

UNIVERSITY OF STIRLING

Subjective Evaluation of Quality of Life after Brain Injury

Measuring quality of life and the impact of
response shift

(Volume 1: Main Text and References)

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Abbreviations

ABI	Acquired Brain Injury
ADL	Activities of Daily Living
BIGI	Brain Injury Grief Inventory
GCS	Glasgow Coma Scale
GOSE	Glasgow Outcome Scale Extended
HADS	Hospital Anxiety and Depression Scale
HRQoL	Health Related Quality of Life
ICU	Intensive Care Unit
INCOM	Iowa-Netherlands Comparison Orientation Scale
IPA	Interpretative Phenomenological Analysis
LOT-R	Life Orientation Test – Revised
MMSE	Mini Mental State Examination
MOS-SS	Medical Outcomes Study – Social Support
MSPSS	Multidimensional Scale of Perceived Social Support
NART	National Adult Reading Test
PCA	Principle Components Analysis
PCRS	Patient Competency Rating Scale
PGI	Patient Generated Index
PTA	Post Traumatic Amnesia
RBANS	Repeatable Battery for the Assessment for Neurological Status
SEIQoL-DW	Schedule for Evaluation of Individual Quality of Life (Direct Weighting)
SF-36	Short-Form 36 Health Survey
SF-36 - MCS	Short-Form 36 - Mental Component Summary
SF-36 - PCS	Short-Form 36 – Physical Component Summary
TBI	Traumatic Brain Injury
TICS	Telephone Interview for Cognitive Status
QoL	Quality of Life
QOLIBRI-OS	Quality of Life After Brain Injury Scale – Overall Scale

Abstract

Introduction: After a brain injury there are often long term consequences impacting on QoL. However, this is a complex issue influenced by many factors. As someone recovers and adjusts it is likely that the way in which they evaluate QoL will also change. The theory of response shift suggests people will change the way they evaluate QoL in the face of changes in their life. The aim of this thesis is to investigate what influences a QoL judgement; examining the possibility of response shift.

Methods: Quantitative and qualitative methods were used in 4 studies. These were a cross-sectional design utilising an individualised QoL measure (SEIQoL-DW); a longitudinal study utilising a 'then-test' approach; a cross-sectional questionnaire study; and a qualitative study using Interpretative Phenomenological Analysis.

Study 1 (Ch.3) Results: Correlations between the QoL measures confirm the validity of the SEIQoL-DW; however, correlations were generally stronger for the simpler Hadorn Scale. There was little overall change in mean QoL when current and retrospective judgements were compared. There was evidence for a change in what areas of life were considered most important to QoL following injury.

Study 2 (Ch.4) Results: Improvements in reported QoL between baseline and follow-up were small. A then-test indicates that any effect of response shift is small, and non-significant in the current research. There was also little evidence for reprioritisation or re-conceptualisation. Examination of other factors associated with QoL suggest that brain-injury specific factors (BIGI, RBANS) play a role in predicting QoL.

Study 3 (Ch.5) Results: QoL was reported as worse post-injury on both Hadorn's scale and the QOLIBRI-OS; a difference that was more pronounced on the QOLIBRI-OS. Differences

were also reported in the importance of different areas of functioning. Change in QoL as measured by the QOLIBRI-OS was significantly influenced by disability as measured by the GOSE, emotional and informational support, and upwards social comparison. Optimism as measured by the LOT, but not upwards social comparison was a significant predictor of change on Hadorn's scale; GOSE and emotional and informational support remain significant predictors. The GOSE, emotional and informational support, emotional coping styles and optimism were significant predictors of current QoL on the QOLIBRI-OS; and emotional and informational support and optimism were significant predictors of QoL on Hadorn's scale. Little evidence was found to suggest that the factors proposed in Sprangers and Schwartz's (1999) model of response shift have predicted relationships with QoL. Two candidate variables were studied: optimism and social support. However neither showed the predicted pattern of relationships. Nonetheless the study supports previous work indicating an influence of optimism and social support on QoL, and indicates that these warrant further study.

There were systematic difference between current and retrospective ratings of importance of domains. The level of importance given to the areas of life defined by the QOLIBRI-OS is higher after injury than before, with the exception of "personal and social life" for which there is no significant difference. The areas of life chosen to reflect that which is measured by the GOSE ("work", "close relationships", and "social and leisure activities") are rated as less important with the exception of "close relationships". These findings provide further support for the idea that QoL domains are re-evaluated after brain injury.

Study 4: This was an in depth qualitative investigation of the experience of recovery and adjustment following TBI. Semi-structured interviews and Interpretative Phenomenological

Analysis (IPA) were used. Interviews were conducted with 4 men who were 3, 7, 12, and 18 years post injury.

Main Outcome and Results: Themes emerging from the analysis were 'Change: In Self and World'; 'Reaching a point of realisation'; 'Support'; 'Adjusting to change/Coping with day to day life'; and 'Participation, Goals and Focus'. These themes cover how participants felt both they and their lives had changed as a consequence of their injury; ways they went about coping and adjusting to changes; the importance of support; and the significance of social integration and participation in feeling satisfied with life.

Summary and Conclusions: These studies provide evidence for response shift in different ways. There is little evidence for recalibration but there is some indication that reprioritization or reconceptualization may take place. Changes in how important different areas of life are before and after injury suggest that participants are changing the way they view and make evaluations of QoL.

Factors identified as being important to QoL judgements were disability, social support (emotional and informational support identified in the questionnaire study and support in the IPA), upwards social comparison, and optimism. The IPA study suggests that functional outcome and participation are important after TBI; while also identifying ways of coping and providing an insight into the experience of recovery from brain injury.

The different QoL measures used provides both evidence for their validity, but also evidence for the different conceptualisations of QoL that are measured by different instruments. The findings have implications both for understanding the QoL of the individual and for research on QoL after TBI.

Chapter 1: Introduction to Quality of Life after Brain Injury

Introduction and Chapter Aims

The aim of this chapter is to provide background to acquired brain injury, and in particular to traumatic brain injury (TBI). This chapter will describe the literature surrounding the impact of TBI on peoples' lives and examine quality of life (QoL) following brain injury. Background will be provided about the concept of response shift, a phenomena that can influence subjective reporting on QoL measures.

Brain Injury

What is Brain Injury?

Acquired Brain Injury (ABI) is a general term covering a variety of types of brain injury occurring after birth, but excluding neurodevelopmental and neurodegenerative disorders. Two types of brain injury are referred to in this thesis; the broad category of ABI and the more specific sub category of traumatic brain injury (TBI). The majority of this research deals with TBI and the consequences of TBI, however the study reported in chapter 5 also includes participants who have a brain injury of other causes. While there are clear differences in the way in which these injuries occur and manifest there are often substantial similarities in the processes an individual must go through as they adjust to the consequences of their injury, especially when an ABI occurs at a younger age. The overall focus of this introduction is on the impact and adjustment to the effects of TBI, reflecting the emphasis of the subsequent studies.

Traumatic brain injury occurs when the brain is injured by an external force, for example through a fall, road traffic accident or assault. It thus differs from other types of acquired

brain injury such as strokes, infections, tumours or hypoxia. TBI may be further complicated by secondary damage which can involve further bleeding (e.g. subarachnoid haemorrhage), swelling of the brain, and increased intracranial pressure (Hannay et al., 2004; King & Tyerman, 2003; Lingsma et al., 2010). In severe TBI the consequences can also be severe and long lasting (Ponsford et al., 2008; Sloan et al., 2007; Colantonio et al., 2004). However, even though the majority of people who have a mild TBI will make a full recovery, having a mild injury does not necessarily mean that there will not be long term consequences (Tsushima et al., 2009; King & Tyerman, 2003). The recovery process following a TBI is difficult to predict, due to the heterogeneous nature of the many factors involved: cause and site of injury, the presence of any secondary damage, the way in which it was treated and the individual nature of the patient themselves. Problems resulting from a TBI may include cognitive difficulties, particularly deficits of attention and memory, emotional distress, fatigue, and executive difficulties (Hux et al., 2009; Hannay et al., 2004; Gouick & Gentleman, 2004).

While individual recovery processes differ there are unfortunately a significant proportion of people who will be left with long lasting difficulties as a direct consequence of their injury. Where gains cannot be made in an individual's level of functioning there will be a requirement for long term strategies and support systems to assist that individual and their family and/or carer on a day to day basis (Greve et al., 2002; Ylvisaker et al., 2007; Kolakowsky-Hayner et al., 2001; Lefebvre et al., 2008).

Prevalence of TBI

TBI may affect people from all walks of life; however, there are higher levels of TBI in some sociodemographic groups. Importantly, TBI is typically commoner in males than females (around 3:1), and is more likely to occur in the younger (15-24) and older (65+) age groups. Motor vehicle accidents tend to be the leading cause of severe TBI, however causes of TBI

differ depending on age group, with a higher proportion of those in the older age group being due to falls (King & Tyerman, 2003; Lee & Stark, 2008; Hannay et al., 2004). TBI is more often found in populations from areas of higher deprivation, with injuries more likely to be caused by an assault, and with individuals more likely to have a history of alcohol or substance abuse (Herbert, 2007; Minns et al., 2008; Dunn et al., 2003; Yates et al., 2006).

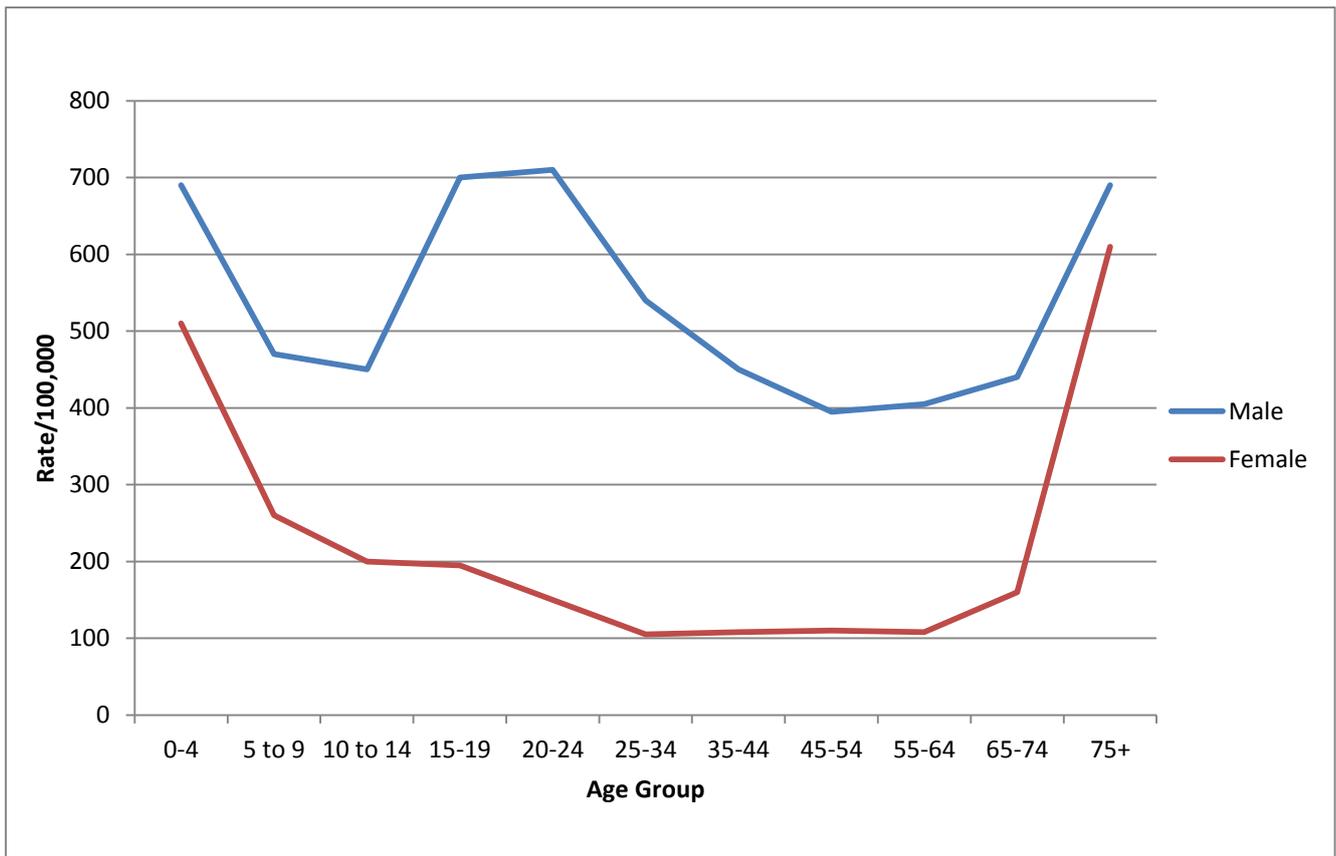


Figure 1.1: Rates per 100,000 of head injury related diagnosis in Scotland. Average annual admission rate by age group 1997/8-2006/7. Reproduced from (Lee & Stark, 2008).

In Scotland in the 10 years from 1997 to 2007 there were 175,458 admissions to hospital following a head injury (Lee & Stark, 2008). Of these 70.3% involved males. For a summary of the rates of hospital admissions into Scottish Hospitals in the years 1997-2007 across different age groups and broken down by gender see Figure 1.1. This figure shows that

there are higher rates of TBI in young men aged between 14 and 24, and that the numbers of TBIs increase in both men and women above the age of 65. This pattern is consistent with that which would be expected from the literature, with the higher levels of TBI in young men most likely being through road accidents and assaults, and the increased rates of TBI in the older population being due to falls (Hannay et al., 2004; King & Tyerman, 2003; Herbert, 2007; Tokutomi et al., 2008; Jacobsson et al., 2007).

Measuring Severity of injury

The severity of a TBI is conventionally described through the use of Glasgow Coma Scale (GCS) and/or post traumatic amnesia (PTA), while brain imaging techniques play a lesser role (Sherer et al., 2008; Caton-Richards, 2010; National Institute for Health and Clinical Excellence, 2007; Hannay et al., 2004; Marshall et al., 1991). The Glasgow Coma Scale (Teasdale & Jennett, 1974) allows for classification of the severity of injury based on levels of consciousness. The GCS is perhaps the most common indicator used to assess severity of injury, and the one used by emergency services and hospital staff when treating a patient with a head injury. The GCS gives a score out of a total possible of 15, with the lowest possible score being 3. The GCS sum score of 15 is composed of 3 components: eye-opening, verbal and motor response on each of which the patient is given a rating. There is some debate over which GCS score should be reported when discussing the severity of injury: GCS at the scene, on admission to hospital, or the 24 hours worst GCS (National Institute for Health and Clinical Excellence, 2007; Zuercher et al., 2009; Sherer et al., 2008). A GCS of 13-15 conventionally represents a mild injury, 9-12 a moderate injury and 3-8 a severe injury. It has become common to further classify GCS 13-15 with evidence of intracranial abnormality as 'complicated mild TBI' as outcome is more often of a level similar

to that of someone who has had a moderate injury as defined by the GCS alone (Williams et al., 1990).

