associated with the quality of the relationship between the partner and the person with ABI as perceived by the partner?

In order to address which brain injury related factors were most predictive of overall relationship adjustment, hierarchical regression analysis was used. For the first step, age of partner, partner number of years of education, financial strain, and satisfaction with premorbid relationship were controlled for on the basis that these may be associated with couple relationship outcomes (e.g. Gagnon et al., 1999; Norris, Snyder and Rice, 1997; Peters et al., 1990). For the second step, a stepwise procedure was adopted entering level of awareness (AQ discrepancy), severity of neurobehavioural symptoms (NRS), initial severity and time since injury as predictors. Table 20 shows the results of the regression analyses for overall relationship adjustment (DAS total score).

Table 20 – Hierarchical regression analyses predicting relationship quality (DAS total score).

| | **R2** | **R2 Change** | **F value for R2 change** | **P value for R2 change** | **Beta** | **P value for Beta** |
|---|---|---|---|---|---|---|
| **Dyadic Adjustment Scale total score** | | | | | | |
| *Model 1* | 0.35 | 0.35 | 5.09 | 0.002 | | |
| Age of partner | | | | | -0.17 | 0.25 |
| Partner years of education | | | | | 0.11 | 0.43 |
| Financial strain | | | | | -0.20 | 0.19 |
| Preinjury relationship satisfaction | | | | | 0.54*** | 0.000 |
| *Model 2* | 0.45 | 0.10 | 5.60 | 0.01 | | |
| Age of partner | | | | | -0.17 | 0.19 |
| Partner years of education | | | | | 0.12 | 0.36 |
| Financial strain | | | | | -1.04 | 0.31 |
| Preinjury relationship satisfaction | | | | | 3.83*** | 0.000 |
| Patient neurobehaviour-al symptoms | | | | | -2.57* | 0.01 |

*** $p < 0.001$

The severity of neurobehavioural symptoms emerged as a significant predictor of relationship adjustment after controlling for potentially relevant background variables. Both models accounted for a significant amount of variance in the dependant variable: relationship adjustment. The second model accounted for 45% of the variance, with neurobehavioural symptoms and satisfaction with preinjury relationship as significant predictors.

In order to investigate *which* neurobehavioural symptoms were most predictive of relationship adjustment, a regression analysis using the subscales of the NRS was intended. Before this, inter-correlations between NRS subscales and correlations with controlling variables (age, years of education of partner, financial strain, satisfaction with preinjury relationship) and relationship adjustment were examined, shown in table 21.

Table 21 – Intercorrelations of NRS subscales with regression controlling variables and relationship adjustment scores

| | **Cognition** | **Metacognition** | **Somatic/anxiety** | **Language** |
|---|---|---|---|---|
| Cognition | —— | .61*** | .66*** | .58*** |
| Metacognition | ----- | ----- | .57*** | .48*** |
| Somatic/anxiety | ----- | ----- | ----- | .51*** |
| Language | ----- | —— | ----- | —— |
| DAS total | -.38** | -.34* | -.41** | -.35* |
| Age of partner | .00 | -.01 | -.19 | -.01 |
| Years of education | .08 | .002 | .10 | -.09 |
| Financial strain | -.01 | 0.6 | .19 | .15 |
| Preinjury relationship satisfaction | -.07 | -.172 | -.08 | -.01 |

Bonferroni correction: $p = 0.05 / 36 = 0.0014$
* $p < 0.05$ ** $p < 0.01$ *** $p < 0.001$

Table 21 shows that all NRS subscales were significantly positively correlated with each other even after a Bonferroni correction ($p = 0.05 / 36 = 0.0014$). Before Bonferroni correction (but not after), subscales were all significantly negatively correlated with relationship adjustment (DAS total score), that is the greater dysfunction in the patient in any of the four neurobehavioural domains, the lower the relationship adjustment.

The subscales of the NRS were entered in the second step of a stepwise hierarchical regression (after controlling for age, education, financial strain of partner and preinjury relationship satisfaction). Table 22 shows the results of the hierarchical regression analyses for relationship quality.

Table 22 - Hierarchical regression analyses for relationship quality using subscales of the NRS as predictors (after controlling for demographics)

| | **R2** | **R2 Change** | **F value for R2 change** | **P value for R2 change** | **Beta** | **P value for Beta** |
|---|---|---|---|---|---|---|
| **Dyadic Adjustment Scale total score** | | | | | | |
| *Model 1* | 0.35 | 0.35 | 5.24 | 0.002 | | |
| Age of partner | | | | | -0.17 | 0.24 |
| Partner years of education | | | | | 0.11 | 0.43 |
| Financial strain | | | | | -0.21 | 0.19 |
| Preinjury relationship satisfaction | | | | | 0.54*** | 0.000 |
| *Model 2* | 0.46 | 0.11 | 6.34 | 0.000 | | |
| Age of partner | | | | | -0.22 | 0.11 |
| Partner years of education | | | | | 0.17 | 0.22 |
| Financial strain | | | | | -0.13 | 0.39 |
| Preinjury relationship satisfaction | | | | | 0.48** | 0.001 |
| Somatic/anxiety subscale | | | | | -2.71* | 0.01 |

* $p < 0.05$ ** $p < 0.01$ *** $p < 0.001$

The somatic/anxiety subscale of the NRS alone emerged as a significant predictor of relationship quality, over and above the significant contribution of pre-injury relationship satisfaction. Together the variables accounted for 46% of variance – very similar to results with the entire NRS.

## 3.3 Subsidiary hypotheses testing

This section will look at whether other demographic factors are associated with the partner's ability to achieve PWB and satisfactory relationship adjustment and investigate the phenomenon of awareness of deficit after ABI in relation to hypotheses specified in the introduction section.

## Exploring whether other factors are associated with partner PWB and relationship quality between the injured person and the partner

### *Gender and marital status*

It was not possible to conduct inferential statistical test to determine whether there was a difference in PWB and perceived relationship quality between male and female partners as there were too few males in the sample (n = 6; 13%). Similarly, too few unmarried couples responded (n = 5; 11%) to allow statistical analyses to look at the impact of martial status on PWB and relationship satisfaction in partners.

### *Length of relationship preinjury*

In order to test whether the length of time in the relationship prior to the injury made a difference to current levels of PWB and relationship quality for partners, independent samples t-tests were carried out by dividing partners into two groups (long vs short preinury relationship) on the basis of the median score on the 'length of time in relationship preinjury' variable. Table 23 shows the means and standard deviations for those in 'shorter' and 'longer' relationships prior to injury.

Table 23 – The descriptive data on well-being and relationship adjustment for those in shorter and longer relationships prior to injury

| | Short relationship preinjury (less than 24.5[1] years together preinjury) | | Longer relationship preinjury (more than 24.5[1] years together preinjury) | |
|---|---|---|---|---|
| | **Mean** | **SD** | **Mean** | **SD** |
| Well-Being | | | | |
| Environmental mastery | 54.2 | 13.8 | 59.4 | 10.0 |
| Personal growth | 68.7 | 10.7 | 65.7 | 12.6 |
| Positive relations with others | 64.7 | 14.5 | 70.1 | 10.6 |
| Dyadic Adjustment * | 106.2 | 19.0 | 107.7 | 13.8 |
| Satisfaction | 37.0 | 7.2 | 37.4 | 4.8 |
| Consensus * | 46.2 | 8.6 | 48.1 | 9.4 |
| Cohesion | 14.2 | 5.0 | 13.0 | 4.8 |
| Affectional expression | 7.6 | 3.4 | 9.2 | 2.2 |

* An outlying case excluded from these variables

[1] Median split

Table 23 shows that there were similar levels of well-being and relationship quality in partners of couples together for and short and longer time preinjury. Indeed, after Bonferroni corrections were made (p = 0.05/8 = 0.00625), no differences were found in *PWB* (EM: t(42) = -.123, p = .903; PG: t(42) = 1.278, p = .208; PR: t(42) = -.405, p = .688) or *relationship quality* (overall Adjustment: t(41) = -.134, p = .894; Satisfaction: t(41) = .854, p = .398; Consensus: t(41) = -.666, p = .509; Cohesion: t(42) = .576, p = .169; Affectional Expression: t(42) = -1.492, p = .143) between groups.

### *Presence of children/adolescents at home*

It was possible that the presence of children at home may impact on the PWB of the partner or the quality of the relationship between the partner and the injured person. Table 24 shows the means and standard deviations on the PWB and relationship adjustment measures for those that did and did not have children aged 18 or younger living at home.

Table 24 - Descriptive data for PWB and relationship quality measures for those with and without children aged 18 years and younger living at home.

| | **No children at home aged 18 or younger (n=32)** | | **Children at home aged 18 or younger (n=14)** | |
|---|---|---|---|---|
| | **Mean** | **SD** | **Mean** | **SD** |
| Well-Being | | | | |
| Environmental mastery | 58.4 | 10.1 | 53.2 | 15.7 |
| Personal growth | 65.7 | 10.9 | 70.6 | 13.2 |
| Positive relations with others | 68.3 | 11.4 | 65.2 | 16.0 |
| Dyadic Adjustment * | 104.68 | 16.9 | 111.9 | 14.6 |
| Satisfaction | 36.8 | 6.2 | 38.0 | 5.8 |
| Consensus * | 46.6 | 9.4 | 48.6 | 8.1 |
| Cohesion | 12.3 | 4.6 | 16.7 | 4.3 |
| Affectional expression | 8.3 | 3.4 | 8.6 | 1.7 |

* One outlying case excluded in each variable

Table 24 shows that means for dimensions of PWB and overall Dyadic Adjustment, relationship Satisfaction, Consensus and Affectional Expression were comparable in the two groups (within one standard deviation of each other). Independent samples t-tests were carried out with those who did and did not have children 18 years or younger living at home and, after Bonferroni corrections were made (p = 0.05/8 = 0.00625), Cohesion emerged as being significantly higher in couples that had at least one child of 18 years or younger living at home (t(44) = -.3096, p = .003). No differences were found in other aspects of the *relationship* (overall adjustment: t(43) = -1.389, p = .172; consensus: t(43) = -.686, p = .496; satisfaction: t(-.677, p = .502; t(42.63) = -1.270, p = .789; affection: t(42.63) = -.270, p = .788) or *PWB* (EM: t(17.97) = 1.337, p = .188; PG: t(44) = -1.315, p = .195; PR: t(19.00) = .756, p = .454)

## Exploring awareness of deficit

The next section is devoted to understanding awareness of deficit in patients: whether patient rate their deficits as less than partners do; whether patients have differential levels of awareness for different domains of functioning; and whether there is a link between impaired awareness of deficit and severity or time since injury.

### *Do patients rate themselves as having fewer deficits and changes since the injury than partners rate patients as having?*

Table 25 shows the means and standard deviations for partner ratings, patient ratings and for 'awareness' discrepancy scores on the Awareness Questionnaire.