PTA is taken as the period of time where the patient is unable to form continuous memories (Hannay et al., 2004). Table 1.1 demonstrates how the period of PTA corresponds with the severity of injury. PTA may be assessed by a series of orientation and memory tests, but is perhaps more commonly estimated retrospectively by interview. While there is some controversy surrounding the best way to assess PTA, high levels of correlation have been reported between these two methods (Brown et al., 2010; McMillan et al., 1996; Andriessen et al., 2009; Ashla et al., 2009).

Table 1.1: Estimates of Severity of Injury Based on Posttraumatic Amnesia (PTA) Duration (Hannay et al., 2004):

Severity of Injury	PTA Duration
Very mild	<5 minutes
Mild	5-60 minutes
Moderate	1-24 hours
Severe	1-7 days
Very Severe	1-4 weeks
Extremely Severe	More than 4 weeks

The GCS is perhaps the most widely used indicator of injury severity, however there are pros and cons to using both the GCS and PTA. There is increasing appreciation that while the GCS is a useful clinical tool, it does not provide a complete classification of injury severity even when supplemented by neuro-imaging results (Saatman et al., 2008). While there is some connection between injury severity and long term outcome the relationship is not a simple one. PTA can be obtained easily but may be subject to error in recollection.

Outcome from TBI

TBI can have a profound effect on the individual's life: high levels of disability and functional impairment, difficulties resuming social and leisure activities, relationship difficulties and marriage breakdown (Thornhill et al., 2000; Dikmen et al., 2003; Koskinen, 1998; Wood & Yurdakul, 1997). Return to work is often difficult, if it is possible at all (Tsaousides et al., 2008; Wehman et al., 2005). There may be changes in the person themselves, with self perception changing, problems with emotional control and personality change (Tyerman & Humphrey, 1984; Kersel et al., 2001; Yeates et al., 2008; Stuss et al., 1992). Patients may lose their sense of 'self' and have difficulty redefining themselves and their role in society; this can lead to further emotional difficulties (Vickery et al., 2005; Wood & Rutterford, 2006; Landau & Hissett, 2008; Chamberlain, 2005). TBI can also have a profound impact on the life of their family and others around them (Svendsen et al., 2004; Lezak, 1987).

Herbert (2007) states that 0.37 per 100,000 of the population require long term care as a consequence of TBI. King and Tyerman (2003) suggest that as many as 1 family in 300 has a member with persisting disability following head injury. Ghajar (2000) reports that of the 1.6 million TBI's that occur in the USA every year 80,000 will result in permanent neurological disability. The numbers of people who are affected in the long term as a result of TBI and the debilitating impact of injury means that there is a strong imperative for gaining a better understanding of how the most positive outcome may be achieved.

Factors influencing functional outcome from TBI

A wide variety of factors are known to affect outcome after TBI, and some of the most important are described in the following sections. Despite the many studies that have been conducted much of the variance in outcome remains unexplained (Lingsma et al., 2010).

Severity

It perhaps goes without saying that the severity of injury is related to outcome with increased severity being associated with poorer outcome, but the relationship is not always a simple one. Especially in the early stages post injury, injury severity is a strong predictor of outcome (Jacobsson et al., 2009; Sigurdardottir et al., 2009; Andelic et al., 2009; Ponsford et al., 2008; Lingsma et al., 2010b; Horneman & Emanuelson, 2009; Sherer et al., 2006; Teasdale & Engberg, 2005). Furthermore complications to the original injury, in terms of secondary injury or structural abnormalities as a consequence of the original insult will also impact on the outcome from injury (Lingsma et al., 2010; Ghajar, 2000). While injury severity is consistently reported as being one of the best predictors of outcome the very individual nature of both injuries and the individuals to which they occur mean that there are a number of cases who may have a severe injury and yet make a good (or better) recovery; equally those who have an apparently mild injury may report long term negative consequences (Tsushima et al., 2009; King & Tyerman, 2003). There are also reports that long term morbidity following a TBI are increased, regardless of levels of severity (Cameron et al., 2008).

Age

The literature shows that having a TBI at an increased age is generally associated with poorer outcomes (Senathi-Raja et al., 2010; Tokutomi et al., 2008). This may be due to differences in plasticity, that is the younger brain's ability to form new connections

(Schönberger et al., 2009; Tokutomi et al., 2008; Levin, 2003; Senathi-Raja et al., 2010).

Increased age is associated with long term cognitive impairment, with a greater difference between older TBI patients and their age-matched controls (Senathi-Raja et al., 2010). Older patients have a higher rate of mortality (Tokutomi et al., 2008). Larger and more frequent brain lesions have been reported in older patients, which in turn will lead to poorer outcomes (Schönberger et al., 2009; Tokutomi et al., 2008).

While this association between age and outcome from TBI may be true for adults it might not apply in the same way to children who suffer a TBI. There is evidence from work with children to suggest the opposite, that is that younger children may have poorer outcomes, especially relating to executive functioning (Sonnenberg et al., 2010; Anderson & Catroppa, 2007).

In adults there may also be some exceptions to the pattern of increased age being associated with poorer outcome: higher levels of psychiatric morbidity have been reported in younger patients following TBI (Deb & Burns, 2007). However these results to appear to go against the general trends associated with outcome. Despite the question over whether age is a factor related to outcome in children, the evidence from the literature relating to adults seems to be fairly conclusive that increased age is associated with a poorer outcome (Jacobsson et al., 2009; Sherer et al., 2006; Senathi-Raja et al., 2010; Lingsma et al., 2010).

Pre-morbid functioning and Cognitive Reserve

There is evidence that where a person has higher levels of pre-morbid functioning, in that they have higher levels of cognitive ability, intelligence and education, they will have a better outcome after injury (Sigurdardottir et al., 2009; Kesler et al., 2003). Education level along with injury severity has been reported to be the most significant predictor of language impairments following TBI (LeBlanc et al., 2006). Higher education levels are often

associated with better outcome after TBI, in terms of employment, productivity and disability levels (Sigurdardottir et al., 2009; Ponsford et al., 2008; Draper et al., 2007; Gollaher et al., 1998; Kesler et al., 2003; Wagner et al., 2002). Higher levels of education are also associated with better memory and cognitive functioning (Sherer et al., 2006; Fay et al., 2010; Kesler et al., 2003). Furthermore, Kesler et al (2003) found evidence to support the theory of cognitive reserve in their MRI study, finding that increased brain size was associated with higher IQ. From this they concluded that a greater pre-morbid brain size helps to protect against the effects of TBI.

The main problem to be faced when assessing the possible impact of cognitive reserve is that it will only ever be possible to gain an estimate of pre-morbid functioning. Estimates of pre-morbid functioning can be made in a number of ways, including evidence of pre-morbid achievements, demographic variables including social class and education (known to be related to performance on IQ tests), and word reading tests such as the National Adult Reading Test (Franzen et al., 1997; Bright et al., 2002). Studies such as that by Kesler et al (2003) provide some alternative by looking at the physical characteristics of the brain, but even these cannot provide a comprehensive picture.

Gender

While there is without a doubt a greater incidence of males that will have a TBI the evidence surrounding the influence of gender on outcome is not conclusive. A review of the literature conducted by Lingsma et al (2010) concluded that the majority of evidence suggests that there is little difference in prognosis after TBI depending on gender. This is reflected in other studies (Moore et al., 2010b; Corrigan et al., 1998). Results suggest that cognitive functioning after TBI does not differ depending on whether the individual is male or female (Moore et al., 2010). While there is some evidence to suggest that outcome may be poorer

for females (Farace & Alves, 2000; Bounds et al., 2003; Wood, 2008), there are other findings which indicate it may be better (Slewa-Younan et al., 2008). It may be that age has a part to play in the effects of gender with older women (>30) showing a poorer recovery (Wood, 2008).

Social Deprivation

Where individuals come from an area of greater social deprivation it has been reported that while there is no difference in levels of illness, there are differences in levels of alcohol abuse, and they are more likely to have been injured through an assault (Dunn et al., 2003). There are also differences in both the patterns and treatment of TBIs in patients from more deprived areas: they are less likely to be treated in ICU, less likely to receive neurosurgery, but also more likely to survive (Dunn et al., 2003).

Difference in geographic location might also have an impact through variation in access to services (Spearman et al., 2007). In children better family environments have been reported to be associated with better outcomes following TBI (Gerrard-Morris et al., 2010)

Quality of life as an outcome measure

Quality of life is often used as an outcome measure in health care research, although less often employed in the specific context of brain injury. The term 'Health Related Quality of life' (HRQoL) is used in the literature in a range of different health conditions to refer to the influence that they have on an individual's QoL. The World Health Organisation (WHOQOL Group, 1995) describes QoL as: *"an individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns"*.

Quality of life is a key way of measuring outcome as it addresses issues that are perhaps of greatest importance to the patient. Individuals may conceptualise and perceive quality of life in very different ways which can be problematic when trying to address the issue of quality of life on a more general level (Browne et al., 1997; Brown et al., 1996; Sprangers & Schwartz, 1999). It has been reported that objective measures used by healthcare professionals often bear little resemblance to a patient's functioning in day to day life, with patients who may appear to be similar on a functional level reporting very different perceptions of their daily quality of life (Guyatt et al., 1993). Quality of life is a multi-dimensional concept that may be addressed from a number of perspectives (Dijkers, 2004). Historically the TBI field has been dominated by objective measures of functional outcome; for example assessed by the Glasgow Outcome Scale (Jennett & Bond, 1975). This allows individuals to be categorized into levels of disability based on the impact their injury has in their daily lives; whether this is independence in the home, ability to work, or other ways in which their injury has affected them. Recent interest in quality of life has made subjective measures popular (Dijkers, 2004). This may relate, for example, to overall satisfaction with life, or satisfaction with different areas of functioning. It is assumed that this subjectivity gives a better understanding of the impact an experience has had on the individual. When

investigating a subjective appraisal of quality of life on an individual level there are a number of instruments that are designed to allow the respondent to nominate the domains that are important to them, and in this way it may be possible to obtain a clearer picture of individual differences, e.g. the Schedule for Evaluation of Individual Quality of Life (SEIQoL; Hickey et al., 1996) or the Patient Generated Index; PGI (Ruta et al., 1994). This approach has a number of benefits in that people conceptualise QoL in different ways and by using an individualised measure some of these differences may be captured (Sprangers & Schwartz, 1999; Browne et al., 1997). There are also global measures in which the individual rates their quality of life on a simple scale from worst possible to best possible, or from delighted to terrible (Cantrill, 1966; Andrews & Robinson, 1991; Hadorn & Uebersax, 1995; Hadorn et al., 1995). These global assessments of quality of life have been described as being useful as they allow the individual to rate their quality of life in a way that is relevant to them rather than using an externally imposed concept (Hadorn et al., 1995). Allowing this individualised conceptualisation of QoL gives a measure that is similar in this respect to the individualised measures previously mentioned. There is also the advantage of a global measure being very short and easy to complete which is often of benefit in encouraging responses.

There are a number of disease-specific questionnaires that have been developed that are designed to examine the issues affecting different patient groups; for example those with cancer (Aaronson et al., 1993; Cella et al., 1993) asthma (Juniper et al., 1996), epilepsy (Devinsky et al., 1995), or indeed brain injury (von Steinbuechel et al., 2005; von Steinbuechel et al., 2010). This is especially useful when assessing the impact of a particular condition or comparing individuals within a specific patient group. The Quality of Life in Brain Injury Scale (QOLIBRI) is a TBI-specific scale in which the individual rates their satisfaction relating to their physical condition, their cognition, their feelings and emotions, their ability to carry out day to day activities, their personal and social life and their current

situation and future prospects (von Steinbuechel et al., 2005; von Steinbuechel et al., 2010; von Steinbuechel et al., 2012)

HRQoL may also be assessed on domains that are more broadly applicable, with measures that are designed to address a wide cross-section of the population. An example of this is the Medical Outcomes Study Short-Form-36 (Ware & Sherbourne, 1992; Ware et al., 1993). The SF-36 addresses questions relating to overall physical and mental health and the impact these have on the individual's life. It has been tested in a TBI population and found to be a reliable and valid measure (Findler et al., 2001). Other examples of generic quality of life measures are the World Health Organisation Quality of life instruments, or WHOQoL (World Health Organization, 1998), the Sickness Impact Profile (Bergner et al., 1981), and the Nottingham Health Profile (Hunt et al., 1981). These generic quality of life measures are not specifically designed for people who have had a brain injury, nor are they designed to elicit the issues specifically relevant to the individual who is completing it.

The influence that cognitive impairment may have on reporting QoL measures requires consideration. It is apparent that there will be a point where the level of cognitive impairment may impair the ability of an individual to evaluate their QoL. Riemsma et al (2001) reviewed the evidence on use of health status measures in people with cognitive impairment. They concluded that there was little validation of health status measures in cognitively impaired populations. They also concluded that in those studies where more than half of participants were cognitively impaired the evidence for validity of the instruments was generally weaker. Results from measures which have not been validated in a cognitively impaired population should be interpreted with caution when applied to a TBI sample, because they are at best poorly understood. Subsequent work has validated a number of measures in TBI. When the SF-36 was investigated in patients with a TBI it was found to be reliable, with Cronbach's α ranging from 0.83 to 0.91 for those with mild TBI and

from 0.79 to 0.92 for those with moderate to severe TBI (Findler et al., 2001). However stronger correlations were apparent between cognitive functioning and the SF-36 subscales in those who had had a brain injury compared to the comparison group.

In the development of the QOLIBRI the internal consistency and test-retest reliability were comparable between subgroups of patients with lower cognitive ability (MMSE<28, TICS<33) and those in normal ranges (von Steinbuechel et al., 2010). A study of 141 adults with TBI of varying severity suggested that the influence of impaired self-awareness, assessed using the Patient Competency Rating Scale, on the QOLIBRI was relatively modest (Sasse et al, 2013). At present there is enough evidence to support the use of self-report QoL measures with people with a level of cognitive impairment to justify their application in TBI.

There is a view in the literature that the use of proxies may be of benefit (Addington-Hall & Kalra, 2001; Selai & Trimble, 1999). On the other hand it can be argued that discrepancies may be reported between the QoL reported by a patient and that reported by an observer, and thus that proxy reports cannot be substituted for the patients' perspective (Sands et al., 2004; Buckley et al., 2012). There is a view that the patient should be considered the expert on their condition regardless of cognitive impairment (Brown & Gordon, 2004).

Regardless of the approach that is taken, cognitive impairment is clearly an issue which should be borne in mind when conducting research with individuals with TBI. The precise influence of cognitive impairment on quality of life judgements in people with TBI has yet to be fully elucidated.

Positive Outcomes following TBI

Factors influencing QoL after TBI

While it is to be expected that functional outcome has a significant influence on quality of life after a brain injury, factors which are not directly related to functional abilities may also have an impact. Influences on QoL after brain injury include emotional status, cognitive impairment, and TBI symptoms such as fatigue (Truelle et al., 2010).

There are many factors which will have an influence on QoL after a brain injury; ranging from health perceptions and self-concept (Steadman-Pare et al., 2001; Vickery et al., 2005), ability to engage in day to day life (McCarthy et al., 2006; Corrigan et al., 2001), and return to work (Steadman-Pare et al., 2001; Oppermann, 2004). These influences have been reviewed in the literature (Dijkers, 2004; Berger et al., 1999). However, there is evidence from the literature that people who have had a TBI sometimes report satisfaction with life that is better than might be expected (Koskinen, 1998; Jones et al., 2010; Mailhan et al., 2005; Hawley & Joseph, 2008; McGrath, 2004).