Table 25 – Means and standard deviations for partner ratings, patient ratings and for 'awareness' discrepancy score on the AQ.

| | Mean | St Dev | Minimum | Maximum |
|---|---|---|---|---|
| Patient rated | 37.55 | 10.98 | 20.00 | 64.00 |
| Partner rated | 32.12 | 8.08 | 19.00 | 49.00 |
| Awareness discrepancy score* | 5.44 | 8.08 | -8.00 | 26.00 |

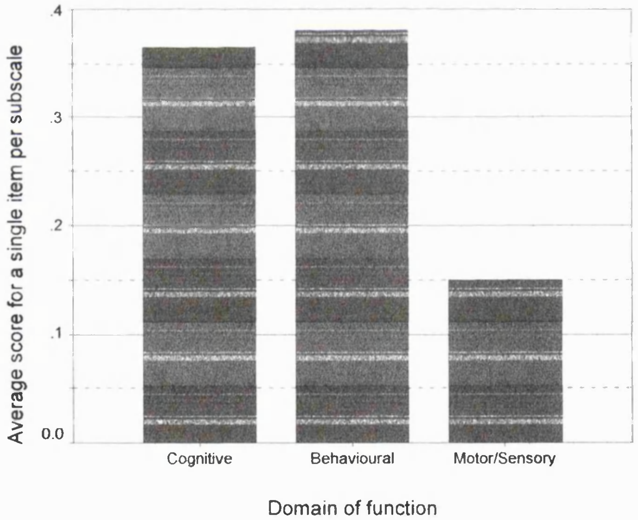
* Awareness discrepancy was calculated by subtracting the partner rating from the patient rating on the Awareness Questionnaire. A positive score indicates low awareness of deficit in the patient. A score of 0 indicates good awareness (good agreement between partner and patient). A negative score indicates hyperawareness (patient more aware of deficits than partner).

Table 25 shows that patients rate themselves as having changed less than partners rate. Results of a paired samples t-test was showed that partners rated patients as being significantly lower in overall functioning than patients rated themselves (t(45) = 4.623, p = .000).

*Do patients show different levels of awareness for different functional deficits?*

To understand whether different levels of awareness existed for different functional modalities, a repeated measures One-Way ANOVA was conducted. As each subscale on the Awareness Questionnaire contained a different number of items (Cognitive = 7, Behavioural/Affective = 6, Motor/Sensory = 4), the average discrepancy per item was calculated for each subscale discrepancy in order that the three subscales were comparable. Figure 7 shows the average discrepancy per item in the domains of Cognitive, Behavioural/Affective and Motor/Sensory function.

Figure 7 - Average discrepancy per item on Awareness Questionnaire subscales measuring cognitive, behavioural and physical (motor/sensory) domains of function.



ANOVA analysis showed that level of awareness did differ by domain of function (Wilk's Lambda = .786; F(2,43) = 5.838, p = 0.006). Further pairwise paired t-tests were conducted, which, even after Bonferroni correction (p = 0.005/3 = 0.017), showed that patients had significantly lower awareness of cognitive functions (t(44) =3.183, p = 0.003) and behavioural functions (t(44)

= 3.207, p = 0.003) than of physical functions. There was no difference between levels of awareness of cognitive and behavioural functions (t(45) = -.252, p = .802).

*Do levels of awareness of deficit in the patient show any change over time after injury?*

To explore whether the length of time that had lapsed since injury was linked with levels of awareness, bivariate correlations were performed for time since injury and global level of awareness and awareness of particular domains of function. Table 26 shows the correlations performed on the data to examine the link between awareness and time since injury. A Bonferroni correction was needed as several correlations were performed (p = 0.05/4 = 0.0125).

Table 26 – Correlations showing the link between awareness of deficit and length of time since injury.

| Variables correlated with 'time since injury' | N | Pearson correlation | Sig. (2-tailed) |
|---|---|---|---|
| Level of global awareness of deficit | 46 | .201 | .181 |
| Level of awareness of cognitive deficits | 46 | .176 | .241 |
| Level of awareness of behavioural deficits | 46 | .289 | .052 |
| Level of awareness of physical deficits | 45 | - .014 | .928 |

Awareness discrepancy was calculated by subtracting the partner rating from the patient rating on the overall Awareness Questionnaire and for each domain. A positive score indicates low awareness of deficit in the patient. A score of 0 indicates good awareness (good agreement between partner and patient). A negative score indicates hyperawareness (patient more aware of deficits than partner).

Table 26 shows there were no significant relationships found between length of time since injury and level of awareness, either globally or by domain of function.

*Are levels of awareness of deficit linked with the initial severity of the injury?*

In order to test whether severity of injury was linked to levels of awareness, independent samples t-tests were performed, shown in table 27.

Table 27 – Results of comparisons of levels of 'awareness' between different severity groups

| | **Mild/moderate** | | **Severe** | | **df** | **T value** | **P value** |
|---|---|---|---|---|---|---|---|
| | **Mean** | **SD** | **Mean** | **SD** | | | |
| Global Awareness | 5.80 | 8.55 | 5.75 | 8.08 | 41 | .019 | .985 |
| Cognitive awareness | 2.67 | 4.70 | 2.77 | 3.51 | 41 | -.080 | .937 |
| Behavioural awareness | 2.00 | 3.55 | 2.54 | 3.74 | 41 | -.455 | .651 |
| Motor awareness | 1.13 | 1.60 | .13 | 1.64 | 40 | 1.919 | .062 |

Table 27 shows that, both before and after Bonferroni correction ($p = 0.05/4 = 0.01$), there were found to be no significant differences between severity groups for either global level of awareness of deficit or awareness of deficit in cognitive, behavioural or physical domains of function.

# Discussion

The discussion will be subdivided into five main sections. The first will provide a brief overview of the aims, methods and findings of the current study. The next will attempt to make sense of what was found by discussing findings in light of previous studies and literature in the field of acquired brain injury and psychological research more widely. The next section will discuss strengths and limitations of the study, followed by a section containing suggestions for future research. The final section will deal with theoretical, scientific, research, clinical and professional implications of the study.

## 4.1 Overview of aims, methods and findings of the study

The current study used a sample of patients with acquired non-progressive brain injury and their partners to investigate the Psychological Well-Being (PWB) of partners of ABI persons and the nature of the relationship the partner has with the injured person. The brain injury and demographic factors that were associated with these were explored. The study also looked into the construct of awareness of deficit after brain injury and correlates of this phenomenon. Couples were contacted through a brain injury rehabilitation unit and local branches and day centres of a brain injury charity. The study was quantitative, involving postal questionnaires followed by a telephone interview with partners for final data collection.

Results showed that, in comparison with a normative sample, partners were largely able to achieve adequate Psychological Well-Being (PWB) or to ‘flourish’ in the domains of ‘Personal Growth’ (PG) and ‘Positive Relations with Others’ (PR) but their ‘Environmental Mastery’ (EM) was significantly lower than a normative sample.

In terms of the brain injury factors that were associated with the PWB of partners, the patients current level of functioning and, with more specific analysis, his/her ability to carry out activities of daily living, emerged as predictive of Environmental Mastery in the partner. However, no brain injury related factor (awareness of deficit, time since injury, severity and *either* patient functioning *or* presence of neurobehavioural symptoms) appeared to have sufficient predictive value for the Personal Growth or Positive Relations with Others dimensions of PWB. No other demographic factors (presence of children at home, length of relationship prior to injury) emerged as associated with PWB dimensions. Owing to lack of males and unmarried partners in the sample the association between gender and PWB could not be addressed.

The overall quality of the dyadic relationship (Dyadic Adjustment) between the partner and the injured person, levels of consensus and satisfaction were significantly lower in the current sample compared with a normative sample. However, level of relationship cohesion and expression of affection were comparable. Nearly a third of the sample fell below the commonly used criteria to discriminate between poorly and well-adjusted couples, suggesting poor relationship adjustment in about 1 in 3 couples. Most partners retrospectively rated themselves satisfied to extremely satisfied with their relationship with the injured person prior to injury (although about a tenth were not satisfied prior to injury) and, in terms of change of relationship satisfaction since the injury, about half said they were less satisfied now, about a third, about the same level of satisfaction and nearly a fifth felt they were *more* satisfied now. About a third of those who were more satisfied reported existing pre-injury relationship difficulties.

The only brain injury factor that emerged as a significant predictor of the overall quality of relationship between the injured person and their partner was the severity of neurobehavioural symptoms in the patient. No other brain injury factors emerged as significantly predictive (awareness of deficit, time since injury, severity). Further analysis showed that it was the 'somatic/anxiety' symptoms that were most predictive, where greater severity of these symptoms in the patient was associated with lower relationship adjustment for the partner. Satisfaction with preinjury relationship showed a significant positive correlation with current overall relationship quality and emerged as a significant predictor of current relationship quality in the same direction: the greater the degree of satisfaction with the relationship before injury, the better the overall relationship quality following injury.

Couples who had children at home aged 18 or younger had significantly greater relationship cohesion (but were no different in overall adjustment, consensus, expression of affection and satisfaction) than those with no children at home of this age. Length of time in relationship preinjury was not associated with relationship outcomes. Again, owing to lack of male and unmarried partners, the association between gender or marital status and perceived relationship quality could not be examined.

In exploring the construct of impaired awareness of deficit after brain injury, patients were found to rate themselves as having a significantly lower level of perceived changes than partners rated them and 'awareness' was more impaired for cognitive and behavioural difficulties than for physical difficulties. There appeared to be no direct link between initial severity of the injury or time since injury and level of awareness of deficit in the patient, either overall or by domain of function.

## 4.2 Interpreting findings

### Main Hypotheses

The following section will encompass an interpretation of findings in light of theoretical and research literature and will be divided sections according to the research questions specified in the introduction.

### Exploring the Psychological Well-Being of partners of individuals with ABI

On comparison with a sample from the general population, partners were significantly less able to shape their environment to suit their needs and choices (Environmental Mastery). This finding supports previous findings after ABI that spouses (or other family caregivers) have to adapt to changes in their environment such as becoming chief caretaker or supervisor of the injured person (e.g. Lezak, 1988), having to reduce or give up working hours outside the home (Wallace et al., 1998), having increased additional responsibilities in the household such as having to manage finances (Leathem et al.,, 1996), increased or sole parenting responsibilities (Lezak, 1988) and having to make decisions alone (e.g. Gosling and Oddy 1999). The lower Environmental Mastery of the current sample suggests that spouses and unmarried partners, even up to 11 years after injury, continue to have difficulties in managing everyday affairs and feel less able to change or improve their surrounding context (Ryff, 1989). This also has implications for long-term adjustment after ABI: a better sense of mastery has been linked to better adjustment of families (e.g. Kosciulek et al., 1993; Kosciulek, 1994; Kosciulek, 1996).

However, the fact that at least some aspects of Psychological Well-Being are preserved in partners after ABI is an encouraging finding, considering the vast amounts of literature that report high levels of distress, stress, burden and psychopathology in spouses and spouse carers after ABI (e.g. Minnes et al., 2000; Schultz et al., 1988; Gervasio and Kreutzer, 1997; Linn et al., 1994). As the Personal Growth dimension of PWB was within normal limits it suggests that partners are able to continue to develop and grow psychologically despite the ongoing struggles of ABI. This echoes literature in the field of ABI that suggests many partners and family members can continue to function well in the aftermath of ABI (Perlescz et al., 1999; Bishop and Evans, 1999) and even report positive outcomes such as strengthening of the family unit, deeper faith and maturity, re-evaluation of priorities and growth (Sachs, 1985; Perlescz et al, 1989; cited in Adams, 1996). Interestingly, this study finds that partners perceive they continue to have warm, satisfying, trusting relationships with others. This contradicts studies in the field of ABI that suggest partners or spouses suffer socially: less participation in leisure activities than before (Wallace et al., 1998), underutilization of social support and less contact with people outside the household (Leathem et al., 1996) with resultant feelings of isolation, loneliness and a sense of 'living in a social limbo' (e.g. Rosenbaum and Najenson, 1976; Lezak, 1988). These differences may be due to differences in what is measured. Whilst the current study is examining the partners' interpretations of their quality of relations with others, other studies have addressed amount and quality of social support from specifically defined individuals in their social network (e.g. Leathem et al., 1996) or conclusions have been rooted in observations by clinicians, not empirical investigation (e.g. Lezak, 1988).

### Exploring the quality of the relationship between the partner and the person with ABI as perceived by the partner

The overall adjustment or quality of the relationship appears to be lower than in the normal population. Family relationship functioning after ABI has been found to be worse off than normative samples (Groom et al., 1998) and families of psychiatric patients (Kreutzer et al., 1994a). Difficulties include problems with communication, affective involvement and the roles divisions in families (Kreutzer et al., 1994a). Only a few studies are devoted solely to the marital or partner relationship but these also find lower levels of overall adjustment in comparison to controls after TBI (e.g. Peters et al., 1992) a finding replicated in this study with a mixed sample brain injured patients and their partners. However we must be aware that although nearly a third would be considered 'poorly adjusted', about two thirds fell *above* the conventional cut-off (e.g. Pistrang and Barker, 1998) suggested that many were able to maintain adequate overall relations with the brain injured person.

In terms of specific dynamics, the satisfaction the partner feels with their relationship is lower than would be expected in the normal population. Satisfaction with relationships after injury has been reported by spouses to be lower than before injury and uninjured spouses commonly report greater dissatisfaction with the relationship than do their injured husbands (Gosling and Oddy, 1999) and spinal cord injured control spouses (Peters, Stambrook, Moore, Zubek, Dubo and Blumenstein, 1992). The ability to reach agreement (consensus) is also significantly lower than norms. Many spouses report having extra responsibilities since the injury (Leathem, Heath and Wooley, 1996) and having to make decisions alone (Gosling and Oddy 1999). Other studies highlight the negative communication patterns between wives and their brain injured husbands including criticism, over involvement and hostility (Flanagan, 1998). Through informal discussions in the current study, some partners mentioned making nearly all decisions due to the husband's lack of interest and motivation and inability to understand implications of decisions. However others reported that the couple would have actively have conflict over matters through the injured persons personality changes (inability to control temper, stubbornness, lack of insight). Therefore it is difficult to conclude the source of lack of consensus: the subscale may be measuring disagreement through *active conflict* and/or *absence of agreement.*

Interestingly, the level of verbal and physical displays of affection is similar to a normative sample. This contradicts other studies that report a lower level of affection in the spousal relationship after ABI (Peters, Stambrook, Moore, Zubek, Dubo and Blumenstein, 1992) with less affection shown by the injured person (Gosling and Oddy, 1999) and the partner (Oddy and Humphrey, 1980). Research has also noted significant negative changes in the sexual functioning of the injured person (Kreutzler and Zasler, 1989; Sandel, Williams, Dellapietra and Derogatis, 1996) and in the sexual relationship between the injured person and their partner (Gosling and Oddy, 1999). However, we must be aware that although we can make tentative conclusions about adequacy of the *level* of expression of affection, we can glean little about the *quality* of these encounters. Spouses of brain injured patients have described sexual encounters as "boring, flat, or feeling wrong" and their partner's sexual advances to be sometimes 'coercive' (Gosling and Oddy, 1999). Therefore it is possible that sexual and other types of affection *are* shown but less pleasure is gained from the experience. The level of cohesion also seems to be preserved in this sample, again contradicting findings that cohesiveness between partners is lower after ABI (Peters, Stambrook, Moore, Zubek, Dubo and Blumenstein, 1992). This is an encouraging finding as high cohesiveness in families is said to promote positive adaptation after ABI (Kosciulek, McCubbin and McCubbin, 1993; Kosciulek, 1994; Kosciulek, 1996). Similarly, though, this subscale addresses the level of interaction and activities performed together in everyday life.

Perhaps if more time is spent at home by both partners – the patient, through loss of work and social activities (Anderson, 1992; Koskinen, 1998), and the partner, through needing to care for the patient (e.g. Chawalsz, 1992; Lezak, 1988) and increased responsibilities (e.g. Leathem, Heath and Wooley, 1996) – there will inherently be a greater level of 'togetherness' or being together, again saying little about the *quality* of interactions. Indeed that fact that dyadic satisfaction is lower than in a normative sample, suggests that quality suffers. On the other hand, the results may indicate that relationship outcomes are not universally negative and, although some dynamics are troubled after injury, several remain intact.

Measures of premorbid relationship satisfaction and change suggested a general trend for satisfaction to decrease as a result of the injury in couples. Gosling and Oddy (1999) similarly noted that spouses rated their satisfaction with relationship as lower following injury. Interestingly, a small proportion in the current study felt they were *more* satisfied, a third of whom reported relationship problems prior to injury. Therefore a proportion could see positive changes in their relationship after injury. Although formal findings do not shed light on these positive changes subsequent to injury, informal discussions whilst collecting data, partners mentioned feeling they spend more time together, getting to know each other better and getting along better. Other studies have also noted that relationship outcomes are not always negative: some spouses report good companionship, mutual affection, commitment, feeling stronger and more in control in their relationship (Gosling and Oddy, 1999), that the couple have grown closer to their husband since the injury and that they rely on each other more (Leathem, Heath and Woolley, 1996). Positive changes in the level of satisfaction seemed to occur in a minority of this sample too, some of whom but by no means all, had experienced premorbid relationship difficulties.

### Which, if any, brain injury related factors are associated with dimensions of partner Psychological Well-Being?

Patient current functioning and, more specifically, the ability of the patient to carry out activities of daily living independently, emerged as predictive of better Environmental Mastery in partners. This dimension of PWB pertains to having a sense of mastery, competence and control in managing the environment and being able to choose or create contexts suitable to personal needs and values. The PCRS subscale 'Activities of Daily Living' includes items pertaining to the patient's ability to prepare meals, dress him/herself, drive a car, take care of finances, do laundry, washing the dishes and tend to personal hygiene. We can speculate that if a patient is less competent in daily living activities then the partner, who is close contact with the patient, may be the one required not only to assist the patient in a caregiver capacity (e.g. helping him/her dress, wash, tend to personal hygiene) but also to take on the roles that the patient is no longer capable of performing owing to cognitive, behavioural or physical difficulties (e.g. driving, managing household finances). This may lead to the partner feeling less able to have mastery and control over their environment and create an environment reflective of their own personal choices and needs (Ryff, 1989). Research has found that higher dependency needs or lower competence in the patients with ABI has been linked to higher levels of burden and stress in 'caregivers' (e.g. Koskinen, 1998; Minnes, Graffi, Nolte, Carlson and Harrick, 2000). However, we must acknowledge several caveats. Firstly all subscales of the PCRS were highly inter-correlated therefore we cannot say with certainty it is the patients ability in activities of daily living alone which was associated with partner PWB EM. In addition, it has been acknowledged that partners and caregivers after ABI may be particularly vulnerable to depression, anxiety and other symptoms of psychopathology (e.g. Linn, Allen and Willer, 1994), which may dispose them to 'inaccurate' perceptions of the patient's abilities. However, coping and stress and caregiver burden models acknowledge the importance of appraisal and 'subjective' ratings rather than objectivity (e.g. nature of the stressor or burden) in determining outcomes for partners (Oddy, Humphrey and Uttley, 1978; Livingston and Brookes, 1988; Knight et al, 1998). Therefore, the conclusion that can be drawn is the partner's *perception* of the patient's abilities is strongly tied into their ability to manage and have control over their environment.

It was noteworthy that no aspect of patient functioning (activities of daily living, cognitive, interpersonal, emotional PCRS subscales) was able to predict Positive Relations with Others and Personal Growth in partners nor did the level of cognitive function, interpersonal and emotional function (PCRS subscales) significantly predict environmental mastery. This contrasts with other studies that have found a positive association between patient functioning and spousal negative outcomes. In general, lowered functioning of the patient has been associated with high caregiver burden and strain up to 10 years after injury (Minnes, Graffi, Nolte, Carlson and Harrick, 2000; Koskinen, 1998). Poor functioning in *particular domains* has also been associated with spouse/carer negative outcomes: poor patient cognitive functioning with greater negative life changes for the spouse (Wallace et al., 1998); greater emotional changes in the patient with stress in the relative (McKinlay et al, 1981); and worse behavioural functioning in the patient with poorer carer physical and mental health (Anderson, 1995), stress (Oddy et al, 1978), distress in family caregivers (Kreutzer, Gervasio and Camplair, 1994b) and strain in relatives (Koskinen, 1998). Researchers in the field of positive psychology have noted that positive outcomes are distinct from negative ones and have different correlates (e.g. Conway and MacLeod, 2002; Ryan and Deci, 2001). Although statistical power was admittedly limited, it is possible that factors salient to negative outcomes in partners after ABI are not the same ones that effect aspects of positive functioning (e.g. Personal Growth and Positive Relations with Others). Alternatively this lack of association may be due to methodological limitations of the study that will be discussed in a later section.

Interestingly, the level of awareness of the patient did not emerge as having a significant influence on PWB of the partner. A lack of association between awareness of deficit and partner or 'significant other' outcomes echoes findings in previous research (e.g. Wallace and Bognor, 2000). However, contradictory findings in other quantitative studies have found a link between level of awareness in the patient and carer psychological distress (e.g. Ergh et al, 2002) or 'significant other' perceived stress (Groom et al, 1998).

Similarly wives of head injured men cited their husbands' lack of insight and acceptance of disabilities as one of their major concerns (Willer, Allen, Liss and Zicht, 1991). This lack of association may be due to the absence of an effect but, equally, measurement issues may be salient here and will be considered later on.

Findings also suggest that the Well-Being of the partner was not significantly correlated with, or predicted by, the time lapsed post injury. Several studies do find relationships between time since injury and spousal negative outcomes: that anxiety, mood and psychological problems remain high over the year following injury (Livingston, Brooks and Bond, 1985b) or increase over time (MacNamara, Gummow, Goka and Gregg, 1990; cited in Low, Payne and Roderick, 1999) or, alternatively, decrease over time after injury (e.g. reduction in perceived stress; Groom et al, 1998). The current study is consistent with findings in other studies that observe no link between time lapsed since the injury and psychological outcomes in spouses and caregivers (Linn et al, 1994; Kreutzer, Gervasio and Camplair, 1994b; Gervasio and Kreutzer, 1997). It could be argued that acquired brain injury consists of both an acute phase of traumatic events (surrounding the injury itself), followed by ongoing struggles and hassles involved in dealing with the repercussions of the injury in daily life (e.g. Oddy and Herbert, 2003). The fact that the current functioning of the patient emerged as predictive of Environmental Mastery PWB beyond time since injury may imply that *psychological recovery of the partner* after injury is complicated by injury related factors or deficits that are ongoing and are differentially salient to the partner at different times.

Severity of initial injury was also not seen to be a significant predictor of dimensions of PWB. This is similar to the findings of other studies, that severity of injury is not associated with spousal or caregiver ratings of their anxiety, depression and other symptoms of psychopathology (Linn et al, 1994; Gervasio and Kreutzer, 1997; Groom et al, 1998; McKinlay et al, 1991; Rosenbaum and Najenson, 1976; Kreutzer, Gervasio and Camplair, 1994b). Further studies have found severity as only salient to spousal negative outcomes *early* after injury (Livingston, Brooks and Bond, 1985a; McKinlay et al, 1981) and, later on, have found that the functioning of the patient is more predictive (Wallace, Bognor, Corrigan, Clinchot, Mysiw and Fugate, 1998). As the length of time since injury for partners was up to eleven years after injury, it is therefore unsurprising that patient current functioning emerged as predictive of PWB Environmental Mastery and not severity.

### Which brain injury related factors are associated with the quality of the relationship between the partner and the person with ABI as perceived by the partner?