Mailhan et al (2005) report a paradoxical relationship between level of disability and satisfaction with life. In this study of 74 participants with TBI life satisfaction was investigated as a cognitive appraisal of the individual's situation in life across different domains: functional life, social life, material life and spiritual life using the Subjective Quality of Life profile (Dazord et al., 1998), cognitive impairment, disability (using the Glasgow Outcome Scale Extended, and Disability Rating Scale) and independence in activities of daily living (ADL). A principal components analysis was conducted on contributing factors to better understand life satisfaction after TBI. They identified 3 factors which contributed to overall satisfaction: social and family relationships (accounting for 23.1% of the variance), physical health, functional status and self-image (8.5%) and cognition and inner life (6.2%). When they compared reported life satisfaction of participants with different levels of

disability they also made paradoxical findings. Mailhan et al (2005) report that individuals with moderate disability reported the lowest levels of life satisfaction, with participants with severe disability not differing significantly in their reported life satisfaction from those with a good recovery. This finding was mainly due to high satisfaction with social and family relationships: participants with severe disability did not report being satisfied with other areas of functioning (physical health/functional status and cognition/inner life). The authors suggest that this difference might be due to individuals with severe disability having lower expectations in that they do not compare with their pre-injury life in the way that someone with a moderate disability might. The authors relate their findings to studies of other medical conditions (Dazord et al., 1996); individuals report lower satisfaction on domains related to their illness, but report satisfaction close to that of a healthy population for relationship domains.

Reports of apparently paradoxical relationships between severity of injury and QoL are not unusual in the literature. Findler et al (2001) found lower SF-36 scores in patients with mild injury than those with moderate or severe injuries. A U-shaped trend with severity of injury was found by Hawley and Joseph (2008). They followed up 165 TBI survivors 9 to 25 years post injury and found that participants who had had a moderate TBI reported lower levels of positive change in their outlook than those who had a mild or severe injury. Here the authors suggest the result is due to those individuals who had a moderate injury having to struggle with changes in their identity in the same way that those with more severe injury, however at the same time they had to fulfil their pre-injury social roles in life leading to difficulties in adjustment. A limitation of this study is that the number of cases with moderate injury was relatively small (N=24).

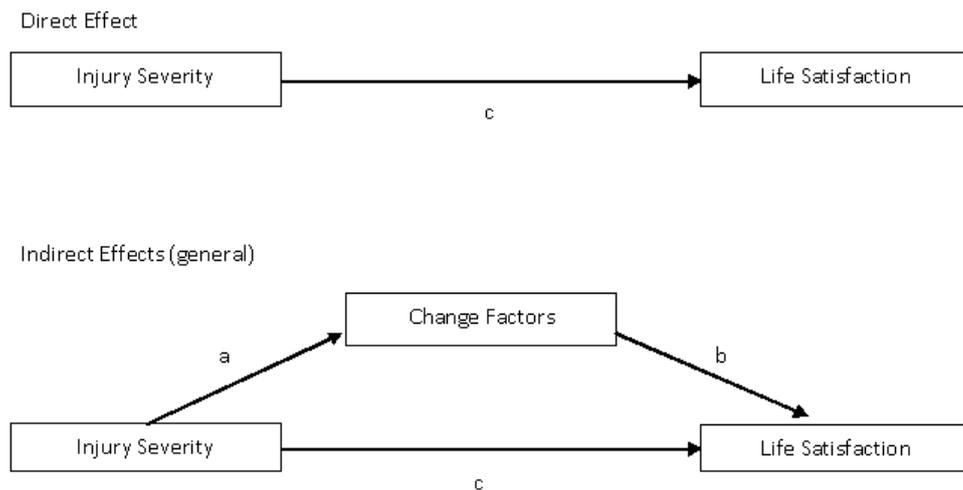
A recent study published by Jones et al (2010) investigated the effects of injury severity on life satisfaction in 630 individuals with ABI recruited through the brain injury charity

'Headway'. They developed a brief questionnaire the Trauma and Recovery Experiences Assessment Tool (TREAT) to investigate the impact of personal and social changes on perceived QoL. They used questions designed to address changes in personal identity: 'having had a brain injury has made me a stronger person' and 'I think of myself as someone who has survived a brain injury' (survivor identity); and questions to investigate change in social networks. Paradoxically they found that life satisfaction was significantly positively associated with injury severity. The study by Jones et al (2010) is particularly interesting as it begins to provide evidence for potential mechanisms that may underlie these findings.

Jones et al's (2010) results indicate that identity strength, survivor identity, number of improved relationships and support services were significant mediators of the association between injury severity and life satisfaction (see figure 1.2). They argue that personal and social factors buffer the effects of injury severity. On this account people with severe injuries report higher life satisfaction because they have more sense of being a 'survivor' and a feeling of greater personal strength, along with a belief that they have stronger relationships and more support. Where these results differ from those of Mailhan et al (2005) is that they look at injury severity rather than level of disability; however they begin to provide an explanation for these paradoxical findings.

The model proposed by Jones et al (2010) for indirect effects (Figure 1.2) includes a mediator variable. Mediation refers to the way the relationship between an independent and a dependent variable may be accounted for either partially or completely by a third variable. There are similarities between the mediational effect described by Jones et al (2010) in their model and the Sprangers and Schwartz (1999) model of response shift that is considered in the context of this thesis. The Sprangers and Schwartz (1999) model involves elements of both mediation and moderation and these concepts and analytical approaches will be considered later (Chapter 5). Jones et al (2010) employed both Baron and Kenny's (1986)

approach to mediation along with bootstrapping techniques as described by Preacher and Hayes (Preacher & Hayes, 2004; Preacher & Hayes, 2008). The Preacher and Hayes (2008) approach allows for the indirect effects of multiple mediators to be examined.



Conceptual framework of the mediation effect of change on the relationship between injury severity and well-being. From Jones, Haslam, Jetten, Williams, Morris and Saroyan (2010).

Figure 1.2: Conceptual framework of the mediation effect of change on the relationship between injury severity and well-being. From (Jones et al., 2010)

Lack of Awareness and reported quality of life

Anosognosia or a lack of awareness of deficits could also be an explanation for the paradoxical findings surrounding quality of life after acquired brain injury. It is well documented that some individuals are not fully aware of their ability level or the negative impact that their injury has had on their life (Prigatano, 2005; Prigatano, 1991).

Furthermore, there is evidence that patients rarely complain of cognitive or emotional and behavioural problems even when these difficulties are frequently observed by others (Sbordone et al., 1998). In relation to quality of life Koskinen (1998) reports that individuals

with low levels of awareness (measured by the Patient Competency Rating Scale, PCRS) following TBI report high levels of satisfaction with life, however their relatives report high levels of strain. It has been reported that emotional problems increase with severity of injury except in the most severe groups who show a lack of awareness of any problems (Golden & Golden, 2003). Despite this, there is also evidence that problems of awareness are more prevalent in the earlier stages post injury (Fleming & Strong, 1999; Newman et al., 2000; Godfrey et al., 1993).

It has been found that TBI patients showed poorer memory performance than age, sex and education matched controls, but that they were aware of this fact. It should also be noted that at 2-10 months post injury this was in the relative early stages of recovery (Livengood et al., 2010). Dirette and colleagues (Dirette & Plaisier, 2007; Dirette et al., 2008) have found that patients with mild TBI tend to over-estimate the extent of their deficits, while those with more severe injuries under-estimate these in the early stages after injury. However those with more severe injuries gradually gain awareness of their difficulties as time progresses.

A longitudinal study was conducted to investigate how awareness changes in the first year post injury in 123 participants with moderate to severe injury (mean GCS was 7.5), and to investigate what baseline factors were associated with awareness at follow up (Hart et al., 2008). It was found that differences between self and significant other ratings on the PCRS were significant at both baseline and follow up, but the difference was greater at baseline. The same pattern was apparent with the Awareness Questionnaire. Correlations between self and significant other responses were greater at follow-up than they were at baseline.

Pagulayan et al (2007) also used a longitudinal study to address the question of awareness after TBI. They were interested in gathering information from a wide range of people with TBI so as not to specifically select those who receive inpatient rehabilitation. Participants

were 120 individuals with complicated mild to severe TBI admitted consecutively to a trauma centre, along with their significant other. The Sickness-Impact Profile (Bergner et al., 1981; Gilson et al., 1975) was completed by participants, and by their significant other with reference to the participant. Discrepancies between reports were used as the measure of awareness. They found a high level of consistency between the participant and their significant other on the SIP at 1 month post injury; around 10% of participants were under-reporting symptoms at this time. In fact, whilst not significantly different they found that participants tended to report a higher level of problems than did their significant other. They did however find that there was a slightly decreased level of awareness in the psychosocial domain in relation to the physical domain. By one year post injury they found that levels of both reduced awareness and hyperawareness had declined.

Fleming and Strong (1999) reported impaired awareness at 3 months but improvement at 12 months. Similarly Newman et al (2000) found problems on admission to rehabilitation but not on discharge; and Godfrey et al (1993) found impaired awareness in persons with TBI at 1 year post injury, but not at 2 or 3 years.

Without ruling out the possibility that a lack of self-awareness may account for some of the positive reports of satisfaction with life, there is an increasing level of argument emerging from the literature to suggest that there are other factors that contribute to positive reporting of life satisfaction or quality of life. These are more related to psychological changes than to a simple lack of awareness. Jones et al (2010) argue that if an individual sees their injury as a source of strength then this implies an awareness of the difficulties and challenges that their injury has caused them to face. Jones et al (2010) argue that the only way that their results can make sense is if the participants did have an awareness of their difficulties. Collicut, McGrath and Linley (2006) report that increased anxiety is associated with positive changes after injury. They cite participants' willingness to volunteer

information on negative aspects of their recovery as being evidence that the participants in their study were aware of their condition.

To investigate further the possibility that poor awareness led to reporting of higher life satisfaction Mailhan et al (2005) used the 'poor self-appraisal' score of the Neurobehavioural Rating Scale – Revised (Vanier et al., 2000). While they did find that there was a higher level of anosognosia in the severe disability group, there was not a significant correlation between anosognosia and life satisfaction (Spearman rank correlation coefficient: $\rho=-0.1$, $p>0.1$)

Mechanisms underlying positive changes

Qualitative research investigating positive changes provide some insight into how such changes may occur. For example Muenchberger et al (2008) conducted an Interpretative Phenomenological Analysis (IPA) using 'life story' interviewing. They recruited 6 individuals with TBI chosen to represent different time periods since injury, ranging from 1 to over 25 years. The consequences of all injuries are described as 'significant' determined by self-reports of time spent in rehabilitation. In conducting their interviews they asked participants to describe their life story by dividing it into 'chapters'. This methodology allowed them to contextualise the information and examine the individual's sense of identity at different points in their life. In this study they looked specifically at people who had a positive productive outcome and examined the processes they went through to reach a 'positive' outcome. Their analysis suggested that individuals had to come to terms with the loss of identity and then redeveloped a new identity for their post injury self.

Another Interpretative Phenomenological Analysis by Shotton et al (2007) examined the experiences of 7 men and 2 women who had had a TBI between 2 and 6 years previously. Injury severities ranged from GCS 3 to 11. Four themes were identified from their data; these related to the participant's experiences of gradually coming to understand that they

have had a TBI and feeling detached from reality in the early stages of recovery ('*Waking up": Understanding TBI*'); ways in which they coped with their limitations ('*I keep going": Coping after TBI*'); the beliefs that they held about their injury in terms of having a positive outlook, recognising that life is not fair and recognising that life would have changed even if they had not been injured ('*I knew I'd get better": Beliefs about TBI*'); and the search for positive changes that have occurred since injury ('*The benefits have far outweighed the consequences": Searching for positives*'). This analysis may provide some indication of how people adapt to the consequences of their injury in a positive way. This may be through actively looking for positive changes that have occurred, it may be through being able to gradually come to understand and accept what has happened, or it may be through making comparisons with those who are worse off. Shotton et al (2007) describe one participant who saw her life in a much more negative way than the other participants which they suggest was due to her not experiencing the same detachment in the early stages post injury that was described by other participants. She did not use coping strategies, did not make any social comparisons and did not see any positives coming from her injury. The experiences of the participants who did experience a more positive outcome may be of benefit in better understanding the process that people go through when adjusting to the effects of a TBI.

Similar to the analysis conducted by Shotton et al (2007), Nochi (2000) also found that people looked for positives in their situation (in 6 out of the 10 cases investigated), and that they use social comparison as a way of coping after TBI (7 out of the 10 cases), comparing with those who were in a worse situation. However they also discuss a number of other narratives that emerged from their study relating to the coping and adjustment process following TBI. Nochi (2000) conducted this research in people who were happy with their life after TBI in the hope of better understanding the processes which underlie their positive adjustment. They discuss social comparison under the theme ('*the self better than others*'),

finding positive effects of their injury (under the theme '*the grown self*'); but also an attempt to return to being the person they were before their injury ('*the recovering self*'), people trying *not* to compare with others, on the premise that the individual is normal because everyone is different ('*the self living here and now*'), and an externalisation of problems (i.e. it is not the TBI, it is society; '*the protesting self*').

While there are undoubtedly similarities between these analyses, there are also differences. Nochi (2000) describes an externalisation of problems, whereas Shotton (2007) describes an acceptance of responsibility (in terms of the injury; in that they should have been wearing a seatbelt/helmet etc). However it seems likely that the differences that emerge in qualitative research are due at least in part to individual differences. It is very unlikely that there is a singular process that all patients will go through following a TBI. Despite this there does seem to be a level of consistency across the published research relating to adaptation. A clearer understanding of the processes involved can only be of benefit in facilitating adaptation in those who suffer a TBI.

Post traumatic growth

Post traumatic growth has been described in the literature as a way in which individuals adapt and change in response to disability, making personal gains and changes in perception which allow positive interpretation (McGrath, 2004; Collicutt McGrath & Linley, 2006; Powell et al., 2007). This may be associated with improvements in QoL. McGrath (2004) discusses the need for 'transformation' rather than 'restoration' models of brain injury rehabilitation. She talks about psychological resilience, positive appraisal and reframing the event. This need and indeed ability to see things in a positive light can be of benefit to the individual recovering from a brain injury. This was investigated further by Collicutt, McGrath, and Linley (2006) using the Post-Traumatic Growth Inventory (Tedeschi & Calhoun, 1996). The

post traumatic growth inventory is a 21 item questionnaire answered on a 6 point Likert scale addressing the areas: 'relating to new possibilities', 'relating to others', 'personal strength', 'spiritual change', and 'appreciation of life'. The results reported by Collicutt, McGrath, and Linley (2006) suggest that people who were undergoing inpatient rehabilitation following ABI had scores that were similar to survivors of accidents and assaults, but lower than for people with chronic illness or bereavement. The authors conclude from this research that post-traumatic growth is possible after an acquired brain injury. There was a significant relationship between the post traumatic growth score and the HADS anxiety score which may suggest that there is an emotional impact of engaging in psychological change.