Nearly all partners in the study rated the patients as having undergone at least some degree of personality change (single item measure, NRS). Furthermore, the severity of neurobehavioural symptoms, a measure of personality and behavioural changes in the patient, emerged as a significant predictor of the quality of relationship between the partner and the injured person. Lezak (1988) roughly divides the emotional consequences of brain injury into those that are direct (the effects of actual organic damage) and indirect (the person's emotional reactions to their deficits and changes). It is not possible to say what the source of the changes (organic or psychological reaction to difficulties) are in this sample but that if the partner witnesses and experiences these symptoms in everyday life, there are more likely to be relationship difficulties. On closer inspection, it seemed that the subscale measuring patient hostility/uncooperativeness, suspiciousness, depressive mood, anxiety, tension and reports of concern with self-reported physical symptoms (e.g. headaches, dizziness) was most closely linked to relationship adjustment. The brain injury literature notes that greater degree of personality change and psychosocial maladjustment in the patient is related to greater family relationship dysfunction after ABI (e.g. Douglas and Spellacy, 1996; Kreutzer, Gervasio and Camplair, 1994b) and difficulties between spouses and their head injured partners (Peters, Stambrook, Moore and Esses, 1990). More specifically, Linn, Allen and Willer (1994) found that patient social aggression predicted spousal *depression* and Gosling and Oddy (1999) found that mood swings, aggression and motivational difficulties were *subjectively problematic* for spouses. Many papers look at the association between the patient's level of function and their relationships (e.g. Peters, Stambrook, Morre and Esses, 1990; Douglas and Spellacy, 1996) though less often *which* perceived symptoms are of most salience to the *relationship* between the partner or spouse. This study suggests that perceived mood problems in the patient, such as depression and anxiety, as well as hostility and uncooperative behaviour and suspiciousness, are linked with poorer partner relationship adjustment. However we must take care is suggesting that somatic/anxiety symptoms alone are of importance to the partner relationship as all subscales of the NRS were significantly inter-correlated. Instead it may be safer to conclude that personality change more generally is important, whilst being aware that this study says little about direction of causality.

Satisfaction with preinjury relationship was highly associated with current relationship quality: the greater the degree of satisfaction with the relationship before injury, the better the relationship adjustment following injury. This suggests that the nature of the relationship after injury is strongly related to the state of the relationship before injury. However, we must be cautious in making conclusions from these measures for a number of reasons: the use of a single item measure and the tendency for bias in retrospective reports (premorbid satisfaction); and the difference in what the scales are measuring (premorbid *satisfaction* VS post injury *overall relationship adjustment*).

The current study found that the level of awareness of deficit in the patient was not significantly associated with the quality of the relationship between the spouse or partner and the injured person contrary to other studies that suggest awareness and acceptance of disability is a particular problem for spouses (e.g. Willer et al., 1991) and is linked, albeit modestly, to the functioning of family relationships (Ergh et al., 2002). The implication is that other neurobehavioural symptoms (e.g. depression, anxiety, hostility, uncooperativeness) are more strongly associated with the functioning of the partner relationship than awareness of deficit although, again difficulties with measurement of awareness will be discussed.

The severity of the injury was not significantly predictive of relationship adjustment contrary to other studies has been found a significant association between greater initial severity of injury and poorer family relationships and spousal relationships (e.g. Douglas and Spellacy, 1996; Livingston, Brooks and Bond, 1985a; Peters, Stambrook, Moore and Esses, 1990). Literature on spousal and caregiver *personal psychological outcomes* after brain injury suggests that initial severity of injury is more closely associated earlier after injury and later on, the patient's level of functional abilities and personality changes become more important (e.g. Livingston, Brooks and Bond, 1985a; McKinlay et al, 1981; Wallace, Bognor, Corrigan, Clinchot, Mysiw and Fugate, 1998). This may be also true in the case of *relationship* outcomes. This would explain why relationship functioning in this sample, largely in the chronic phase of injury, is more associated with aspects of patient presentation (i.e. everyday observed neurobehavioural symptoms) than severity of initial injury.

Time since injury was also not shown to be predictive of the quality of the relationship after injury, which is interesting considering the high rates of divorce and separation after ABI (e.g. Gosling and Oddy, 1999) and the fact that time since injury has been shown to be predictive of eventual relationship breakdown (Wood and Yurdakul, 1997). However, other studies have found no link between length of time and relationships, or that family and spousal relationships improve over time as they adjust to the new life with the injured person (e.g. Bishop and Evans, 1995; Kreutzer, Gervasio and Camplair, 1994b; Groom et al. 1998; Kosciulek, McCubbin and McCubbin, 1993). One implication is that recovery and adjustment in family relationship dynamics follows a non-linear path with considerable individuals differences, explained better by level of residual impairments of the patient (i.e. neurobehavioural symptoms) and others factors, than by a simple 'time is a healer' model.

## Subsidiary hypotheses

### Exploring whether other factors are associated with the Psychological Well-Being of the partner and relationship quality between the injured person and the partner

The trend for increased martial satisfaction with increasing age has been explained as partly due to the decrease in child care responsibilities and resultant lower conflict over related issues in the ageing couple (Gagnon, Herson, Kabakoff and Van Hasselt, 1999; Norris, Snyder and Rice, 1997). This research contradicts findings that lower child care responsibilities are associated with better relationship outcomes - couples in the present study report no greater relationship strain with the presence of children. Moreover, the presence of children seemed to be associated with *better* functioning in certain respects (i.e. cohesion). We could speculate that the presence of children may increase 'cohesion': partners may spend more time together engaged in activities around child care and the family. Similarly, the strains related to having children at home seem not to be related to different levels of PWB for partners, suggesting that presence of children at home may have no specific association with 'flourishing' or positive psychological functioning of partners.

The length of relationship preinjury showed no association with measures of well-being or relationship satisfaction. Linn et al. (1994) showed that spouses married to the brain injured person for longer, experienced less distress (anxiety) than those together for a short time, and Wood and Yurdakul (1997), that couples together for longer prior to injury were more likely to stay together after injury. The current sample tended to have been in long relationships prior to injury: only six of the sample had been together for less than 10 years prior to injury. These were too few for formal analysis (looking at well established vs less well established relationships) thus this variable may be of greater consequence than found here.

It was not possible to conduct inferential statistical tests to determine whether there was a difference in PWB and perceived relationship quality between partners of different gender and marital status as there were too few male (n = 6; 13%) and unmarried partner responders (n=5; 11%). The higher rate of responding of female partners or carers is typical in the research after ABI (e.g. Flanagan, 1998; Gervasio and Kreutzer, 1997; Anderson, 1995). There is also a tendency for partner studies after ABI to include only married spouses (e.g. Gosling and Oddy, 1999; Peters, Stambrook, Moore, Zubek, Dubo and Blumenstein, 1992) which may be through desire to create homogeneity, through lack of response from unmarried partners or, possibly, through greater vulnerability to breakdown of the unmarried partner relationship.

### Exploring awareness of deficit

Similar to the large body of research of awareness of deficit after brain injury (e.g. Sherer, Hart and Nick, 2003), the current study found that patients tended to rate their deficits and changes as significantly less than did partners. In addition, patients in the current study showed better 'awareness' for physical deficits and than cognitive and behavioural disturbances. This dissociation is consistent with Schacter's neuropsychological DICE model ('Dissociable Interactions and Conscious Experience'; 1989) that suggests damage to connections between individual 'modules' and the 'Conscious Awareness System' (CAS) presents in the patient as unawareness of specific individual functions. It is also consistent with previous studies that show brain injured patients tend to overestimate their abilities in social, emotional, behavioural and 'executive' functions with more accuracy in physical or sensory domains (e.g. Prigatano et al., 1991; McKinlay et al, 1981; Port, Wilmott and Charleston, 2002).

In the current study, there appeared to be no association between the severity of the injury or the length of time since the injury and the level of awareness in the patient. Some studies have found greater initial severity to be linked to lower awareness of deficit (e.g. Allen and Ruff, 1990; cited in Crisp, 1991; Prigatano et al., 1998; Levin et al, 1987) yet others have seen no effect of severity on awareness of deficit (e.g. Brooks and McKinlay, 1983;

McKinlay and Brooks, 1984; Prigatano and Altman, 1990). Similarly, although clinicians feel that awareness tends to improve over time (e.g. Crisp, 1991; Sherer et al, 1998) and several studies have established this trend (e.g. Godfrey et al, 1993; Allen and Ruff, 1990) other studies, like the current one, have also observed no relationship between time and awareness in ABI patients (e.g. Bechtold Korte, Wegener and Chwalisz, 2003). Yet other studies have established decreases in awareness over time (e.g. Wallace and Bognor, 2000) and fluctuations (e.g. Krefting, 1989; cited in Crisp, 1991). Evidently other factors play a part in the presentation of awareness in the patient beyond simply the time since the injury and the severity. Neuroanatomical studies and models implicate the frontal lobes (particularly the right), the right partial lobe, the 'heteromodal cortex' and the right hemisphere in general in the maintenance of normal self awareness (e.g. Damasio and Anderson, 1993; Stuss, 1991; Heilman et al, 1993; Ranseen et al., 1990; McGlynn and Schacter, 1989; Prigatano, 1991). In addition, psychodynamic formulations emphasize the importance of social, emotional and personality factors in Anosagnosia (e.g. Weinstein, 1991). Therefore the nature of organic damage as well as contextual factors should be considered in more detail in a comprehensive formulation.

## 4.3 Strengths and limitations

### Generalisability of the findings

Limits on external validity of the findings result from the type of sample obtained. As most were white British and Christian or Catholic, generalisability is minimized to other ethnic and religious groups: different values, attitudes, meanings and expectations may exist about chronic illness and caregiving which could effect psychological and relationship outcomes for partners. Similarly, the social class of couples was largely I and II suggesting a relative degree of affluence (at least before the injury). We must be careful not to generalize results to all sociodemographic groups, where those in less advantaged groups may have different experiences and other factors such as housing, finances and even subcultural values and attitudes may play a different role. Couples where injury was from TBI were different in some respects to couples where injuries were from other causes (PWB Positive Relations with Others, patient emotional functioning on the PCRS). Although these findings may be a result of type I error (as the effect disappeared after Bonferroni correction) we must be careful in generalizing to all ABI couples. A possible strength of the study was the inclusion of unmarried couples, a group who have been neglected in previous research looking at partner outcomes after ABI (e.g. Gosling and Oddy, 1999; Peters, Stambrook, Moore, Zubek, Dubo and Blumenstein, 1992). However, the response to recruitment was low both from unmarried couples and male partners. Whether different factors are influential for these groups is not known.

Little information was available on those that did not participate, either through choice or exclusion (e.g. patient too impaired to fill out the questionnaire, patient in rehabilitation/hospital/residential care). Response bias may exist where certain types of couples were responders: perhaps those where the patient was particularly high or low in functioning; those in need of 'help'; or who, alternatively, are having few difficulties. The lack of knowledge about non-responders threatens generalizability of findings to all couples after ABI.

It could be argued that external validity was enhanced through response to the study by couples inhabiting a wide geographical area of considerable demographic diversity: including urban, suburban and rural areas (inner and outer London, Kent, Milton Keynes). Representativeness may have been increased in this sample through recruitment both through a community brain injury rehabilitation unit and the non-statutory sector, and not, as in previous research, though self help groups alone (e.g. Linn et al, 1994).

### Design

The cross sectional and non-experimental nature of the study meant it was difficult to make causal attributions about the link between independent variables and the outcomes of PWB or relationship quality.

There is a long list of potentially important variables relevant to PWB of partners and relationship quality (particularly in the case of Personal Growth and Positive Relations with Others). Choice of variables was guided by previous research (albeit about negative partner outcomes), but was limited by both what was practicable and statistical power afforded by the sample. Clearly other variables could have contributed to variance in regression equations. Negative or stressful life events as well as more positive events were mentioned by partners as having occurred in their lives since the injury (e.g. death of a parent, health problems and failing of a business; birth of a grandchild, receipt of a compensation settlement). In addition, partners mentioned unmeasured aspects such as ‘childishness’, ‘selfishness’ and ‘physical aggression’ in the patient as particularly difficult for them: these may have proved deserving of inclusion.