Powell et al (2007) also used the post traumatic growth inventory to investigate the positive changes that occur following a brain injury. They found that people who were in the earlier stages post injury (1-3 years) had significantly lower scores for post traumatic growth than those who were later (9-12 years), suggesting that scores will increase with time. It should however be noted that both groups reported life satisfaction as being better before their injury, so even if post traumatic growth does occur it will not necessarily lead to the improvements in life satisfaction or QoL that are reported by some individuals following TBI.

Response Shift

It appears from the literature that the tendency for people to report positive changes after what would normally be perceived to be a negative event is fairly universal, in that it is observed across many different medical conditions. In the context of TBI it has emerged from qualitative research and has been reported in quantitative studies as post traumatic growth as well as other 'change factors' (as reported by Jones et al, 2010; see figure 1.2).

A concept which has been developed in the literature surrounding quality of life over the past decade is that of 'response shift'. Response shift may occur on a range of self-report measures, but for the current purposes the focus is on quality of life as a consequence of internal changes. These may be changes in internal standards, values, or a change in conceptualization of what quality of life is (Sprangers & Schwartz, 1999; Schwartz & Sprangers, 2000). For an illustration of the response shift process see Figure 1.3.

This theory emerged in response to counter-intuitive findings; that people with life threatening disease or disability may report stable QoL and people with severe chronic illness report QoL similar to that of healthy people (Andrykowski et al., 1993; Bach & Tilton, 1994). Differences are apparent in the self-reported QoL of people with illness or disability and that reported by their relatives or health care providers (Daltroy et al., 2000; Daltroy et al., 1999; Sprangers & Schwartz, 1999).

The model of response shift put forward by Sprangers and Schwartz (1999) proposes that when a person experiences a change in their life (such as a change in health) this will act as the 'catalyst' for change in quality of life. Certain mechanisms (such as coping, social comparison, social support, goal reordering, reframing expectations, and spiritual practice) will then bring about a response shift process which in turn leads to a change in perceived quality of life. The mechanisms that are used will be influenced by 'antecedents' (e.g. sociodemographics, personality, expectations, and spiritual identity), and as a result different mechanisms will be used by different individuals.

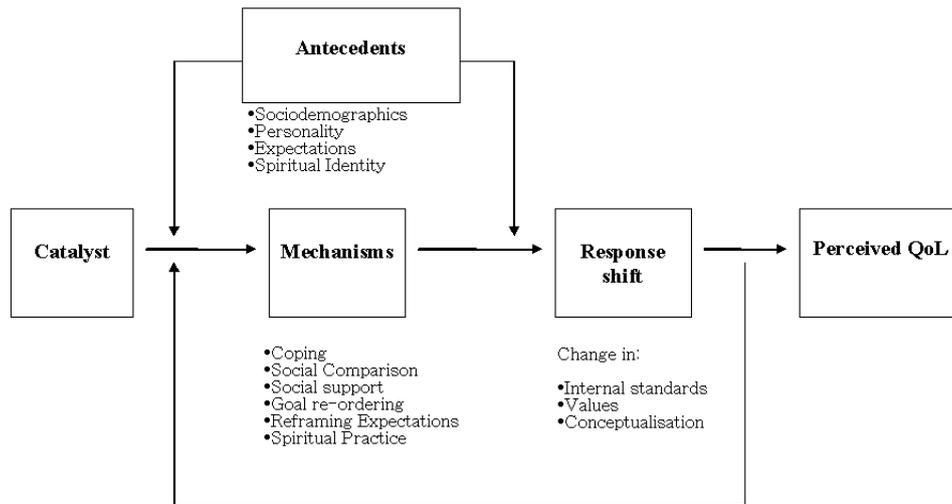


Figure 1.3: A theoretical model of response shift and quality of life (QoL). From Sprangers and Schwartz (1999).

Recently there has been some debate over the validity of term response shift (Ubel et al., 2010; Sprangers & Schwartz, 2010; Ubel & Smith, 2010). For example Ubel et al (2010) argue that the term is misleading as it is used to group distinct phenomena. Furthermore, by saying a person's 'response' has 'shifted' it suggests that people who report high quality of life in a situation where it would not be expected are mistaken. They argue that scale recalibration should not be associated with other types of response shift as it is a source of measurement error rather than a genuine change in quality of life. Ubel et al (2010) argue that if someone has adapted emotionally to negative changes they have made a 'true change', but that if this change is due to scale recalibration it is not. The central question is whether or not scale recalibration does in fact reflect real changes in quality of life. In response to this Sprangers and Schwartz (2010) agree that response shift should not become a term that encompasses 'everything' as it would lose its usefulness. However they defend the use of the term as it describes the overall process. They suggest that 'adaptation' is a mechanism of the process and 'scale recalibration' along with other types of response shift

are the consequence, but by breaking response shift down into these it is likely to lead to further confusion. They do however suggest that there is some merit in investigating the three types of response shift (scale recalibration, revaluation and re-conceptualisation) separately.

In considering these arguments it becomes increasingly important to have a clear definition of what is being measured. If someone reports their quality of life as having changed, and genuinely perceives that this change has occurred, does the fact that this change has occurred for one reason rather than another make it more valid? Ubel's (2010) suggestion that scale recalibration should be considered as a source of measurement error rather than a real change in QoL perhaps loses some of its strength if it is perceived QoL that is of interest, as the individual may indeed be experiencing a real change in QoL. This would be consistent with Sprangers and Schwartz's defence of the term response shift (Sprangers & Schwartz, 2010) in that scale recalibration could potentially be a consequence of emotional adaptation.

This model of response shift has not been examined in the literature in relation to traumatic brain injury, although some of the constituent factors have been reported as having an association with reported quality of life. For example social support and interactions are often reported to be important to QoL following TBI (Kalpakjian et al., 2004; Steadman-Pare et al., 2001; Corrigan et al., 2001; Cicerone & Azulay, 2007; Pierce & Hanks, 2006; Tomberg et al., 2007). Different coping styles and spirituality have also been found to impact on reported QoL (Seibert et al., 2002; Tomberg et al., 2005; Anson & Ponsford, 2006; Tomberg et al., 2007; Finset & Andersson, 2000; Seibert et al., 2002). Social Comparison has also been investigated in people with TBI (Arenth et al., 2006).

Despite the controversy surrounding the term 'response shift' there is a phenomenon of change consistently reported in the literature. Response shift provides a concept that

encompasses these changes in a way that others may not. It also allows work from people with a wide range of health conditions to be linked together and more broadly understood (Schwartz et al., 2006; Ahmed et al., 2009). Understanding why some people are able to make these changes and some are not would be of benefit to those involved in the health care and rehabilitation of people with long term illness and disability. A better understanding of the underlying processes could help clinicians identify positive characteristics and behaviours that will enable the individual to make changes and also allow them to identify risk factors that mean an individual is less able to adapt to the consequences of injury. Response shift has not previously been implicated as a factor influencing adjustment to brain injury. Its strong theoretical basis also lends itself well to a structured investigation of processes underlying change in perceived QoL. As a consequence of this novel aspect, and strong theoretical background it was selected as a particular focus of this investigation.

Chapter 2: Investigating the way in which people evaluate QoL:

Methods and Approach

The focus of this research is the impact brain injury has on the individual and in particular its impact on perceived quality of life. This chapter gives a description of and justification for the measures used, also providing an outline of how these methods and measures were utilised in the context of this research.

Measuring Response Shift

There are a number of ways in which response shift may be measured and these have been discussed at some length in the literature. Most notable is the 'then test' method.

Statistical methods such as structural equation modelling, latent trajectory analysis, and recursive partitioning and regression tree modelling have also been used, as have assessment of vignettes, and preference based methods (King-Kallimanis et al., 2011; Schwartz et al., 2011; Ahmed et al., 2011; Schwartz et al., 1999; Korfage et al., 2007).

'Then test'

The 'then test' is when QoL judgements at time 1 (T1) and time 2 (T2) are compared with a retrospective judgement concerning T1 made at T2 (see figure 2.1). As the judgements made at T2 are considered to have been made using the same frames of reference this is considered to be a better estimate of the change in QoL; the difference between the T1 judgement and the retrospective T2 judgement of QoL at T1 is thought to be representative of response shift (Schwartz & Sprangers, 2010).

There are three main types of effect described by the 'then test' model; the 'reported effect', the 'recalibration response shift effect', and the 'adjusted time effect'. The 'reported effect' is the measured difference between a rating given at T1 and that given at T2. The 'adjusted time effect' is the difference between a current and a retrospective rating made at T2. The 'recalibration response shift effect' is the difference between reported effect and the adjusted time effect. While it will only be possible to obtain a true 'then-test' measurement when ratings are made at two time points it will be possible to obtain an 'adjusted time effect' when using a cross-sectional research design. This will involve obtaining a measure for current QoL and a retrospective measurement for a point in time past.

Ring et al (2005) use the SEIQoL-DW (an individualised measure of QoL, described in more detail in the following section) and a then test procedure to investigate response shift following dental implants. This allowed a specific examination of treatment effects following the dental procedure and the corresponding effect of response shift. An important characteristic of way that response shift was investigated in this study in comparison to the current research is that they were able to utilise a true pre-test post-test design. This is not possible in the context of brain injury; at best, it will only be possible to gain a measure of change in the weeks and months following injury. In traditional assessments of change the difference between T1 and T2 is taken as a measure of treatment effect. Where a pre-test, post-test, and then-test procedure is used it is assumed that employing the same frame of reference at T2 allows a more accurate representation of the treatment effect. As a consequence the difference between the two pre-test time point ratings will provide a measure of response shift. The difference between the pre-test and post-test judgements made at T2 will provide a more accurate representation of change in subjective QoL. This includes both the 'reported effect' and the 'response shift effect' to give an overall 'adjusted

time effect' (see figure 2.1). Should it not be possible to obtain a T1 rating of pre-test (i.e. in a cross-sectional research design) it will be possible to obtain a measure equivalent to the 'adjusted time effect' using a current and retrospective judgement. What will not be possible using this approach is to identify what proportion of change is accounted for by response shift

The then test has been widely used in a variety of populations with measures relating to quality of life, anxiety, and depression, among others (Korfage et al., 2007; Hinz et al., 2011).

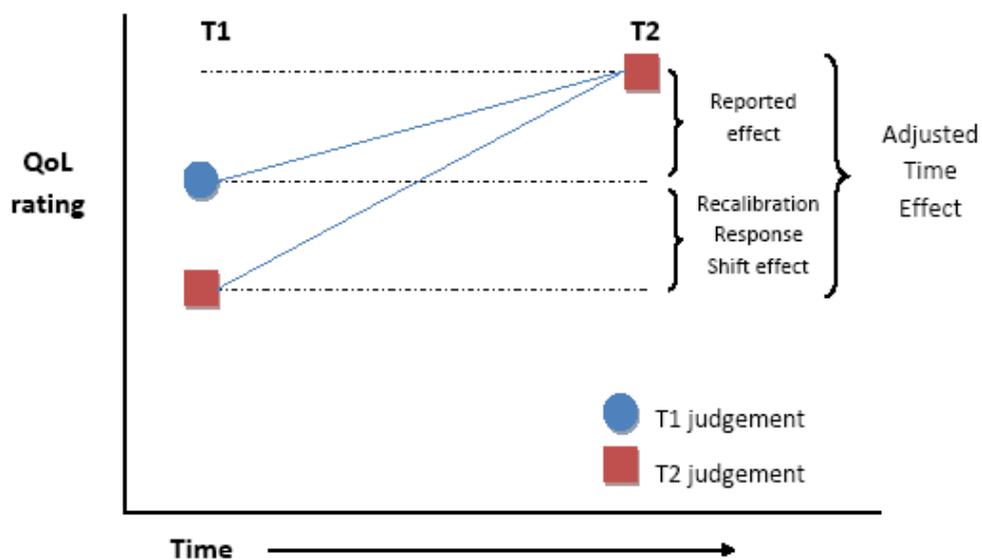


Figure 2.1: The Then-test (based on figure from Sprangers and Schwartz, 2010). The “then-test” involves administering QoL questionnaires at baseline (T1) and at follow-up (T2). In addition to assessing QoL at T2 respondents are asked to think back to how they were doing at T1 and to answer the questionnaire retrospectively (“then”). Recalibration response shift is estimated by computing the difference between the original QoL rating at T1

and the retrospective rating made at T2. The adjusted time effect is estimated by computing the difference between the QoL rating at T2 and the T2 retrospective rating of QoL at T1.

In patients with HIV participating in antiretroviral treatment, changes in QoL between a current and retrospective QoL judgement were reported to correlate more strongly with the clinical changes in body mass index, plasma viral load and haemoglobin levels, than did the change between a current and baseline judgement (Nieuwkerk et al., 2007). Results such as these indicate that a retrospective judgement might not only be a means to investigate response shift, but may in fact be a more accurate way of measuring changes in QoL.

Korfage et al (2007) utilised then test judgements to look at response shift following a diagnosis of prostate cancer. Unlike the majority of similar research into the consequences of changes in health the participants had been recruited from a screening programme and so a pre-test judgement was available from before they received their diagnosis of prostate cancer. This enabled retrospective judgements to be made for 2 time points. Pre-test, post-test and then-test judgements were made on the SF-36 mental health and vitality subscales and the EuroQoL. In this study, the then-test (retrospective) judgement of QoL before diagnosis was found to provide rating of health that was better than the rating of health that was made at the time before a diagnosis was given.

While the 'then test' has been proposed as a more valid way of comparing judgements at two time points it has limitations. It has been argued that the then test is particularly susceptible to recall bias, and that its power and interpretability may be influenced by statistical noise (Schwartz et al., 2006). Kievit et al (2010) found that retrospective ratings of health were generally poorer than they had been rated at T1; but that this difference was consistent regardless of changes in health. They suggest that this is evidence to suggest that a change does not therefore reflect a change in standards of measurement, and thus caution

should be used when interpreting findings from then test research. With this in mind it should also be noted that Schwartz and Sprangers (1999) argue that response shift effects are found to be more prevalent for subjective measures than they are for objective measures suggesting that they are measuring something distinct from any recall bias.

It has also recently been suggested that by asking participants to make a retrospective judgement, their T2 judgement may also be affected. Nolte et al (2012) investigated this by comparing T2 ratings on the health education impact questionnaire (a 42 item measure looking at 8 different domains (positive and active engagement in life, health directed behaviour, skill and technique acquisition, constructive attitudes and approaches, self-monitoring and insight, health service navigation, social integration and support, emotional well-being) of groups who either did or did not also complete a then test rating of the same measure. T2 scores were consistently higher for those participants who also completed the then test. This possibility is something that should be borne in mind when interpreting any results from a T2 judgement that has been obtained alongside a then test judgement.

Individualised QoL Assessment

The individualised methods described by Schwartz and Sprangers (1999) in their review of methods for investigating response shift include the Repertory Grid Technique, Cantril's ladder, and the SEIQoL-DW. These methods focus on eliciting from the individual the factors which contribute to their overall judgement, thus allowing analysis of changing values and re-conceptualisation. While labour intensive, these methods have the advantage of allowing the individual aspects of response shift to be addressed in terms of re-conceptualisation, reprioritization, and changes in internal values. As a brief description, the Repertory Grid technique involves an interview aimed at eliciting the meaning or understanding of different areas of life; Cantril's ladder is a 0-10 visual analogue scale, where the respondent is able to

specify the criteria on which they evaluate QoL. Prior to making an evaluation of their current QoL the respondent gives an indication of what 'best possible' or 'worst possible' would mean for them in terms of QoL, thus the term 'self-anchoring' is used; the SEIQoL-DW involves the participant identifying five domains which are important to their QoL which they then rate for relative importance and satisfaction.

Qualitative investigation

Qualitative research in a variety of forms has been used to investigate issues relating to response shift. This has included techniques such as thematic analysis with themes emerging relating, among others, to changing standards, different points for comparison, reprioritization and changing perspectives (Westerman et al., 2007; Sinclair & Blackburn, 2008; Korfage et al., 2007). Qualitative research is particularly useful as it can allow for the identification of aspects and processes that would not be possible by quantitative data alone. It also allows for a clearer understanding of what is influencing an individual's subjective judgement. It has been argued that there should be a focus on using qualitative investigation to better understand the experiences of people who have had a brain injury (DePalma, 2001). Things have moved on in the intervening time period, with many studies using qualitative techniques to research the ways in which people adjust to brain injury. Understanding is growing, but there is still very much a need to address these issues in different ways in order to build a comprehensive and meaningful picture.

It has been argued that differences found between free-text responses and Likert questionnaire scales are representative of a form of response shift, in that the frames of reference and methods of comparison differ between groups (Ogden & Lo, 2012). In terms of differing frames of reference they use the example of diet as described by the three groups of participants they studied: students, towns-people, and homeless people. They

noted a difference between a focus on health and content of meals by students and townspeople, compared to a general lack of interest noticeable in the people who were homeless. The latter provided very little description of their meals, with only meal timings given any comment. Ogden and Lo (2012) give the example of living conditions as a means of explaining differences in methods of comparison: homeless people tended to compare with their own circumstances, perhaps in harder times; students tended to compare their student accommodation with their parental homes, in terms of both physical accommodation and social aspects of their accommodation. Also discussed is the time frame on which participants base their ratings, as this will influence how ratings are made. Again the example of homeless people is given as they rate their health and quality of life as being reasonably high, although their qualitative answers do not reflect this. They also rate their levels of tiredness and hunger as being much higher than their qualitative responses would suggest. While Ogden and Lo's (2012) paper does not directly address the phenomena of response shift it does provide an interesting perspective on how the different mechanisms that may operate by comparing these different population groups. It also demonstrates the potential use of qualitative data analysis as a means of understanding the mechanisms, thought processes, and influencing factors that come into play when a subjective quantitative judgement is made.

Addressing response shift in the context of this project

In order to build a broad picture of how people adjust to the consequences of brain injury a variety of methods are used in the following chapters. These are split into four studies, each having a distinct approach to the topic. These different approaches were used with the aim of addressing the research question from different perspectives. For the sake of overall orientation these four designs are described below:-

1. Chapter 3. "Individualised versus global assessments of quality of life after head injury and their susceptibility to response shift". An individualised method was used in the form of the SEIQoL-DW (Schedule for Evaluation of Individual Quality of Life; Hickey et al., 1996) in a cross sectional study aimed at addressing how perceived quality of life changes after injury, and more specifically, how an individual's perception of quality of life changes. This study also allowed comparison of the strengths and weaknesses of different quality of life measures: the SEIQoL-DW and Hadorn's overall scale.
2. Chapter 4. "Changes in Evaluation of QoL after TBI: A longitudinal study". A longitudinal study was conducted to enable the 'then test' to be used. Participants were interviewed at two different time points; the first being between 3 and 9 months post injury (T1), the second interview following on 6 months later (T2). A T1, T2, and then-test judgement were made on Hadorn's overall quality of life scale to gain a measure of how much response shift takes place in the 6 month period covered by the study. Schwartz et al (2006) provide a description of how to measure response shift effect size, which by using a 'then-test' research design it was possible to apply. In addition to this overall 'then-test' approach to measuring overall quality of life this study used a number of other measures to build a broad picture of the patient group being studied. With the SF-36, HADS, and a number of other measures it was again possible to look at how these measures compare as well as considering other factors which may influence any judgements that are made.
3. Chapter 5. "Investigation of factors influencing quality of life in people with Acquired Brain Injury attending a Headway group". A cross-sectional questionnaire design was used in order to recruit a greater number of participants. The population in this study differed from those in the other three as they were recruited through the brain injury charity 'Headway'. The study also included those with Acquired brain injury (ABI) unlike the more specific TBI population in the other studies. This allowed a greater

number of people to be approached across a much wider geographical area. By recruiting a greater number of people it was possible to look in some detail at what may influence a QoL judgement. Therefore it was an aim of this study to use measures that reflect some of the potential 'antecedents' and 'mechanisms' described by Sprangers and Schwartz in their model of response shift (Schwartz & Sprangers, 2000; Sprangers & Schwartz, 1999). In terms of 'antecedents' sociodemographic characteristics were considered along with personality traits in the form of the Life Orientation Test – Revised (LOT-R; Scheier et al., 1994). Under the heading 'mechanisms', coping, social comparison, and social support were measured. The measures used for this were the Brief-COPE (Carver, 1997), the Iowa Netherlands Comparison Orientation Measure (INCOM; Gibbons and Buunk, 1999), and the Medical Outcomes Study Social Support Survey (MOS-SS; Sherbourne and Stewart, 1991). The MOS-SS was selected here over the MSPSS which was used in the longitudinal study as it was felt to address a wider range of aspects of support (i.e. practical, informational) rather than focussing in on the availability of perhaps the more emotional aspects of support that the MSPSS does.

4. Chapter 6. "Understanding the Subjective Experience of Recovery from TBI: An Interpretative Phenomenological Analysis". A qualitative research design was used in order to obtain a clearer understanding of the experience of recovering and adjusting to the consequences of a brain injury. Due to the exploratory nature of the enquiry Interpretative Phenomenological Analysis (IPA) was used. This method is aimed at building a picture and understanding of how an individual makes sense of an experience. It is a double-hermeneutic approach; in that it involves the researcher trying to make sense of the way in which the participant has made sense of their experience. This was a small (four participants) study, but IPA is a method which benefits from a small purposively selected sample. By only using a small sample the aim is to select individuals who are similar in their experience to better understand the

experience itself. A semi-structured interview format with open ended questions was used but the approach taken in the interview was very much aimed at allowing and encouraging the participant to put forward their own interpretation and understanding. Lack of generalisability is always an issue with qualitative research, however it allows a comprehensive analysis of the reactions of specific individuals and given the individual nature of this was felt to be useful. Qualitative approaches may aid identification of issues that are of importance but are perhaps obscured when a quantitative approach is used. In addition it may identify points for consideration in future research.

Participant Recruitment

Participants were recruited from two main sources in the course of this research: NHS rehabilitation centres and through Headway. In the study reported in Chapter 3, a cross-sectional retrospective study, patients were recruited at the Centre for Brain Injury Rehabilitation in Dundee, identified through records from inpatient rehabilitation and the associated brain injury clinic. The study reported in Chapter 4 involved patients recruited from rehabilitation and neuropsychological services in Fife, Lothian, and Glasgow. This was a longitudinal study investigating changes in the first year post brain injury. A wider geographical area was targeted in this study due in part to the specific inclusion criteria in this study, most notably the shorter time scale involved.

In Chapter 5, where a different approach was used in the form of self-report questionnaires, participants were recruited through their involvement with Headway groups. Partly this was to enable a greater number of people to be approached, but it also allowed for a different demographic to be studied. While there is a certain level of homogeneity in that they all have involvement with Headway these participants represented a much wider geographical area, from across the United Kingdom. They also had very different experiences in terms of

rehabilitation, with a number reporting that they had no involvement with rehabilitation services. This study also recruited people with brain injuries from a variety of causes; including both TBI and ABI; again enabling consideration of the issues affecting a broader clinical and demographic group. People attending Headway are typically seeking support for problems and this affects the nature of the sample. This group of individuals are, thus, not representative of all people with head injury, only a specific subset for whom the impact of their injury may be more profound. However, because the impact of injury is possibly more pronounced in this sample it may be that individual factors influencing recovery or adjustment processes may also be more pronounced.

In the final study, reported in Chapter 6, participants were recruited through the Community Treatment Centre for Brain Injury in Glasgow. As this was a qualitative study, using Interpretative Phenomenological Analysis (IPA), it comprised of interviews with a small group of individuals who had lower moderate to severe disability (on the GOSE) as a consequence of their injury. This was because the aim of this study was to gain an in-depth understanding of a small group of individuals that could then be looked at in the context of the results from the quantitative results in the preceding chapters.

Measures used in the course of this thesis

This section gives a description of the measures used alongside the justification for their inclusion. Further evidence from the literature is included as necessary to support the inclusion of measures.

The reliability data where it is available from previous research for each of the measures used in the study is presented in table 2.1.

Table 2.1: Reliability data for the measures used in the course of this thesis

Measure	Internal Reliability in non-neurological sample	Test/retest reliability in non-neurological sample	Used previously in a cognitively impaired sample?	Internal Reliability in neurological sample	Test/retest reliability in neurological sample
Hadorn's scale	N/A	(de Boer et al., 2004)report 3 week test-retest reliability for a visual analogue scale for measuring QoL as very high, with an ICC of .87.	Yes (Steadman-Pare et al., 2001)	N/A	Not available
SEIQoL-DW	Not available	A systematic review (Wettergren et al., 2009) reports evidence that scores are reasonably stable over time, but that between 35-81% of cues may change over a 3-6 month period.	No	Not available	Not available
QOLIBRI	N/A	N/A	Yes. Designed for this purpose.	0.75 to 0.89 on individual subscales, and 0.95 for the scale total (von Steinbuechel et al., 2010),	ICCs ranging from 0.87 to 0.91 ((von Steinbuechel et al., 2010),
SF-36	Consistently shown to be high. MCS and PCS are generally over .90 (Ware et al., 1994)	Test retest reliability has been shown to be high with a maximum mean difference of 0.80 (Brazier et al., 1992) .	Yes. Widely used.	Cronbach's α = 0.68-0.87 in mild TBI; 0.79-0.92 in moderate to severe injury (Findler et al., 2001).	Not available
HADS	Good. Consistently reported to be >0.80 on both subscales (Zigmond & Snaith, 1983; Whelan-Goodinson et al., 2009; Bjelland et al., 2002)	Test retest reliability has been shown to be high (Hermann, 1997),.	Yes. Widely used.	TBI: Cronbach's α of 0.94 (total), 0.88 (depression), and 0.92 (anxiety) (Whelan-Goodinson et al., 2009).	Not available
TICS	Not available	Consistently shown to be good (Plassman et al., 1994; Brandt et al., 1988; Brandt & Folstein, 2003)	Yes	Not available	1 month test – retest found to be excellent in stroke patients (r=0.90; (Desmond et al., 1994).
GOSE	N/A	N/A	Yes	High rates of inter-rater agreement (Wilson et al., 1998) .	Good test-retest reliability (kappa .92; (Pettigrew et al., 2003).

Measure	Internal Reliability in non-neurological sample	Test/retest reliability in non-neurological sample	Used previously in a cognitively impaired sample?	Internal Reliability in neurological sample	Test/retest reliability in neurological sample
RBANS	α .76 to α .95 with high levels of agreement between raters (intraclass correlations .85) (Randolph, 1998).	1 year test-retest coefficients of .58 to .83 for the Index scores (Duff et al., 2005).	Yes	Cronbach's α = 0.84 in TBI sample (McKava et al., 2007) .	Not available
Silver lining questionnaire	Good internal consistency (α = 0.93; (Sodergren et al., 2002),).	Good test-retest reliability ($r=0.90$; $p<0.001$; (Sodergren et al., 2002),).	No	Not available	Not available
BIGI	N/A	N/A	Yes	Cronbach's α for loss =.74; adjustment α =.58. (Ruddle et al., 2005).	Test re-test $r=.89$ for loss; .58 for adjustment (Ruddle et al., 2005).
INCOM	Good Cronbach's α ranging from .77-.84 (Gibbons & Buunk, 1999).	Not available	Yes (Arenth et al., 2006)	Not available	Not available
PCRS	N/A	N/A	Yes	Strong internal reliability has been reported (patients α =.91, relatives α =.93 (Fleming et al., 1998)	High levels of test-retest reliability ($r=.97$ for patients, and $r=.92$ for relatives (Prigatano et al., 1990).
MSPSS	Good internal reliability (α =.91 for significant other; α =.87 for family, α =.85 for friends, α .88 for total.; (Zimet et al., 1988)	Good test-retest reliability ($r=.72$ for significant other; $r=.85$ for family, $r=.75$ for friends, $r=.85$ for total.; (Zimet et al., 1988) .	Yes	Good internal reliability (α =.88 for significant other; α =.79 for family, α =.85 for friends; (Tessler, 2007),).	Not available
MOS-SS	Cronbach's α for 4 subscales ranges from .91-.96; for the overall scale α =.97 (Sherbourne & Stewart, 1991)	1 year test-retest reliability =.78 (Sherbourne & Stewart, 1991)	No	Not available	Not available
NART	Internal reliability has been shown to be high (>.90) (Crawford et al., 1988)	Good test-retest reliability has been demonstrated (O'Carroll, 1987; Smith et al., 1998; Morrison et al., 2000),.	Yes	Internal reliability has been shown to be high (>.90) (Crawford et al., 1988)	Good test-retest reliability has been demonstrated in people with dementia (O'Carroll et al, 1987) .

Measure	Internal Reliability in non-neurological sample	Test/retest reliability in non-neurological sample	Used previously in a cognitively impaired sample?	Internal Reliability in neurological sample	Test/retest reliability in neurological sample
Brief COPE	Cronbach's α ranges from .50 to .90 on different subscales (Carver, 1997).	Good 1 year test-retest reliability ($r=.58-.72$; (Cooper et al., 2008) .	The full version of the COPE has been used in a brain injured population (Tomberg et al., 2007; Tomberg et al., 2001; Tomberg et al., 2005)	In mild TBI; internal consistency of subscales range between $\alpha=0.43$ $\alpha=0.97$ (substance use; Snell et al., 2011),.	Not available
LOT-R	Cronbach's α for full scale =.78 (Scheier et al., 1994)	Test-retest correlations range from .56 to .79 (Scheier et al., 1994)	Yes (Tomberg et al., 2005; Ramanathan et al., 2011)	Not available	Not available

Hadorn's scale

Scale Description

Hadorn's scale (Hadorn & Uebersax, 1995) is a simple QoL scale that involves rating overall QoL on a scale from 0 to 10 where 0 is the worst possible and 10 is the best. Originally developed and described in the context of cancer patients it has since been used with people who have had a TBI (Steadman-Pare et al., 2001). It is useful as it allows for the respondent to rate their QoL as a proportion of an ideal, allowing for 'internal calibration' in that they are rating in a way that is relevant to them. The term 'internal locus' is also used to describe the way in which a subjective interpretation is used as the criteria on which to base the QoL judgement (Steadman-Pare et al., 2001). This subjectivity may be perceived to be a threat to the reliability and validity of this measure, however Hadorn and Uebersax (1995) argue that an overall rating of QoL may be a better way of assessing QoL as the respondent is generating for themselves the criteria on which to base a judgement. Using a simple scale has also been argued to increase compliance in comparison with other, more complex, QoL measures.