The sample size was met, suggested by power analysis prior to conducting the study (based on Cohen’s 1992 recommendations 42 participants were required for a 5 variable regression). However this was only able to detect conventionally specified ‘large’ effect sizes. Just as for all studies of limited sample size, the absence of an effect does not prove that none is present, but that with the sample size obtained none was detected. Greater power may have obtained different results.

### Measurement issues

Given the caveats above, the lack of predictive value of awareness on partner well-being may indeed reflect that awareness has no influence on the partner’s ability to achieve psychological well-being. However, this is surprising considering research that has found a positive link between this and both the functioning of the partner and the patient’s relationships (e.g.

Ergh et al. 2002). In addition, several partners in the current study mentioned that the patient's low self awareness was a particular problem for them. It may be, then, that absence of significant findings reflects measurement difficulties. The AQ requires individuals to rate abilities now compared to before the injury, and injuries in the current sample were sustained up to 11 years ago. Having to recall an accurate picture of the patients functioning before injury to compare to current functioning may be subject to bias, particularly long after injury. Indeed this may, in itself, be a difficult task for some patients with severe cognitive and memory problems, threatening the reliability of the data.

Although measuring the difference between 'objective' 'significant other' ratings of patient functioning and the patient's own ratings is arguably the most common method of measuring awareness in patients with ABI (e.g. Ergh et al, 2002; Groom et al, 1998), 'significant other' ratings have been shown to be subject to bias from mood and personality factors (McKinlay and Brooks, 1984). Had awareness been measured in another way or with multiple measures (e.g. clinician ratings; comparison of patient ratings with neuropsychological test results or clinician ratings), criterion validity could have been established for this measure and relationships may have been observed between awareness and these other ratings. In addition, the AQ measure, whilst being short with good psychometric properties, could be criticised for only tapping various aspects of functioning and awareness thereof (content validity). However, as many patients were no longer in regular contact with clinicians; clinician ratings can also contain bias (e.g.

Fordyce and Roueche, 1986); and neuropsychological assessment can be low in ecological validity (Ponsford, 1988); 'significant other' ratings using this short face-valid measure, was chosen as the most advantageous after consideration.

Criticisms could be leveled at the single item measures in the study (personality change, satisfaction with premorbid relationship, change in relationship satisfaction as a result of injury and financial strain). Other studies of families after brain injury also use single item measures (e.g. 5 point financial strain scale; Moore, Stambrook, Peters and Lubusko, 1991). Although they had good face validity, true validity and reliability are unknown. In addition, the nature of retrospective analysis by partners about their premorbid relationship may be subject to bias. As a consequence, the use of single item measures was kept to a minimum in statistical analyses (rating of perceived financial strain and premorbid relationship satisfaction in regressions), and were used only when it was felt appropriate (e.g. 'financial strain' rather than 'monthly income').

The normative groups used to compare data on PWB and relationship satisfaction were different in some respects to the current sample. Ryff's (1989) group were largely similar (age, ethnicity, marital status, number of children) although there was no available information on financial situation or social class with which to compare to the current sample. Ryff's (1989) sample was also American and the current one, British, thus sociocultural factors may impact differentially. In addition the normative sample for relationship adjustment was similar in some respects (years of education, number of children) but different in others (American, somewhat younger, a greater proportion of males than the current sample, data from nearly 30 years ago) which hinders exact comparisons being made.

Quantifying severity of injury is an endeavour possessing certain difficulties. Studies have shown that the measurement of severity via depth or duration of coma, especially where there is little loss of consciousness, is a less reliable measure of brain damage than PTA (Wilson, Pentland, Currie and Miller, 1994 cited in Richardson, 2000). Problems with measurement were minimized by: attempting to use 'objective' clinician ratings obtained from medical files and by prioritizing length of PTA (followed by GCS score then length of coma) when possible.

In addition, the Neurobehavioural Rating Scale was not used in the way that authors initially recommended – a clinician rated scale based on information gained from interview with the patient and other sources (e.g. partners perceptions, documented evidence; Levin et al, 1987). It was used as a semi-structured interview schedule to obtain *partner perceived ratings of severity of neurobehavioural symptoms* and not as an 'objective' measure of symptoms, as studies that suggest spousal and carer outcomes are more associated with their 'subjective' perceptions of patient functioning than 'objective' ratings (e.g. Oddy, Humphrey and Uttley, 1978; Livingston and Brookes, 1988), particularly in the absence of short, appropriate, available neurobehavioural measures. The consequences of these amendments on the reliability and validity of the measure are unknown.

## 4.4 Future Research

It would always be recommended to replicate the study, particularly with a larger sample size: similar findings would suggest that findings were not erroneous or due to chance (a type I error) or as a result of sampling bias. With a longer time frame, attempts could be made to obtain greater variability in social class, ethnicity, and geographical area and to include a greater number of male and unmarried partners to look at the effects of these factors.

Owing to not wanting to overburden partners, only three dimensions of well-being were rated by partners in the current study. Certainly it would be interesting to explore how the other three domains of PWB, namely Self-Acceptance, Autonomy and Purpose in Life (e.g. Ryff, 1989) were affected by brain injury and which brain injury and other demographics factors contributed to enhanced or depleted levels of these.

The current study found that the partner's perception of the brain injured persons functioning and neurobehavioural symptoms were significantly predictive of their PWB and relationship quality respectively. The measures of patient functioning (PCRS, NRS) addressed what the partner *observed* in the patient in everyday life. It may have been interesting to go beyond observations and understand the *attributions* partner make about symptoms. For example, Lezak (1988) suggests that family members may sometimes believe that the apathy, silliness, heightened reactivity and irritability in patients are deliberate and under their control and not, as can be the case, a result of organic damage. It would be interesting to understand the role of attributions about symptoms in the outcomes of partners and spouses.

A longitudinal study, whilst difficult within this time frame, would allow a clearer comparison of the links between brain injury symptoms (e.g. levels of awareness of deficit, neurobehavioural symptoms, patient functional ability) and the PWB and relationship quality of partners at different time points. For example, several partners mentioned that certain symptoms had been more severe and more disturbing for them earlier on after the injury. It would be interesting to follow a sample of partners from early after injury, perhaps as they are admitted to hospital or referred to rehabilitation services, to understand the pattern of PWB and relationship quality over time and factors that are most linked to changes in PWB and relationship dynamics.

Furthermore, in order to increase the amount of variance explained in PWB and relationship quality, future research could focus on attempting to measure other potentially important neglected variables. These could include personality variables of the patient and the partner (e.g. optimism, humour), illness variables (mental and physical health), life events (both positive and negative), social factors (social support and involvement with others outside the immediate family) and facets of family function (e.g. flexible) and coping (e.g. problem or emotion focused). Including these may afford us more understanding of the factors most strongly associated with positive functioning and relationship adjustment in partners to develop intervention appropriately.

Since the positive functioning of partners is relatively unexplored, qualitative research may be helpful in giving us more in-depth information about which aspects of positive functioning are preserved or even enhanced through the struggles of adaptation to ABI. In particular, it may allow us to understand more clearly *how* the presence of children is associated with greater cohesion between partners; whether the reduced consensus between partners is due to *active conflict* or *absence of discussion* about every matters and decisions; and would also allow us to examine which, if any, aspects of the patient's disturbed awareness are most salient to partners (e.g. denial vs 'organic' unawareness; unawareness of particular functions).

In terms of awareness of deficit, future research could attempt to use multiple measures of awareness to increase validity or address different aspects of impaired awareness in the same study. For example, in terms of Crosson et al's (1989) 'Pyramid Model', authors describe a dissociation between three levels of awareness. It is *intellectual awareness* - the patient's knowledge of the existence of their impairments – that is being measured in the context of this study. However, both *emergent awareness,* the ability to recognise deficits as they occur, and *anticipatory awareness,* the ability to anticipate that the problem will occur in future, are not addressed in the current study yet may be of significance to partner outcomes.

While Lezak (1988, 1986) describes spouses as 'living in a social limbo', we can speculate that partners by their unmarried nature have even less societal standing than married spouses after injury and, as a result, may have even greater difficulties adjusting to the new relationship and life with the injured person. Perhaps a lower rate of response by unmarried partners is owing to the tendency for this relationship to breakdown. However, these are speculations and research is needed to investigate the plight of the unmarried partner and his/her relationship with the injured person.

## 4.5 Implications

### Theoretical, scientific and research implications

This study highlights the importance of examining the experience of partners and spouses after ABI. It suggests that partners may function well in certain respects and less well in others. This implies a need to address multiple aspects of functioning when addressing outcomes. Moreover a move towards 'positive psychology' in the brain injury research field is recommended since, historically, the field has been dominated by a focus on negative outcomes, such as distress, burden and psychopathology. Similarly the relationship between the injured person and the partner can be strained in some aspects but not others, implying the need in research studies to use multifactorial measures of relationship adjustment to get a more accurate picture of relationship dynamics.

The study also provides some insights into the theoretical underpinnings of Psychological Well-Being as developed and empirically validated by Ryff and colleagues (e.g. Ryff, 1989, Ryff and Singer, 1995). The fact that the EM domain was significantly reduced in partners and predicted by a brain injury factor (ie patient functioning) yet PG and PR were within normal limits and were not predicted by brain injury factors, lends a degree of support to the construct validity of PWB: that dimensions may represent distinct entities (e.g. Ryff, 1989).

Literature on human functioning after one-off traumatic events suggests that individuals tend to follow four major paths (Bonanno, 2004) – *chronic* (where functioning remains below normal levels), *delayed* (functioning is normal at the start and decreases later on), *recovery* (transient reduction in functioning followed by a return to normal levels) and *resilience* (maintenance of normal functioning throughout). The fact that a) time since injury did not emerge as a significant predictor of well-being and b) well-being remained adequate in certain domains (PG and PR), provides extremely tentative support for the *resilience* pathway of individuals in some aspects of function after traumatic life changing events. However, as partners were not recruited until the chronic phase, we were not able to examine any transient drop in function followed by return to normal function – the *recovery* pathway – which may have been present.

The current study found that awareness of deficit, both globally and for domains of function, were not significantly different between injury groups. This supports the use of the 'Awareness Questionnaire' in a population of individuals with different causes or aetiologies of injury, such as stroke, anoxia and cerebral infection. However, we must be aware that the current study says little about whether the AQ is *really* measuring 'awareness' in the patient.

### Clinical and professional implications

This study implicates the importance for clinicians to address the needs of the spouse or partner when considering a comprehensive care package after ABI. It may be appropriate to assess the degree of perceived control the partner has over their environment (Environmental Mastery) and, where relevant, provide practical assistance to help partners to manage their increased responsibilities and roles after ABI. This many include the provision of respite care or adequate day services with hours to suit partners who may be balancing child care and work activities; or financial support for partners to hire home-help or in-house care for the injured person. Financial support may be particularly relevant as nearly a quarter felt they were under considerable financial strain. In addition, couple therapy may be recommended to target dynamics of the interpersonal relationship between the injured person and the partner that have become strained after brain injury. However, this study also cautions against overpathologizing: some areas of individual functioning and of the relationship may be preserved or even enhanced. For example, partners were found to continue to be able to grow and develop and have warm trusting relationships with others; and the relationship to contain adequate levels of affection and cohesion. A comprehensive assessment of psychological functioning and relationship dynamics would be helpful in teasing out where intervention is most needed.

The presence of children aged 18 and below at home was linked to better cohesiveness, or together time, in the relationship. However, more time spent together does not equal a better quality of relationship. Indeed, there was no difference in satisfaction, consensus, expression of affection or overall marital adjustment between those with and with out children. It may be then that children are experiencing both parents as being *present* in the home or during family activities but with difficulties in the *quality* of the relationship between their parents. Thus the impact of spousal difficulties on children should be addressed in the clinic as part of routine assessment and, when necessary, family therapy provided.

Findings also suggest that premorbid factors should not be overlooked. An unsatisfactory premorbid relationship was highly associated with a poor current relationship between the spouse/partner and the injured person. This emphasizes the importance of conducting a full assessment of the nature of the premorbid relationship, in addition to other aspects of premorbid functioning, and should act as a caution to professionals to avoid blaming all relationship difficulties on 'the brain injury'.

This study also has implications for the organization and funding of services. The vast majority of partners were in the chronic stage of injury: intensive rehabilitation will have subsided for many and contact with specialist services, diminished, or ceased completely. However, it seems that partners may continue to have difficulties in certain aspects of psychological function and their relations with the injured person, both of which are significantly associated with perceived aspects of the patients functioning. Perhaps continued support and intervention for partners much later after injury would be helpful for some who continue to experience difficulties adjusting to and coping with the extraordinary and life changing events surrounding acquired brain injury.

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# Appendices

PPENDIX A

tters of Ethical Approval

North Central London NHS
Health Authority

Holbrook House
Cockfosters Road
Barnet, Herts, EN4 0DR
Tel 020 8272 5500
Fax: 020 8272 5700
☑ *Tick box as appropriate*

Insull Wing
110 Hampstead Road
London, NW1 2LJ
Tel: 020 7853 5353
Fax: 020 7853 5355
☐ *Tick box as appropriate*

Chair Marcia Saunders
Chief Executive Christine Outram

22nd July 2003

Anne Whelan,
18B Yew Grove,
Cricklewood,
London NW2 3AD.

Dear Ms. Whelan,

**03/18: Partner experiences following brain injury**

Acting under delegated authority I write to acknowledge receipt of your letter dated 16th July 2003 and the enclosed clarification requested by the LREC in our letter to you dated 2nd May 2003. The additional recruiting mechanism does not appear to raise any additional ethical issues. There is now no objection on ethical grounds to the proposed study. I am therefore happy to give you the favourable opinion of the LREC:

**Paperwork reviewed**
LREC application form
Protocol
Patient Consent form
Patient Information sheet
CV of lead researcher
Finalised questionnaire

**Please note that this opinion alone does not entitle you to begin research**

The Barnet, Enfield & Haringey LREC considers the ethics of proposed research projects and provides advice to NHS bodies under the auspices of which the research is intended to take place. **It is the NHS body, which has the responsibility to decide whether or not the project should go ahead,** taking into account the ethical advice of the LREC. Where these procedures take place on NHS premises or using NHS patients, the researcher must obtain the agreement of local NHS management who will need to be assured that the researcher holds an appropriate NHS contract and that indemnity issues have been adequately addressed.

**The following conditions apply to this project**

- The LREC will require a copy of the final report on completion of the project and require details of the progress of the project periodically (i.e. annually for longer projects)
- The committee must receive immediate notification of any adverse or unforeseen circumstances arising out of the project.
- If data is to be stored on a computer in such a way as to make it possible to identify individuals, then the project must be registered under the Data Act 1998. Please consult your department data protection officer for advice.
- Failure to adhere to these conditions set out above will result in the invalidation of this letter of no objection.

I confirm that LRECs are fully compliant with the International Committee on Harmonisation/Good Clinical Practice (ICH) guidelines as they relate to the responsibilities, composition, function operations and records of an Independent Ethics Committee/Independent Review Board.

Please forward any additional information/amendments regarding your study to the LREC Co-ordinator at the above address.

Your application has been given a unique reference number 03/18 please use it on all correspondence with the LREC.

Yours sincerely

Alison O'Kane

**Alison O'Kane**
**LREC Co-ordinator**
**Barnet, Enfield & Haringey**

## Appendix B

### Rough protocol for initial telephone conversation with partner/spouse

**Introduce self**

- Name and title
- where I am calling from i.e. research setting

**Introduce project**

Roughly….."I am carrying out a piece of research looking at the perspectives and experiences of partners after brain injury, and I was wondering whether this would be something you would be interested in participating in? I can tell you a bit more about it before you decide if you and your partner/husband/wife might be interested in participating…."

**Explain their potential involvement**

"I would send you out a questionnaire pack. This involving you filling out most of the questionnaires but there is a questionnaire for your partner/husband/wife to fill out too. If both of you decide to take part, you would fill these out and send them back to me in the stamped addressed envelopes that I will provide for you. It is important that you and your partner/husband/wife fill your questionnaires out separately so that I get your own unique perspectives on things"

**Briefly check if they meet inclusion/exclusion criteria**

- If they still together in a relationship
- Patient communication problems
- Patient/partner fluency in English (if suspected not)

**Voice ethical considerations**

Emphasis, for both the partner and the patient, on: freedom to participate or not; that they can withdraw at any time; that some questions are quite personal.

**Answer their questions**

**Check their address and contact details**

**Give my contact details**

For if they need any help filling out questionnaires or have any other questions (this is also on the questionnaire pack)

## Appendix C

## Information sheets and consent forms

### TAKING PART IN RESEARCH

You are being invited to take part in a research project.

Here is some information to help you decide whether or not to take part. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish.

Ask us if there is anything you do not understand or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

1. You may or may not receive any direct benefit from taking part in the study. However information obtained during the course of the study may help us to learn about the perspectives and needs of partners of people who have sustained a brain injury, to contribute to how people in your position can be better understood, supported and helped in the future.

2. It is up to you to decide whether to take part or not. If you do decide to take part you will be given an information sheet and a consent form, to read and sign. Even if you decide to take part, you are free to withdraw at any time and without giving a reason.

3. All the information collected about you during the course of the research will be kept strictly confidential. Any published report of the research will not identify you.

4. Consumers for ethics in research (CERES) publish a leaflet entitled 'Medical Research and You'. This leaflet gives more information about medical research and looks at some questions you may want to ask. A copy may be obtained from CERES, PO Box 1365, London N16 0BW.

# INFORMATION SHEET

## 1. Study Title
Exploring partners' experiences after brain injury.

## 2. What is the purpose of the study?
The purpose of the study is to find out how brain injury affects partners/spouses.

## 3. Why have we been chosen?
Your details have been identified through one on these sources: Headway charity or from the files at X where one partner will have been referred for rehabilitation at some point in the past.

## 4. Who is organising the study?
I am the primary researcher. My name is Anne Whelan. I am training to be a Clinical Psychologist at University College London. Before my training, I worked in the field of Brain Injury for some time. The present research is an important part of my course and training programme. I am working with Ana Bajo, Associate Clinical Scientist at X, and Dr Linda Clare, Lecturer in Psychology at UCL. We aim to publish the results of the research so that what we find out can be used to help other couples where one partner experiences a brain injury.

## 5. What will happen to me if I take part?
You will be asked to fill out a pack of questionnaires and return them to me in the envelope provided. This will be followed by a brief telephone interview to fill out some additional questionnaires.

This is the end of your involvement. However, once the results are available, I will be happy to contact you if you wish to know the outcome of the study.

## 6. Are there disadvantages in taking part in this study?
There are no obvious disadvantages.

## 7. What are the risks in taking part?
There are no obvious risks.

## 8. What are the possible benefits of taking part?
In taking part, you will be improving our understanding of the experience of being the partner of a brain-injured person which may allow others in your position to get more appropriate support and help in the future.

## 9. Is the researcher being paid for including me in the study?
No.

## 10. Confidentiality - who will know I am taking part in the study?
All information collected from you will be kept strictly confidential. Any information that you provide during the study will be anonymised so that you cannot be recognised from it.

## 11. LREC Approval
The Local Research Ethics Committee which approved the study is the 'Barnet, Enfield and Haringey Local Research Ethics Committee'.

### 12. What will happen to the results of the study?

If you would like, I can contact you with information about the outcome of the study. If the study is published, I can send you a copy of the paper.

### 13. Contact for further information

You can contact me at X. Please leave a message if I am not there and I will call you back.

Thank you ever so much for agreeing to take part in this study.

For office use only:
**Centre No**..........................................................
**Study No**.............................................................
**Patient ID No**.....................................................

## CONSENT FORM

**Title of Project:** Exploring partners' experiences after Brain Injury

**Name of Researcher:** Anne Whelan

Please tick these boxes:

| | | |
|---|---|---|
| 1 | I confirm that I have read and understand the enclosed information sheet | |
| 2. | I understand that my participation is voluntary and that I am free to withdraw at any time without my medical care or legal rights being affected | |
| 3. | I am willing to allow access to my files at X (if applicable) but understand that strict confidentiality will be maintained and only the researcher will view them | |
| 4. | I agree to take part in the above study | |

Please fill out your name and the date and sign here:

| | | |
|---|---|---|
| Name of Participant<br>(block capitals) | Date | Signature |

The participant is aware of the nature and demands of the research.

| | | |
|---|---|---|
| ANNE WHELAN | | |
| Name of Researcher<br>(block capitals) | Date | Signature |

## Appendix D

## Awareness Questionnaire – Patient and Partner forms

### ‘Patient’ (person with brain injury) questionnaire

This is a 2 sided questionnaire to be filled out by the person who has had a brain injury. Please put a number on the line beside each statement that best describes your functioning in each area now, compared to before the injury.

Name: ______________________ Date: ______________

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Much Worse | A little worse | About the same | A little better | Much better |

_______ 1. How good is your ability to live independently now as compared to before your injury?

_______ 2. How good is your ability to manage your money now as compared to before your injury?

_______ 3. How well do you get along with people now as compared to before your injury?

_______ 4. How well can you do on tests that measure thinking and memory skills now as compared to before your injury?

_______ 5. How well can you do the things you want to do in life now as compared to before your injury?

_______ 6. How well are you able to see now as compared to before your injury?

_______ 7. How well can you hear now as compared to before your injury?

_______ 8. How well can you move your arms and legs now as compared to before your injury?

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Much Worse | A little worse | About the same | A little better | Much better |

_______ 9. How good is your coordination now as compared to before your injury?

_______ 10. How good are you at keeping up with the time and date now as compared to before your injury?

_______ 11. How well can you concentrate now as compared to before your injury?

_______ 12. How well can you express your thoughts to others now as compared to before your injury?

_______ 13. How good is your memory for recent events now as compared to before your injury?

_______ 14. How good are you at planning things now as compared to before your injury?

_______ 15. How well organised are you now as compared to before your injury?

_______ 16. How well can you keep your feelings in control now as compared to before your injury?

_______ 17. How well adjusted emotionally are you now as compared to before your injury?

END

## Partner questionnaire

This is a 2 sided questionnaire to be filled out by the partner of the brain injured person. Please put a number on the line beside each statement that best describes the brain injured person's functioning in each area now, compared to before his/her injury.

Name: ______________________________ Date: ____________________

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Much Worse | A little worse | About the same | A little better | Much better |

_______ 1. How good is the patient's ability to live independently now as compared to before his/her injury?

_______ 2. How good is the patient's ability to manage his/her money now as compared to before his/her injury?

_______ 3. How well does the patient get along with people now as compared to before his/her injury?

_______ 4. How well can the patient do on tests that measure thinking and memory skills now as compared to before his/her injury?