Hadorn's scale has similarities to other global scales, for example Cantril's ladder. Cantril's ladder is described by Schwartz and Sprangers (1999) as being a useful way of addressing reconceptualisation and changing internal standards. Cantril's ladder also consists of a 0-10 worst to best rating, with the possible addition of describing 'anchors', that is the context in which a judgement is made. There is evidence going back some years that single item measures, while not providing the same level of detail and sensitivity, can be useful in providing a meaningful assessment of QoL (Bowling, 2005a; Cunny & Perri, 1991; de Boer et al., 2004).

A copy of Hadorn's scale in the format it was used in Chapter 3 is included as Appendix 2.1. This was used in a similar format in Chapter 4, with participants rating overall QoL for current time, before injury, and at T2 for QoL at T1.

Validity/Reliability

Hadorn et al (1995) examine the validity of their overall scale in a cancer population, finding it to be a valid and consistent method for investigating QoL. However, the reliability of Hadorn's scale has not been investigated specifically within a cognitively impaired sample. Steadman-Pare et al (2001) used it in their investigation of factors influencing QoL after TBI and found significant correlations with a number of factors that are generally associated with QoL (specifically physical functioning and mental health) supporting the validity of Hadorn's overall scale as a useful way of assessing subjective QoL.

Use in the current thesis

In this thesis Hadorn's overall scale was used as a measure of subjective QoL in Chapters 3, 4, and 5. This was set out simply on a visual analogue scale from 0-10, where 0 signified worst possible quality of life to 10 best possible QoL. This scale was also used to provide retrospective judgements of QoL. In face to face interviews, when rating current QoL participants were asked "*Here we have an overall scale representing your overall quality of life. I would like you to indicate on this scale where your quality of life is at the moment, if 0*

is the worst life could possibly be and 10 is the best". After doing this they were asked, *"I would like you to think back to how your life was before your injury (... or 6 months ago, at the time I last met with you), where about on this scale was your quality of life then?"*. In the questionnaire format the question was phrased *"How would you rate your life as it is at the moment?"*, followed by *"How would you rate your life as it was before your injury?"*.

Hadorn's overall QoL scale was selected for use because of its simplicity. It was felt that the benefits of participant generated criteria for evaluation of QoL were of particular importance when studying perceived QoL and how it may change. In the first study pre-injury and post-injury judgements of QoL were made on both Hadorn's scale and the SEIQoL-DW (further detail on this in the next section), allowing for comparison between these two measures. Aspects of the validity of Hadorn's scale are examined in Chapter 3, and the results support its use in TBI.

Schedule for the Evaluation of Individual Quality of Life – Direct Weighting

Scale Description

The Schedule for the Evaluation of Individual Quality of Life, direct weighting procedure, (SEIQoL-DW; Hickey et al., 1996) is an individualised assessment of QoL. Administration begins by asking participants to nominate the five areas of their life which are most important to them. For example; this might be family, work, hobbies, health, and financial security. Prompts are available if the participant struggles to think of appropriate domains, however the aim is that they will nominate areas of their life themselves thus ensuring that the QoL domains rated are respondent rather than researcher imposed. Some consideration has been given in the literature to the potential differences between domains generated with or without the use of cues (Westerman et al., 2006). The participant describes what they mean for each of the domains that they nominate, to allow their definitions to be

clearly understood. Weighting the nominated domains involves the use of a disc with five movable segments each of a different colour. Each segment is labelled with a nominated QoL domain. The participant is asked to move each of the segments to indicate the proportionate level of importance each area has in their life (i.e. 'weights'). A score from each of these segments is calculated to give a proportion of a total of 100. An example is shown in Figure 2.2.

The SEIQoL-DW has been widely used in QoL research, especially in the context of response shift. It has been used in a variety of different population and patient groups; including, patients with HIV (Hickey et al., 1996), cancer (Waldron et al., 1999), and carers of people with brain injury (Hickey et al., 1997). It has been used as part of a then test procedure in patients who have undergone dental implants (Ring et al., 2005), and in cardiac rehabilitation (Dempster et al., 2009). In these studies the then test procedure was conducted in a pre-test and post-test of a clinical intervention. The SEIQoL-DW has not been used in patients with TBI before, possibly because of concerns about cognitive impairment in this population. However, the direct weighting procedure makes the task relatively straightforward from the participant's perspective, and is much simpler than the weighting judgements made in the original SEIQoL.

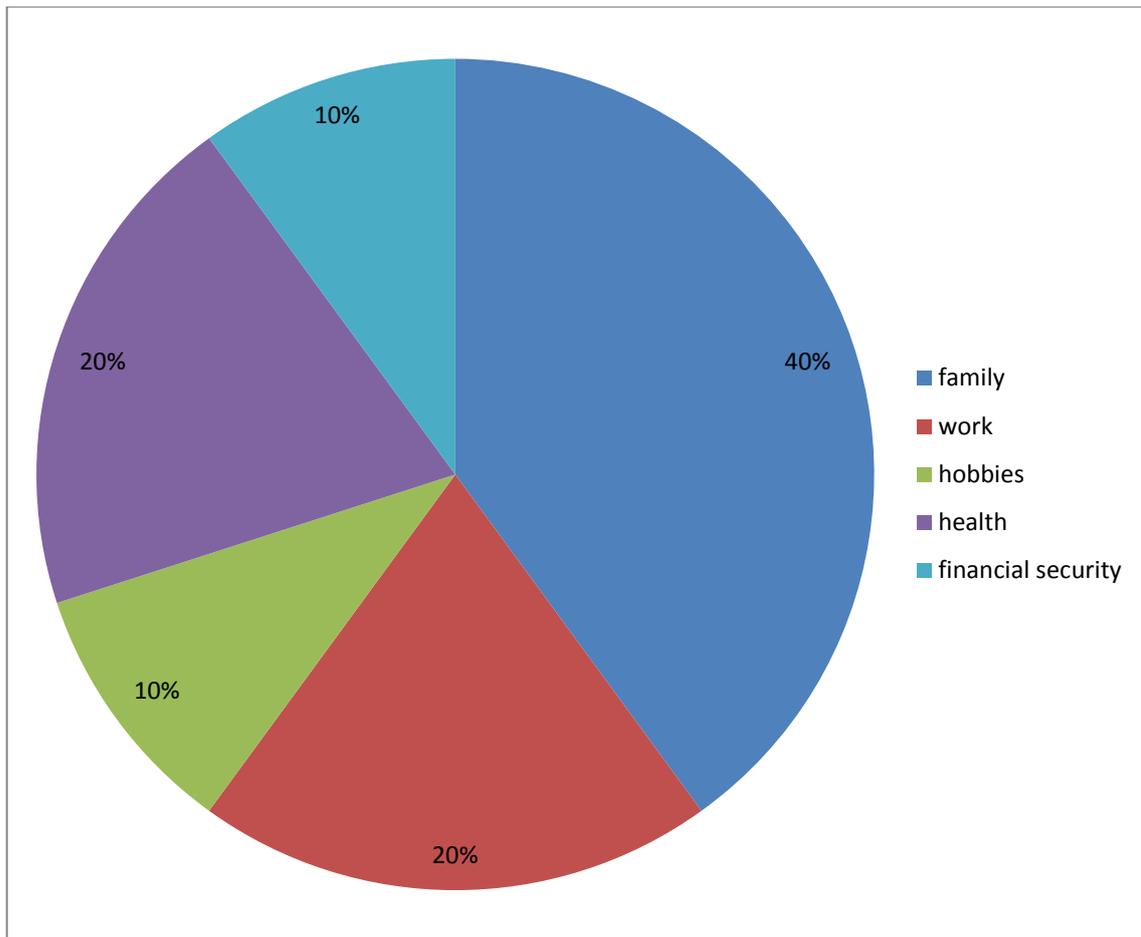


Figure 2.2: Illustration of how the SEIQoL-DW disc might look after nomination of QoL domains and allocation of importance levels

Following nomination of areas and levels of importance, participants rate their satisfaction in each of the areas. This is done using a bar chart (i.e. a visual analogue scale) on which participants indicate their level of satisfaction in each area ('levels'). The bars are then measured to give a score out of a maximum possible of 100. A combination of these values is used to calculate an overall SEIQoL-DW score out of a maximum of 100 (Σ (levels x weights)).

Reliability/Validity

A review has been published of the psychometric properties of the SEIQoL-DW (Wettergren et al, 2009). They report moderate to strong correlations with other self report measures

indicating convergent validity, with weaker correlations found with measures of health status indicating that the SEIQoL-DW is measuring a specific construct other than health. Evidence for test-retest reliability of the SEIQoL-DW is more limited with some suggestion that there are changes in the way that the measure is completed, however two of three studies investigating this found the levels to be acceptable (Browne et al., 1997; Patel et al., 2003). Wettergren et al (2009) conclude that the SEIQoL-DW is a valid way of assessing QoL with promising results for test-retest reliability, they do however suggest that the measure has its limitations, especially with an elderly population where there are reports of difficulty in completing the measure (McKee et al., 2002).

Use in the current thesis

The SEIQoL-DW has not been used with people who have cognitive impairment, consequently the aim of using of the SEIQoL-DW in Chapter 3 of the current research was partly to investigate the feasibility and validity of its use with a TBI population.

QOLIBRI Overall Scale

Scale description

The QOLIBRI scales were developed as a disease specific measure of health related QoL for TBI (von Steinbuechel et al., 2010). The original scale consists of 37 items in six domains; cognition, self, daily life and autonomy, social relationships, emotions, and physical problems. In addition to scores for each of these domains a total score for QoL is obtained. A shorter version of this was developed as an index measure of QoL after brain injury (the QOLIBRI-OS; von Steinbuechel et al., 2012) This is a six item scale addressing physical condition, cognitions, emotions, functions in daily life, personal and social life, and current situations and future prospects. Satisfaction in these areas is rated on a five point scale. The resulting score gives a measure of QoL out of a total possible 100.

The QOLIBRI overall scale in the format it was presented in the study reported in chapter 5 is included in Appendix 2.2. This includes Hadorn's scale as they were presented together.

Reliability/Validity

Von Steinbuechel et al (2010) demonstrate the validity of the QOLIBRI scale, with expected correlations found with a variety of instruments in a large scale investigation of the properties of this measure. For example, relationships were found between the physical problems scale of the QOLIBRI and the SF-36 PCS, the QOLIBRI emotions scale was associated with HADS anxiety, and SF-36 MCS, daily life and physical problems correlated most strongly with the GOSE. Internal consistency of the measure is good, with Cronbach's α ranging from 0.75 to 0.89 on individual subscales, and 0.95 for the scale total (von Steinbuechel, 2010). Test re-test reliability was also good with ICCs ranging from 0.87 to 0.91 (von Steinbuechel, 2010). This investigation of the reliability of the QOLIBRI demonstrates that it is a valid and useful way of investigating QoL, even when some cognitive impairment is present. A shorter version of the QOLIBRI, the QOLIBRI-OS correlates strongly with the QOLIBRI total scale (von Steinbuechel et al, 2012). It has good internal reliability with Cronbach's α of 0.86. Internal consistency and test-retest reliability was also found to be satisfactory to good.

Use in the current thesis

The QOLIBRI-OS was used to measure current QoL in the study reported here in Chapter 5. The overall scale rather than the full QOLIBRI was used for reasons of simplicity. It was also used as a basis on which to make a retrospective QoL judgement from before injury. Participants also rated the importance of the areas of life assessed by the QOLIBRI-OS along with 'work', 'close relationships', and 'social and leisure activities', which were included because of their similarities to areas assessed by the GOSE.

Short Form 36

Scale Description

The Short-Form 36 (SF-36) is a measure of health-related QoL that has eight different subscales (Ware et al., 1993; Jenkinson et al., 1996; Jenkinson et al., 1993). These can be used to calculate two component summary scales (the Physical Component Summary, PCS; and the Mental Component Summary, MCS). The eight subscales cover: Physical Functioning; Role Limitation due to Physical Problems; Role Limitation due to Emotional Problems; Social Functioning; Mental Health; Energy/Vitality; Pain; and General Health Perception. Questions are given in a multiple choice format. The SF-36 is a popular measure and has been used in a wide range of conditions.

Reliability/Validity

The SF-36 has been used in studies involving individuals with brain injury and its reliability and validity has been investigated in the context of traumatic brain injury (Findler et al., 2001). Findler et al (2001) report good values for Cronbach's α indicating good internal reliability; especially with moderate to severe injury ($\alpha = 0.68-0.87$ in mild TBI; $0.79-0.92$ in moderate to severe injury). They also report significant correlations with measures of health problems typically found by people who have had a TBI indicating that it has satisfactory construct validity as a measure of health related QoL. They also report that the SF-36 was able to distinguish between individuals who had had a brain injury and healthy controls. Interestingly Findler et al., (2001) report that individuals with mild TBI had lower SF-36 scores than those with more severe injuries.

Use in the current thesis

The SF-36 was used in Chapters 3, and 4; the Physical Component Summary and Mental Component Summary Scales are used to provide a concise summary of functioning on this measure that can be used for comparison with the other measures included in the study.

Scores on the PCS and MCS are standardised to give a population mean of 50 and standard deviation of 10.

Hospital Anxiety and Depression Scale

Scale Description

The Hospital Anxiety and Depression Scale (HADS; Zigmond and Snaith, 1983) measures emotional distress on two subscales, each consisting of 7 items. Again, this measure is widely used across a wide range of diseases. It has high levels of internal consistency and test-retest reliability, and is useful in picking up mild anxiety and depression symptoms in a non-psychiatric sample (Hermann, 1997). Hermann (1997) reviewed the history of use of the HADS in research and clinical contexts and concludes that it is a valid and reliable measure for use in clinical populations. The HADS consists of 14 items, 7 on each subscale. The total possible score on each subscale is 21, with a cut off minimum of 8, indicating that symptoms may be clinically significant. Each item consists of a statement followed by four possible options which are scored from 0-3. For example a question on the depression subscale is 'I still enjoy the things I used to enjoy'; with options being 'definitely as much', 'not quite as much', 'only a little', or 'hardly at all'. On the anxiety subscale an example is 'I feel tense or wound up', with the possible answers: 'most of the time', 'a lot of the time', 'from time to time or occasionally', or 'not at all'.

Reliability/Validity

The HADS has been used previously in brain injured populations and has been found to be a reliable measure of emotional distress in people who have had a brain injury. Some reservations have been expressed about the structure of the HADS (Dawkins et al., 2006; Skilbeck et al., 2011). Dawkins et al (2006) examined the factor structure of the HADS and found a three rather than two factor structure; they conclude however that it is a useful

measure for looking at anxiety and depression in people with ABI. Similarly Skilbeck et al (2011) report a three factor solution which they call depression, anxiety and psychomotor. Nonetheless, the conventional anxiety and depression scales are widely accepted in the literature, and this is the form that is used here. Whelan–Goodinson et al (2009) report that the reliability of the total scale, depression, and anxiety is good with Cronbach’s α of 0.94, 0.88, and 0.92 respectively.