_______ 5. How well can the patient do the things he/she wants to do in life now as compared to before his/her injury?

_______ 6. How well is the patient able to see now as compared to before his/her injury?

_______ 7. How well can the patient hear now as compared to before his/her injury?

_______ 8. How well can the patient move his/her arms and legs now as compared to before his/her injury?

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Much Worse | A little worse | About the same | A little better | Much better |

_______ 9. How good is the patient's coordination now as compared to before his/her injury?

_______ 10. How good is the patient at keeping up with the time and date now as compared to before his/her injury?

_______ 11. How well can the patient concentrate now as compared to before his/her injury?

_______ 12. How well can the patient express his/her thoughts to others now as compared to before his/her injury?

_______ 13. How good is the patient's memory for recent events now as compared to before his/her injury?

_______ 14. How good is the patient at planning things now as compared to before his/her injury?

_______ 15. How well organised is the patient now as compared to before his/her injury?

_______ 16. How well can the patient keep his/her feelings in control now as compared to before his/her injury?

_______ 17. How well adjusted emotionally is the patient now as compared to before his/her injury?

END

## APPENDIX E

# NEUROBEHAVIORAL RATING SCALE

H.S. Levin; J.E. Overall, K.E. Goethe, W. High, R.A. Sisson

DIRECTIONS: Place an X in the appropriate box to represent level of severity of each symptom.

| | Not Present | Very Mild | Mild | Moderate | Mod. Severe | Severe | Extremely Severe |
|---|---|---|---|---|---|---|---|
| **INATTENTION/REDUCED ALERTNESS**—fails to sustain attention, easily distracted; fails to notice aspects of environment, difficulty directing attention, decreased alertness. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **SOMATIC CONCERN**—volunteers complaints or elaborates about somatic symptoms (e.g., headache, dizziness, blurred vision), and about physical health in general. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **DISORIENTATION**—confusion or lack of proper association for person, place, or time. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **ANXIETY**—worry, fear, overconcern for present or future. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **EXPRESSIVE DEFICIT**—word-finding disturbance, anomia, pauses in speech, effortful and agrammatic speech, circumlocution. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **EMOTIONAL WITHDRAWAL**—lack of spontaneous interaction, isolation, deficiency in relating to others. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **CONCEPTUAL DISORGANIZATION**—thought processes confused, disconnected, disorganized, disrupted; tangential social communication; perseverative. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **DISINHIBITION**—socially inappropriate comments and/or actions, including aggressive/sexual content, or inappropriate to the situation, outbursts of temper. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **GUILT FEELINGS**—self-blame, shame, remorse for past behavior. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **MEMORY DEFICIT**—difficulty learning new information, rapidly forgets recent events, although immediate recall (forward digit span) may be intact. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **AGITATION**—motor manifestations of overactivation (e.g., kicking, arm flailing, picking, roaming, restlessness, talkativeness.) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **INACCURATE INSIGHT AND SELF-APPRAISAL**—poor insight, exaggerated self-opinion, overrates level of ability and underrates personality change in comparison with evaluation by clinicians and family. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **DEPRESSIVE MOOD**—sorrow, sadness, despondency, pessimism. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **HOSTILITY/UNCOOPERATIVENESS**—animosity, irritability, belligerence, disdain for others, defiance of authority. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **DECREASED INITIATIVE/MOTIVATION**—lacks normal initiative in work or leisure, fails to persist in tasks, is reluctant to accept new challenges. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **SUSPICIOUSNESS**—mistrust, belief that others harbor malicious or discriminatory intent. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **FATIGABILITY**—rapidly fatigues on challenging cognitive tasks or complex activities, lethargic. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **HALLUCINATORY BEHAVIOR**—perceptions without normal external stimulus correspondence. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **MOTOR RETARDATION**—slowed movements or speech (excluding primary weakness). | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **UNUSUAL THOUGHT CONTENT**—unusual, odd, strange, bizarre thought content. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **BLUNTED AFFECT**—reduced emotional tone, reduction in normal intensity of feelings, flatness. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **EXCITEMENT**—heightened emotional tone, increased reactivity. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **POOR PLANNING**—unrealistic goals, poorly formulated plans for the future, disregards prerequisites (e.g., training), fails to take disability into account. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **LABILITY OF MOOD**—sudden change in mood which is disproportionate to the situation. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **TENSION**—postural and facial expression of heightened tension, without the necessity of excessive activity involving the limbs or trunk. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **COMPREHENSION DEFICIT**—difficulty in understanding oral instructions on single or multistage commands. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **SPEECH ARTICULATION DEFECT**—misarticulation, slurring or substitution of sounds which affect intelligibility (rating is independent of linguistic content.) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

# Appendix F

## Partner rating of personality change

How different in personality is your partner now compared to before the injury? (circle the one that applies)

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
| The same | A little Different | Somewhat Different | A lot Different | Completely Different |

## Appendix G

## Patient Competency Rating Scale – Partner version

### Rating the Patient's Abilities - filled out by partner/spouse

The following is a questionnaire that asks you to judge your partner's ability to do a variety of very practical skills. Some of the questions may not apply directly to things they often do, but you are asked to complete each question as if it were something they "had to do". On each question you should judge how easy or difficult a particular activity is for them and mark the appropriate space.

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

_____ 1. How much of a problem do they have in preparing their own meals?

_____ 2. How much of a problem do they have in dressing themselves?

_____ 3. How much of a problem do they have in taking care of their personal hygiene?

_____ 4. How much of a problem do they have in washing the dishes?

_____ 5. How much of a problem do they have in doing the laundry?

_____ 6. How much of a problem do they have in taking care of their finances?

_____ 7. How much of a problem do they have in keeping appointments on time?

_____ 8. How much of a problem do they have in starting a conversation in a group?

_____ 9. How much of a problem do they have in staying involved in work activities even when bored or tired?

_____ 10. How much of a problem do they have in remembering what they had for dinner last night?

_____ 11. How much of a problem do they have in remembering names of people they see often?

_____ 12. How much of a problem do they have in remembering their daily schedule?

_____ 13. How much of a problem do they have in remembering important things they must do?

_____ 14. How much of a problem do they have in driving a car if they had to?

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

_____ 15. How much of a problem do they have in getting help when they are confused?

_____ 16. How much of a problems do they have in adjusting to unexpected changes?

_____ 17. How much of a problem do they have in handling argument with people they know well?

_____ 18. How much of a problem do they have in accepting criticism from other people?

_____ 19. How much of a problem do they have in controlling crying?

_____ 20. How much of a problem do they have in acting appropriately when they are around friends?

_____ 21. How much of a problem do they have in showing affection to people?

_____ 22. How much of a problem do they have in participating in group activities?

_____ 23. How much of a problem do they have in recognising something they do or say has upset someone else?

_____ 24. How much of a problem do they have in scheduling daily activities?

_____ 25. How much of a problem do they have in understanding new instructions?

_____ 26. How much of a problem do they have in consistently meeting their daily responsibilities?

_____ 27. How much of a problem do they have in controlling their temper when something upsets them?

_____ 28. How much of a problem do they have in keeping from being depressed?

_____ 29. How much of a problem do they have in keeping their emotions from effecting their ability to go about the day's activities?

_____ 30. How much of a problem do they have in controlling their laughter?

# Appendix H

## Measures of Severity

### *Glasgow Coma Scale score (GCS; Teasdale and Jennett, 1974)*

The Glasgow Coma Scale yields a total score between 3 (no response) and 15 (alert and well oriented)

| | |
|---|---|
| 13-15 | mild |
| 9-12 | moderate |
| 3 to 8 | severe |

### Length of Post-Traumatic Amnesia (PTA; Jennett and Teasdale, 1981; Kraus and McArthur, 1996)

The length of time of confusion following head injury / coma before the reinstatement of continuous memory (Medical Disability Society, 1988).

| | |
|---|---|
| < 5 mins = very mild | MILD |
| > 5 mins and < 1 hour = mild | |
| > 1 hour , < 24 hours = moderate | MODERATE |
| > 24 hours and < 1 week = severe | SEVERE |
| > 1 week and < 4 weeks = very severe | |
| > 4 weeks = extremely severe (Russell, 1971) | |

### Length of coma or loss of consciousness (Williamson, Scott and Adams, 1996)

| Mild | Moderate | Severe |
|---|---|---|
| <20 minutes | 20 mins-36 hr | >36 hours |

## Appendix I

## Ryff Scales of Psychological Well Being – Environmental mastery, personal growth and positive relations with others

### Well-Being Questionnaire - rated by the partner/spouse

**Please put a number on the line beside each statement that best describes you. Thank you ever so much.**

| **1** | **2** | **3** | **4** | **5** | **6** |
|---|---|---|---|---|---|
| **strongly disagree** | **moderately disagree** | **slightly disagree** | **slightly agree** | **moderately agree** | **strongly agree** |

______ 1. In general, I feel I am in charge of the situation in which I live.

______ 2. The demands of everyday life often get me down.

______ 3. I do not fit very well with the people and the community around me.

______ 4. I am quite good at managing the many responsibilities of my daily life.

______ 5. I often feel overwhelmed by my responsibilities.

______ 6. If I were unhappy with my living situation, I would take effective steps to change it.

______ 7. I generally do a good job of taking care of my personal finances and affairs.

______ 8. I find it stressful that I can't keep up with all of the things I have to do each day.

______ 9. I am good at juggling my time so that I can fit everything in that needs to get done.

______ 10. My daily life is busy, but I derive a sense of satisfaction from keeping up with everything.

______ 11. I get frustrated when trying to plan my daily activities because I never accomplish the things I set out to do.

______ 12. My efforts to find the kinds of activities and relationships that I need have been quite successful.

______ 13. I have difficulty arranging my life in a way that is satisfying to me.

______ 14. I have been able to build a home and a lifestyle for myself that is much to my liking.

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| **strongly disagree** | **moderately disagree** | **slightly disagree** | **slightly agree** | **moderately agree** | **strongly agree** |

______ 15. I am not interested in activities that will expand my horizons.

_____ 16. In general, I feel that I continue to learn more about myself as time goes by.

_____ 17. I am the kind of person who likes to give new things a try.

_____ 18. I don't want to try new ways of doing things - my life is fine the way it is.

_____ 19. I think it is important to have new experiences that challenge how you think about yourself and the world.

_____ 20. When I think about it, I haven't really improved much as a person over the years.

_____ 21. In my view, people of every age are able to continue growing and developing.

_____ 22. With time, I have gained a lot of insight about life that has made me a stronger, more capable person.

_____ 23. I have the sense that I have developed a lot as a person over time.

_____ 24. I do not enjoy being in new situations that require me to change my old familiar ways of doing things.

_____ 25. For me, life has been a continuous process of learning, changing, and growth.

_____ 26. I enjoy seeing how my views have changed and matured over the years.

_____ 27. I gave up trying to make big improvements or changes in my life a long time ago.

_____ 28. There is truth to the saying you can't teach an old dog new tricks.

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| **strongly disagree** | **moderately disagree** | **slightly disagree** | **slightly agree** | **moderately agree** | **strongly agree** |

_______ 29. Most people see me as loving and affectionate.

_______ 30. Maintaining close relationships has been difficult and frustrating for me.

_______ 31. I often feel lonely because I have few close friends with whom to share my concerns.

_______ 32. I enjoy personal and mutual conversations with family members or friends.

_______ 33. It is important to me to be a good listener when close friends talk to me about their problems.

_______ 34. I don't have many people who want to listen when I need to talk.

_______ 35. I feel like I get a lot out of my friendships.

_______ 36. It seems to me that most other people have more friends than I do.

_______ 37. People would describe me as a giving person, willing to share my time with others.

_______ 38. I have not experienced many warm and trusting relationships with others.

_______ 39. I often feel like I'm on the outside looking in when it comes to friendships.

_______ 40. I know that I can trust my friends, and they know they can trust me.

_______ 41. I find it difficult to really open up when I talk with others.

_______ 42. My friends and I sympathize with each other's problems.

## Appendix J

## Details of Psychological Well Being scales chosen for the study

### *Environmental Mastery*

The partner of a brain injured person may need to take on many extra responsibilities both in caring for the inured person and in taking on the extra roles previously undertaken by the patient as well as their own original chores. Environmental mastery measures sense of mastery and competence in managing the environment, controlling the complex array of external activities, making effective use of surrounding opportunities and being able to choose or create contexts suitable to personal needs and values.

### *Personal growth*

There is some suggestion that individuals may actually grow and develop from experiencing traumatic events such as the struggles in coping with brain injury of a family member (Adams, 1996). This subscale measures the feeling of continued development, of seeing the self as growing and expanding, being open to new experiences, having a sense of realizing potential, improving self and behavior over time and increasing in self knowledge and effectiveness.

### *Positive relations with others*

The partner of a person with brain injury may experience social difficulties as a result of brain injury such as social isolation and a reduced social network (Lezak, 1988) This subscale measures the perception of having warm satisfying, trusting relationships with others, being concerned about the welfare of others and being capable of strong empathy, affection, and intimacy; understanding give and take of human relationships.

# Appendix K

## Dyadic Adjustment Scale

### Relationship Questionnaire - filled out by partner/spouse

Most persons have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your partner for each item on the list:

| | Always Agree | Almost always agree | Occasion-ally disagree | Frequent-ly disagree | Almost always disagree | Always disagree |
|---|---|---|---|---|---|---|
| 1. Handling family matters | 5 | 4 | 3 | 2 | 1 | 0 |
| 2. Matters of recreation | 5 | 4 | 3 | 2 | 1 | 0 |
| 3. Religious matters | 5 | 4 | 3 | 2 | 1 | 0 |
| 4. Demonstrations of affection | 5 | 4 | 3 | 2 | 1 | 0 |
| 5. Friends | 5 | 4 | 3 | 2 | 1 | 0 |
| 6. Sex relations | 5 | 4 | 3 | 2 | 1 | 0 |
| 7. Conventionality (correct or proper behaviour) | 5 | 4 | 3 | 2 | 1 | 0 |
| 8. Philosophy of life | 5 | 4 | 3 | 2 | 1 | 0 |
| 9. Ways of dealing with parents or in-laws | 5 | 4 | 3 | 2 | 1 | 0 |
| 10. Aims, goals & things believed important | 5 | 4 | 3 | 2 | 1 | 0 |
| 11. Amount of time spent together | 5 | 4 | 3 | 2 | 1 | 0 |
| 12. Making major decisions | 5 | 4 | 3 | 2 | 1 | 0 |
| 13. Household tasks | 5 | 4 | 3 | 2 | 1 | 0 |
| 14. Leisure time interests and activities | 5 | 4 | 3 | 2 | 1 | 0 |
| 15. Career decisions | 5 | 4 | 3 | 2 | 1 | 0 |

|  | All the time | Most of the time | More often than not | Occasion -ally | Rarely | Never |
|---|---|---|---|---|---|---|
| 16. How often do you discuss or have you considered divorce, separation or terminating your relationship? | 0 | 1 | 2 | 3 | 4 | 5 |
| 17. How often do you or your mate leave the house after a fight? | 0 | 1 | 2 | 3 | 4 | 5 |
| 18. In general, how often do you think that things between you and your partner are going well? | 5 | 4 | 3 | 2 | 1 | 0 |
| 19. Do you confide in your mate? | 5 | 4 | 3 | 2 | 1 | 0 |
| 20. Do you ever regret that you married? (OR lived together?) | 0 | 1 | 2 | 3 | 4 | 5 |
| 21. How often do you and your partner quarrel? | 0 | 1 | 2 | 3 | 4 | 5 |
| 22. How often do you and your partner "get on each others nerves"? | 0 | 1 | 2 | 3 | 4 | 5 |

|  | Every day | Almost every day | Occasion-ally | Rarely | Never |
|---|---|---|---|---|---|
| 23. Do you kiss your partner? | 4 | 3 | 2 | 1 | 0 |

|  | All of them | Most of them | Some of them | Very few of them | None of them |
|---|---|---|---|---|---|
| 24. Do you and your partner engage in outside interests together? | 4 | 3 | 2 | 1 | 0 |

How often would you say the following events occur between you and your partner?

|  | Never | Less than once a month | Once of twice a month | Once or twice a week | Once a day | More often |
|---|---|---|---|---|---|---|
| 25. Have a stimulating exchange of ideas? | 0 | 1 | 2 | 3 | 4 | 5 |
| 26. Laugh together? | 0 | 1 | 2 | 3 | 4 | 5 |
| 27. Calmly discuss something? | 0 | 1 | 2 | 3 | 4 | 5 |
| 28. Work together on a project? | 0 | 1 | 2 | 3 | 4 | 5 |

There are some things about which couples sometimes agree and sometimes disagree. Indicate if either item below caused differences of opinions or were problems in your relationship during the past few weeks (circle yes or no)

| | Yes | No |
|---|---|---|
| 29. Being too tired for sex | 0 | 1 |
| 30. Not showing love | 0 | 1 |

31. The numbers on the line represent different degrees of happiness in your relationship. The middle point, "happy", represents the degree of happiness of most relationships. Please circle the dot/number which best describes the degree of happiness, all things considered, of your relationship.

| 0 | 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|---|
| Extremely Unhappy | Fairly Unhappy | A little Unhappy | Happy | Very Happy | Extremely Happy | Perfect |

32. Which of the following statements best describes how you feel about the future of your relationship? (Circle the number)

5 I want desperately for my relationship to succeed, and *would go to almost any length* to see that it does

4 I want very much for my relationship to succeed, and *will do all I can* to see that it does

3 I want very much for my relationship to succeed, and *will do my fair share* to see that it does

2 It would be nice if my relationship succeeded, but *I cant do more than I am now* to help it succeed.

1 It would be nice if it succeeded, but I *refuse to do any more than I am doing now* to keep the relationship going

0 My relationship can never succeed, and *there is no more than I can do* to keep the relationship going.

## Appendix L

### Rating of preinjury relationship satisfaction

| | Extremely Satisfied | Fairly Satisfied | Satisfied | Fairly UNsatisfied | Extremely UNsatisified |
|---|---|---|---|---|---|
| How satisfied were you with your relationship *before* the injury? | 5 | 4 | 3 | 2 | 1 |

### Rating of change in relationship satisfaction since injury

| | Much less satisfied | A little less satisfied | About the same | A little MORE satisfied | Much MORE satisfied |
|---|---|---|---|---|---|
| How satisfied are you with your relationship *now, compared to before the injury?* | 1 | 2 | 3 | 4 | 5 |

**Appendix M**

## Rating of financial strain

What is your approximate household net monthly income?

..........................................................................................................................

..........................................................................................................................

..........................................................................................................................

..........................................................................................................................

How much do you feel you struggle financially?

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Not at all | A little | Somewhat | A lot | All of the time |

# Appendix N

## Classifying Social Class

I Professional

(e.g. scientists, doctors, accountants, engineers, lawyers, lecturers). People in this category would normally hold a degree and professional qualification.

II Managerial and Technical

(e.g. technicians, administrators, managers, teachers, nursing)

III (N) Skilled – Non Manual

(e.g. clerical, secretarial, civil servant)

III (M) Skilled – Manual

(e.g. farmer, builder, carpenter)

IV Partly skilled occupations

(e.g. nursery nurse, care assistant, market worker)

V Unskilled

(e.g. labourer, shop assistant)

VI Other

(e.g. homemaking, student, unemployed)

## Appendix O

## Letter and Personal details form

Anne Whelan
[address]

[Date]

Dear

### Research - exploring the perspectives and experiences of partners after brain injury

I spoke to you recently on the phone. Thank you for thinking about taking part in this research. The following documents are enclosed in the pack you have received with this letter:

********************

**For you both to read and keep:**

A sheet entitled 'Taking part in research'
This is to help you decide whether to take part in the study.

An 'Information Sheet'
This gives you information about the research.

**For the partner/spouse to fill out and return to me:**

A 'Personal Details' sheet

'Rating the Patients Abilities' questionnaire

'Relationship Questionnaire'

'Well-Being Questionnaire'

**For you both to fill out and return to me:**

2 copies of a 'Consent form'
You sign one each (if you agree to take part in the study) and return both to me

2 copies of a questionnaire
- 'Partner Questionnaire' and 'Patient (person with brain injury) Questionnaire
These 2 questionnaires are designed to measure the functioning of a person who has sustained a brain injury (the 'patient').

I would be grateful if ***both of you could fill out your individual copies*** according to how you view the functioning of the person, in your couple, who has sustained a brain injury (the 'patient') and ***return them both to me***

i.e. the person who has had a brain injury must fill one out about how he/she thinks he/she is doing, and the partner must fill one out in respect of how he/she perceives the person with the brain injury is doing.

Please fill these out independently of one another; I am interested in your individual perspectives on things, even if they are different from each others or other peoples

IT IS IMPORTANT THAT YOU DO NOT INFLUENCE EACH OTHERS ANSWERS IN ANY WAY. If you need help to fill out the questionnaire, please contact me at X on X and I will be happy to do so. If I am not there, please leave a message and I will call you back. Alternatively you could ask another adult you know to help you BUT PLEASE DO NOT ASK YOUR PARTNER FOR HELP.

********************

I should be very grateful to you for agreeing to take part. I hope that the research may help others in a similar position to you in future, and you may find that you derive some benefit from taking part.

You should read all the information and return the questionnaires to me at the X as soon as possible, preferably in the next couple of weeks.

If you have got any queries, please contact me at X. If I am not there, leave a message and I will call you back.

Again, thank you ever so much for your time and help.

Yours sincerely,

**Anne Whelan**
Trainee Clinical Psychologist, UCL

# Personal Details

## Details about the person who has suffered the brain injury

Name of person with brain injury: ……………………………………………………………………

Address: ………………………………………………………………………………………

Telephone Number(s): ……………………………………………………………………

Age: ……………………………………………………………………

Sex: M / F

Cultural and religious background: ……………………………………………………

……………………………………………………

## Details of the partner

Name of partner: ……………………………………………………………………

Address: ………………………………………………………………………………………

Telephone Number(s): ……………………………………………………………………

Age: ……………………………………………………………………

Sex: M / F

Cultural and religious background: ……………………………………………………

……………………………………………………

## Details of brain injury

Date of brain injury: ……………………………………………………………

Details of brain injury (e.g. road traffic accident, fall, assault etc): …………………

………………………………………………………………………………………………………

………………………………………………………………………………………………………

………………………………………………………………………………………………………

**Background details**

How long were you together prior to the brain injury?: ......................................

Did you have any *severe* relationship problems before the brain injury? If yes, please give *brief* details (including if you had any relationship counselling)

..............................................................................................................
.

..............................................................................................................

..............................................................................................................

What is your approximate household net monthly income? ...........................

...........................................................................................................

How much do you feel you struggle financially?

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
| Not at all | A little | Somewhat | A lot | All of the time |

Were you together
at the time of the brain injury? Y / N

Are you still together? Y / N

Do you live together? Y / N

Are you married? Y / N

Have you got any children? Y / N

If yes, what are their names and ages, and do they live with you?...............
....................................................................................................
....................................................................................................
....................................................................................................

## Appendix P

### Missing data management

One item from the Patient Competency Rating Scale (PCRS) of a partner was missing. This was replaced with their average score across all other items in the total scale. The data for one item on the cognitive subscale of the Awareness Questionnaire (AQ) was missing for one patient. The average across existing items in that subscale was taken to replace the missing value. Eleven items were missing from the Dyadic Adjustment Scale (DAS) across participants, with no more than 50% of the items missing in any one subscale for any one participant. These missing values were replaced with their mean of existing scores across that subscale, with appropriate attention paid to the weighting of items. Data on the initial severity of injury was missing for three couples and the net monthly household income for 4 couples. These remained missing.