Use in the current thesis

The HADS is used in Chapter 3 and 4, with both the Anxiety and Depression subscales reported. These allow a measurement of psychological functioning in the study population.

Telephone Interview for Cognitive Status

Scale Description

The Telephone Interview for Cognitive Status (TICS; Brandt and Folstein, 2003) was used to assess cognitive functioning. The TICS is an 11 item test designed to give a brief assessment of cognitive status. Questions relate to orientation, and include tasks such as counting backwards, serial subtraction, word memory, and recognising an object from a verbal description. The total is calculated by summing the score for each item. A maximum score for each item is provided along with a description of acceptable responses. A maximum total score of 41 points is possible. A score of 33-41 indicates no cognitive impairment, a score of 26-32 indicates an ‘ambiguous range’ where cognitive impairment may or may not be present, a score of 21-25 indicates mild cognitive impairment, and a score of less than 20 indicates moderate to severe impairment. It is possible from the TICS manual to obtain an indication of how the TICS score relates to the Mini Mental State Examination (MMSE, Folstein et al 1975). The cut off of 26 is equivalent to an MMSE score of 23 out of a possible 30, which is also where the cut off indicating cognitive impairment lies.

According to the TICS manual scores of 25 or less indicates impairment. Twenty five has also been identified as being the best cut-off point for distinguishing between those who have or do not have cognitive impairment by Desmond et al (1994). Screening tools such as the TICS are relatively insensitive to mild or moderate cognitive impairment in TBI.

Reliability/Validity

The TICS has consistently been shown to have high levels of internal reliability (Brandt et al, 1998; Plassman et al, 1994), with good test-retest reliability (Desmond et al, 1994).

Use in the current thesis

The TICS was used in the first study (Chapter 3) investigating changes in QoL as a simple way in which to screen for severe cognitive impairment (participants with TICS scores less than 26 were excluded).

Glasgow Outcome Scale - Extended

Scale Description

The Glasgow Outcome Scale-Extended (GOS-E; Wilson et al., 1998) is a widely used measure allowing categorisation of levels of disability following brain injury. The original format was a structured interview; however a questionnaire has also been developed and found to be reliable when administered by post (Wilson et al, 2002). The GOSE involves questions relating to activities of daily living (shopping, travel, independence at home, travel, shopping), ability return to work, and to participate in social and leisure activities. Respondents are also asked about any impact their injury might have had on their relationship with friends and family, or on any other area of their life. Categories range from 1-8: from death to good recovery. Possible outcomes are shown in table 2.2. Given that the lowest possible outcomes are 'dead' and 'vegetative state', the range of outcomes for participants included in the current research is from 3-8; 'lower severe disability' to 'upper good recovery'.

Reliability/Validity

Using the structured interviews described by Wilson et al (1998) has been demonstrated to be a reliable way of assessing outcome with a high level of agreement between raters (kappa 0.85). Good test-retest reliability has also been reported (Pettigrew et al., 2003). Good reliability and validity has also been reported in the questionnaire format of the GOSE (Wilson et al., 2002).

Use in the current thesis

The GOSE is used in both its formats in the course of this research; in the original interview format when face to face interviews were used (Chapters 3 and 4); and in the questionnaire format for self-completion by patients (Chapter 5). These are included in Appendix 2.3 in the interview format and Appendix 2.4 in the questionnaire format. Where a self-report measure is used there is always the possibility that there will be an impact of cognitive impairment. The GOSE was completed in most cases only by the participants; however in the interview settings where a family member was present they remained in the interview room while the GOSE was completed, leaving for the remainder of the interview. This helped to ensure the accuracy of the information gathered, however it was not possible to do this in all cases. It was not possible to verify the accuracy of information from the questionnaire study.

Table 2.2: Possible outcomes classified by the Glasgow Outcome Scale-Extended (GOSE; Wilson et al, 1998)

1	Dead
2	Vegetative State (VS)
3	Lower Severe Disability (Lower SD)
4	Upper Severe Disability (Upper SD)
5	Lower Moderate Disability (Lower MD)
6	Upper Moderate Disability (Upper MD)
7	Lower Good Recovery (Lower GR)
8	Upper Good Recovery (Upper GR)

Repeatable Battery for the Assessment of Neuropsychological Status

Scale Description

The Repeatable Battery for the Assessment of Neuropsychological Status (Randolph, 1998) is a series of tests measuring different aspects of cognitive status. These are immediate memory, visuospatial/constructional abilities, language, attention and delayed memory. A total scale score is also calculated. It takes around 25 minutes to complete. It is widely used as a diagnostic instrument in clinical situations and has been tested in patients with a wide range of neurocognitive conditions, including TBI and stroke. Raw scores are calculated based on the guidelines in the test booklet and RBANS manual and are then converted into index scores based on the norms for different age groups. The index scores for each subscale (and the total) are based on a norm of 100, representing scores in the 50th percentile.

Reliability/Validity

Reliability levels for the subscales are reported to range from α .76 to α .95 with high levels of agreement between raters (intraclass correlations .85). Correlations with other equivalent measures demonstrate the validity of the RBANS (Randolph, 1998). The reliability of the RBANS in a TBI population was also demonstrated by McKava et al (2007), with a Cronbach's alpha for the overall scale of 0.84. While the scores for language and attention were less good (α .33 and .16 respectively), those for immediate memory, visuospatial/construction were (α .75 and .76). Correlations between the subscales and equivalent subscales on other neuropsychological tests were strong indicating a good level of validity in this measure. One year test-retest correlations of between .58 and .83 have been reported (Duff et al., 2005). It is expected that there will be some level of practice effects with a cognitive test and so there is a limit to the way in which it can be meaningfully used over time. To account for this parallel forms are available with the RBANS.

Use in the current thesis

The RBANS was used in the longitudinal study (Chapter 4) since it gives a more sensitive and comprehensive indication of the cognitive status of the participant than is obtained using the TICS (used as a screening measure in Chapter 3).

Silver lining questionnaire

Scale Description

The Silver Lining Questionnaire (Sodergren & Hyland, 1997; Sodergren & Hyland, 2000; Sodergren et al., 2002; Hyland et al., 2006; Sodergren et al., 2004) was developed to measure the positive influence that a medical condition may have on a person's life.

Five potential subscales of the Silver Lining Questionnaire have been identified (McBride et al., 2009): 'improved relationships'; 'greater appreciation for life'; 'positive influence on others', 'personal inner strength', and 'changes in life philosophy'. McBride et al (2009)

discuss these in the context of adversarial growth. It is however also possible to use the overall score from the Silver Lining Questionnaire.

Example questions are 'I appreciate life more because of my injury'; 'I am less concerned about failure because of my injury'; 'my injury gave me the opportunity to meet new people'. There are 38 questions which are answered on a 5-point Likert scale ranging from 'strongly agree' to 'strongly disagree'.

Reliability/Validity

The Silver Lining Questionnaire has been shown to have good internal consistency ($\alpha=0.93$; Sodergren, 2002) and good test-retest reliability ($r=0.90$; Sodergren et al, 2002). It has not been used previously in a brain injured population.

Use in the current thesis

There are many reports in the literature concerning adjustment to chronic illness or injury that people may find a positive aspect to their experiences (Muenchberger et al, 2008; Nochi, 2000, McGrath, 2004). This may include a response shift effect, in that people change their perspective, but the concept goes beyond response shift. It includes actual changes such as the opportunity to meet new people, build new relationships, or change their lifestyle. These alterations go beyond the changes described by 're-conceptualisation', 'recalibration', or 'reprioritisation'.

It was felt that the Silver Lining Questionnaire encompassed underlying principles of a variety of similar concepts in the literature; for example 'adversarial growth', 'existential growth', 'benefit finding', 'post-traumatic growth', (Sodergren et al., 2004; Kangas et al., 2011; Collicutt McGrath & Linley, 2006). The Silver Lining Questionnaire was included in the current research with the aim of identifying such positive aspects of experience post injury.

The overall total of the scores from each item was used for analysis of the results from the Silver Lining Questionnaire reported in Chapter 4.

A copy of the Silver Lining Questionnaire is included as Appendix 2.5.

Brain Injury Grief Inventory

Scale Description

The Brain Injury Grief Inventory (BIGI) was designed to address issues relating to loss and adjustment following brain injury (Coetzer et al., 2006; Ruddle et al., 2005). The BIGI consists of 20 questions with three options: 'never', 'sometimes', and 'mostly'. Items are scored 0-2. There are 11 items for loss and 9 for adjustment. Items are not weighted. The total score from each subscale was used for analysis. Example 'loss' questions include; 'I try to avoid thinking and reminding myself that I have had a brain injury', 'I miss the things I cannot do since my injury', and 'life is empty since my injury'. Example 'adjustment' questions include; 'I am able now to think through what the brain injury means to my life', 'I have stopped comparing how things were before my brain injury', and 'I think I understand what has happened to me'. The BIGI was used in the study reported in Chapter 4.

Reliability/Validity

The BIGI has good validity and test-retest reliability (Ruddle et al, 2005). Cronbach's alpha for the 'loss' scale was .74, and on the 'adjustment' scale was 0.62. Test-retest reliability was demonstrated with a correlation of 0.89 for loss, and .58 for adjustment. Correlations with the HADS, Beck Hopelessness Scale, and Grief Experiences Inventory demonstrated that the two subscales of the BIGI measure different constructs.

Use in the current thesis

It was expected that in response to their brain injury and any consequential losses that participants would experience a reaction that may be similar to a grieving process. Changes that occur to a person after a brain injury have been related to losses that require a subsequent grieving process (Coetzer, 2008). Carroll and Coetzer (2011) report that identity change is significantly positively correlated with both loss ($r=.53$) and adjustment ($r=.35$) on

the BIGI following a brain injury. The BIGI was included in the current study to provide a measurement of loss and the extent to which participants had been able to adjust. It was expected that there would be a level of loss reported as a result of injury with the possibility that a higher score on the adjustment subscale may be positively related to reported QoL. The BIGI was used in Chapter 4 and both loss and adjustment subscales are reported. A copy of the BIGI is included in Appendix 2.6.

Iowa Netherlands Social Comparison Orientation Measure

Scale Description

The Iowa-Netherlands Social Comparison Orientation Scale (INCOM) was developed by Gibbons and Buunk (1999) to provide a measurement of comparison orientation. Social comparison is represented in the literature as influencing the way people perceive themselves in relation to others (Festinger, 1954; Schachter, 1959; Wills, 1981; Suls et al., 2002). Gibbons and Buunk (1999) identify a number of reasons for the development of their social comparison measure which are in part related to Festinger's social comparison theory (Festinger, 1954). While only self-evaluation is closely related to Festinger's theory they suggest that motives for social comparison may be wider, and may include self-evaluation, self-improvement and self-enhancement. Gibbons and Buunk (1999) argue that periods of stress or change may precipitate greater social comparison and that it is a strategy utilised more commonly during times of uncertainty. They also identify a number of personal characteristics that may influence the use of social comparison (e.g. depression, self-esteem, neuroticism).

The INCOM consists of 23 items; with 11 items assessing social comparison in general and 6 each for upwards and downwards comparison. Responses are on a 5 point Likert scale. The maximum score on the comparison in general scale is 55, and on the upward and downward

scales it is 30. Example questions include 'I always pay attention to how I do things compared with how others do things' (comparison in general); 'When it comes to my personal life, I sometimes compare myself with others who have it better than I do' (upwards comparison); and 'When I wonder how good I am at something I sometimes compare myself with others who have it worse than I do' (downwards comparison).

Reliability/Validity

The scale was developed using a combination of American and Dutch students, adults, and cancer patients as participants (Gibbons and Buunk, 1999). Internal reliability was good, with Cronbach's alpha for these groups ranging from .77 to .84. This measure has been used previously with people who have had a brain injury (Arenth et al., 2006), however psychometric data are not available in this population.

Use in the current thesis

Social comparison is implicated in the Sprangers and Schwartz (1999) model of response shift as a mediating factor. Previous research with people (Arenth et al., 2006) who have had a brain injury has indicated that there is no difference in the way upwards and downwards social comparison may be used at different time points after injury (1 and 6 months) however there is little understanding about how using social comparison in general may impact on QoL reporting. Anecdotally there is the suggestion that some people in a brain injury rehabilitation setting may compare themselves with others who are worse off. As a consequence they perceive themselves to be lucky in their current situation. This may in part be related to personality traits, but it is also likely that individuals are exposed to others who automatically become comparator groups. On a neurosurgery ward or brain injury rehabilitation unit it is likely that a patient will come into contact with significant morbidity to compare with. As an individual recovers and re-integrates with pre-injury life it is possible that their comparator group may change and as a consequence so too will the way in which comparisons are made.

The aim in the current research was to identify whether there is a relationship between the use of social comparison and reported QoL. The INCOM was used in Chapter 4 to examine whether there is a relationship between the use of social comparison in general and reported QoL. A copy of the INCOM is included in Appendix 2.7.

Patient Competency Rating Scale

Scale Description

Lack of awareness is a well-documented consequence of brain injury (Bach & David, 2006), and it is a phenomenon that may influence judgements concerning QoL. The Patient Competency Rating Scale (PCRS; Prigatano and Klonoff, 1998) is a measure used to assess levels of awareness. Questions related to activities and tasks that are performed as part of

day to day life; for example, self-care, cooking, cleaning, and driving. There are also questions relating to relationships, emotional control, and general coping ability. Answers given by the patient are compared with those given by a relative or a clinician who is involved with their care and is familiar with their level of functioning. Discrepancies between the respondents indicate a lack of self-awareness. There are three ways in which this can be calculated: comparison made between the patient and their relative; between the patient and their clinician; or between the patient and the mean of the scores provided by the relative and clinician. There are 30 questions which are answered on a 5 point scale with the options; 'can do with ease', 'fairly easy to do', 'can do with some difficulty', 'very difficult to do', and 'can't do'. Examples of questions are 'how much of a problem do I/they have preparing my/their own meals', 'how much of a problem do I/they have in keeping appointments on time', and 'how much of a problem do I/they have in adjusting to unexpected changes'. The maximum score is 150, with the difference between the patient and informant (clinician or significant other) ratings being calculated.

Ways of scoring the PCRS vary, with total scores being used, an average of the competency ratings across all items, the number of items scored higher by the patient with brain injury versus that of the informant, or calculating the difference for each item so that patterns of response can be identified. Four broad subscales have been described: Activities of Daily Living, Interpersonal, Cognitive, and Emotional (Leathem et al., 1998). These are not widely used, but were used in the current research reported in Chapter 6 to provide a more in depth understanding of levels of awareness of participants whose interviews were used for Interpretative Phenomenological Analysis. For overall scores Sherer et al (2003) give the following cut off values: clinician-patient scores of <28 indicate mild or no impaired self-awareness, 28-51 indicate moderately impaired awareness, and >51 indicate severely impaired awareness. In the current study the overall score was used for reasons of simplicity, with the exception of Chapter 6 where impairment in different areas was

examined to provide a more detailed analysis of impaired awareness using subscales described by Leathem et al. (1998).

Reliability/Validity

Test-retest reliability has been reported shown to be high with $r = .97$ for patients and $.92$ for relatives (Prigatano et al., 1990). In a separate study intraclass correlations were used to demonstrate acceptable test-retest reliability ($.85$), strong internal reliability was also reported (patients $\alpha = .91$, relatives $\alpha = .93$ (Fleming et al., 1998).

Use in the current thesis

The PCRS was used in Chapter 4 to give an indication of the level of awareness that participants had of their level of disability. It was also used to gain a better understanding of self-awareness of participants in the qualitative study reported in Chapter 6. Copies of the PCRS are included in Appendix 2.8.

Multidimensional Scale of Perceived Social Support

Scale Description

The Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet et al., 1988; Canty-Mitchell & Zimet, 2000; Zimet et al., 1990) is designed to assess levels of perceived social support from different sources: friends, family and significant others. It has been used with people with brain injury (Sady et al., 2010). It consists of 12 items answered on a 7 point Likert scale with options ranging from 'very strongly disagree', to 'very strongly agree'. The three subscales (friends, family, and significant other) are each addressed by 4 questions. Example items include 'there is a special person who is around when I am in need', 'my family really tries to help me', and 'I can count on my friends when things go wrong'. The

total possible score for each subscale will therefore be 28, with the maximum total score being 84. A higher score indicates greater social support.

Reliability/Validity

Cronbach's alpha was reported by Zimet et al (1988) for the subscales 'significant other' ($\alpha=.91$), 'family' ($\alpha=.87$), and 'friends' ($\alpha=.85$), and for the total scale ($\alpha=.88$). Test-re-test reliability was also good at $r=.72$, $r=.85$, $r=.75$, and $r=.85$. Zimet et al (1988) demonstrate validity of the measure by providing evidence to support their hypothesis that social support is related to anxiety and depression. In addition to this Kazarian and McCabe (1991) demonstrated that the measure has good internal reliability ($\alpha= .85$ to $.94$), and correlates with the Social Support Behaviour Scale. The original reliability data from Zimet et al (1988) is from data collected from undergraduates. It has been used extensively with people with brain injury (Malec et al., 2007; Davis et al., 2009; Sady et al., 2010; Muenchberger et al., 2011). Tessler (2007) reports Cronbach's alpha in a brain injured population of $\alpha=.88$ for significant other, $\alpha=.79$ for family, and $\alpha=.85$ for friends. Test-retest reliability data in a brain injured population is not available.

Use in the current thesis

The MSPSS was used in the study reported in Chapter 4. It was included to identify the sources of support that were available to participants. Social support is identified in the Sprangers and Schwartz (1999) model of response shift, and is sometimes cited as an explanation for paradoxical findings in relation to QoL (Mailhan et al, 2005). The total MSPSS score was used for analysis providing a score out of a maximum of 84. The MSPSS is included as Appendix 2.9.

Medical Outcomes Study Social Support Survey

Scale Description

The Medical Outcomes Study Social Support Survey (MOS-SS, Sherbourne and Stewart, 1991) is a nineteen item instrument that measures different types of support; emotional/informational, tangible, affectionate, and positive social interaction. These are answered on a 5-point scale from none of the time to all of the time. The total score on each subscale are: Emotional/informational, 40; Tangible, 20; Affectionate, 15; and Positive Social Interaction, 15.

Reliability/Validity

The MOS-SS has high convergent and discriminant validity (Sherbourne & Stewart, 1991). In developing the MOS-SS high levels of internal reliability were found with Cronbach's alpha for the 4 subscales ranging from .91 to .96, and α for the overall score was .97. Correlations with measures of loneliness, emotional ties, family and marital functioning, and mental health were reported to demonstrate the validity of the measure (Sherbourne & Stewart, 1991). The psychometric properties of the measure have been investigated in a number of different languages, but data from a brain injured or cognitively impaired population are not available.

Use in the current thesis

The MOS-SS was included in the study reported in Chapter 5. This measure assesses different aspects of support from the MSPSS, and was thought to be of more relevance for the group studied in Chapter 5: over a longer recovery period it was felt that the types of support available rather than simply presence of people willing to provide support may be of particular relevance.

The MOS-SS is included as Appendix 2.10.

National Adult Reading Test - Revised

The National Adult Reading Test - Revised (NART-R; (Nelson, 1982; Nelson & Willison, 1991) provides an estimate of pre-morbid levels of intelligence (Crawford et al., 1990; Crawford et al., 2001). The participant is given a list of 50 irregular words to read out one after another. Participants are scored on how many words are pronounced incorrectly.

Reliability/Validity

Levels of test-retest reliability are good, as is inter-rater reliability (O'Carroll, 1987; Crawford et al., 1990). Internal reliability has also shown to be high (>.90) (Crawford et al., 1988). It has also been demonstrated to have good retest reliability in participants with dementia (O'Carroll et al., 1987). Comparisons with controls and with estimates based on other demographic variables have demonstrated that it is a valid way of estimating pre-morbid intelligence levels (Watt & O'Carroll, 1999; Bright et al., 2002; Crawford et al., 1990).

Use in the current thesis

The NART was included in the longitudinal study to provide an estimate of pre-morbid intellectual functioning.

The Brief-COPE

Scale Description

The COPE Inventory (Carver et al., 1989) is widely used and has been employed previously with people who have a brain injury (Tomberg et al., 2007; Tomberg et al., 2005; Finset & Andersson, 2000).

The COPE inventory consists of 60 items which are answered on a four point scale ('I don't do this at all', 'I do this a little bit', 'I do this a medium amount', and 'I do this a lot'). This gives scores for 15 subscales. The COPE can be time-consuming to complete, so a shorter version, the Brief-COPE (Carver, 1997) has been developed, which has also been used

successfully with people with brain injury (Snell et al., 2011). The Brief-COPE can be used to measure dispositional coping and coping styles during a particular time period. The difference between these two approaches is the focus is either on what the person would do in general, or what they would do in response to a particular situation. For this research the focus was on dispositional coping. This was because of the relatively long time period under investigation in some of the studies which would mean that coping in general rather than as a direct response to injury is likely to be more important. There are 14 subscales; self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive re-framing, planning, humour, acceptance, religion, and self-blame. Each of these reflect a different way in which people may choose to cope with a situation they find themselves in (or coping style). Example items include, 'I've been concentrating my efforts on doing something about the situation I'm in', 'I've been getting help and advice from other people', and 'I've been trying to find comfort in my religion or spiritual beliefs'. Items are answered on the same four point scale used in the full version of the COPE inventory.

Reliability/Validity

Internal reliability of the Brief COPE was reported by Carver (1997), with Cronbach's α ranging from .50 (venting) to .90 (substance use). Reliability levels of some scales are relatively low related to the fact that each scale consists of just two questions, but Carver argues that similarities with the main COPE measure provide further support for the use of the Brief COPE. Reliability data is not available in a brain injured sample, although the full COPE has been used before in this population (Tomberg et al., 2007; Tomberg et al., 2001; Tomberg et al., 2005). Internal reliability of the Brief-COPE in a mild TBI population was reported by Snell et al (2011) with scores ranging from $\alpha=0.43$ (self-distraction) to $\alpha=0.97$ (substance use). While the subscales of the COPE and Brief-COPE allow for an in-depth

investigation of the way in which individuals cope there are some practical issues in using these measures relating to the number of subscales. For this reason principle components analysis has been used to reduce the number of variables (Kallasmaa & Pulver, 2000; Finset & Andersson, 2000).

Use in the current thesis

The Brief COPE was used in the study reported in Chapter 5 to investigate the possibility that different ways of coping may influence reported QoL. Given the number of subscales that are involved principal components analysis was used to narrow down the variables for further investigation.

The Brief COPE is included in Appendix 2.11.

Life Orientation Test – Revised

Scale Description

The Life-Orientation Test - Revised (LOT-R) is a widely used measure of dispositional optimism consisting of 10 questions answered on a five point Likert scale (Scheier et al., 1994). This gives a total possible score of 50. Example questions are ‘In uncertain times, I usually expect the best’, ‘I hardly ever expect things to go my way’, and ‘Overall, I expect more good things to happen to me than bad’. It has been shown to have good predictive validity with high levels of internal consistency and test-retest reliability (Scheier et al., 1994). It has also been used with people who have had a brain injury (Ramanathan et al., 2011).

Reliability/Validity

The original reliability data gives Cronbach’s α for the full scale as .78 (Scheier et al., 1994). Test-retest correlations are reported as .68, .60, .56, and .79 at 4, 12, 24, and 28 months demonstrating a reasonable level of stability over time. While the LOT-R has been used

previously with people who have a brain injury reliability data is not available in this population (Tomberg et al., 2005; Ramanathan et al., 2011).

Use in the current thesis

The LOT-R was used in the study reported in chapter 5 to address the impact optimism may have on reported quality of life. The Sprangers and Schwartz (1999) model of response shift identifies personality as an influence on response shift, and dispositional optimism was chosen as a candidate measure.

The LOT-R is included in Appendix 2.12.

Chapter 3: Individualised versus global assessments of quality of life after head injury and their susceptibility to response shift¹

Introduction

There is growing acknowledgement that QoL is a key outcome measure after head injury, and arguably more important to the person concerned than functional outcome. However, there is little current agreement about the best way of assessing QoL. Dijkers (2004), in his review of the literature, describes a number of ways in which QoL as a concept can be approached. One popular strategy is to ask for global rating of life satisfaction, and this typically yields a single estimate, for example, on a 0-10 scale (Hadorn & Uebersax, 1995; Hadorn et al., 1995). On the other hand individualised measures use dimensions elicited from the person themselves, and therefore potentially capture more of the complexity of the concept, in terms of what influences an individual judgement (Dijkers, 2003).

The Schedule for Evaluation of Individual Quality of Life (direct weighting procedure; SEIQoL-DW) (Hickey et al., 1996) is an assessment that has been used to provide a quantitative measurement of individualised QoL. Identifying personal differences may be of specific value in clinical practice as a basis for tailoring rehabilitation programmes to individual needs. Furthermore, gaining a clearer understanding of what is important to individual QoL would potentially allow for a shift of focus in both research and practice away from traditional conceptions of QoL.

¹ The results in this chapter have been published: Blair H, Wilson L, Gouick G, Gentleman D. (2010) Individualised versus global assessments of quality of life after head injury and their susceptibility to response shift. *Brain Injury*. **24 (6)**. 833-843.

The SEIQoL-DW has been used in a variety of populations (Le Vasseur et al., 2005; Moons et al., 2004; Mountain et al., 2004; O'Boyle et al., 1992), including carers of TBI patients (Moules & Chandler, 1999; Hickey et al., 1997), however not with patients who have had a TBI. As a means of evaluating QoL the SEIQoL-DW appears comparatively complex, requiring a certain level of cognitive competence. The participant nominates five areas of daily life, which they then rate for current satisfaction and relative importance. The authors of the SEIQoL acknowledge that it may not be suitable for people with cognitive impairment, and there is therefore an issue with assessing people with TBI. However, the SEIQoL-DW direct weighting measure is less complex than the original SEIQoL concerning which the authors made this assertion. The SEIQoL-DW has been used successfully with elderly people (Mountain et al., 2004), stroke patients (Le Vasseur et al., 2005), and children (Wagner et al., 2004), therefore it is also worth investigating this measure on a TBI population. A purpose of this study was to investigate QoL in patients with TBI using the SEIQoL-DW, in order to address the validity, and to compare it to Hadorn's Scale (Hadorn & Uebersax, 1995), a global assessment of QoL.

Of particular interest was the feasibility of using the SEIQoL-DW in a TBI population. This instrument gives the potential for looking at QoL domains important to the individual. The construct validity of the SEIQoL-DW was studied by examining whether it showed expected relationships with the Medical Outcomes Study SF-36 (Ware et al., 1993; Jenkinson et al., 1996), the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983), and the Glasgow Outcomes Scale-Extended (Wilson et al., 1998). In addition to comparing individualised and global assessments we also wished to study change in perceived quality of life using retrospective judgements. Although it appears self-evident that quality of life will be poorer after TBI than before, this picture may be complicated by 'response shift'. Evidence for response shift can be obtained in a number of ways (Schwartz et al., 1999; Sprangers & Schwartz, 1999; Daltroy et al., 2000; Daltroy et al., 1999; Rapkin & Schwartz, 2004).

However, a simple and direct method is to ask participants about changes in QoL. Response shift may be indicated by differences in the aspects of life that are important or by a change in the overall evaluation of QoL. The SEIQoL-DW is a measure that has been used in the study of response shift, with the use of retrospective 'then test' judgements where the respondent makes a judgement of how things were 'then', i.e. in the past (Ring et al., 2005; Rees et al., 2005). Better than expected QoL ratings are often interpreted as indicating response shift (Norman, 2003). The SEIQoL-DW requires participants to nominate QoL domains, and thus allows for changes indicative of reconceptualization or reprioritisation response shift processes to be identified.

Study Aims

The aims of this study were:

- To evaluate the SEIQoL-DW as a means of assessing QoL in people who have had a traumatic brain injury, and to compare it with the simpler Hadorn's overall scale
- To examine evidence for reconceptualization response shift.

Hypotheses

- The SEIQoL-DW will be a feasible method for investigating QoL in a brain injured population and will be correlated with the Hadorn's scale.
- There will be changes in the domains on the SEIQoL-DW that are nominated as being important to QoL before and after brain injury.

Exploratory Analyses

- Relationships between the QoL Assessments and the other measures (SF-36, HADS, GOSE, and TICS) will be explored.

Methods

Design

This study was cross-sectional. Correlational analyses were used to examine the relationships between measures as a way of assessing the validity of measures. A within group comparison was made of the difference between QoL reported for the current time and retrospectively from before injury. Participants were between one and ten years post injury and were interviewed at a single time point.

Ethical Approval

Ethical approval was obtained from the Tayside Committee for Medical Research Ethics, which was granted on 2nd August 2007 (reference 07/S1401/89). The purpose of the study was explained to participants at the start of the interview, and they were reminded that they were free to withdraw at any time. Written consent was obtained from all participants. Participant information sheet and Informed consent forms are included in Appendix 3.1 and 3.2.

Participants

Twenty eight participants with head injury were recruited from the Centre for Brain Injury Rehabilitation (CBIR) at the Royal Victoria Hospital, Dundee and the associated brain injury clinic.

Inclusion Criteria: Aged 18-65 with a diagnosis of TBI, able to provide informed consent and with no evidence of cognitive impairment indicated by the Telephone Interview for Cognitive Status (TICS>26; Brandt and Folstein, 2003). People in the non-impaired and ambiguous ranges were included and those in the impaired range were excluded.

All TBI patients referred to the service between January 2000 and September 2007 were considered for inclusion. A total of 99 referrals were considered. Initially 20 were excluded

due to current psychiatric problems or drug and alcohol use, 9 had moved away, 6 had major communication difficulties, 2 were deceased, and 2 were excluded for other reasons. The remaining 60 patients were initially contacted by letter, and were provided with information about the study. They were asked to agree to being contacted about participation in the study. For those that did not reply, a follow up letter was sent. Thirty two of the 60 responded, three of whom did not attend for interview, leaving data available for 29. One of these was excluded due to unexpectedly impaired cognitive functioning, leaving 28 subjects in the study.

Measures and procedure

The following measures were used (described in detail in Chapter 2):-

- Quality of life: SEIQoL-DW (Hickey et al., 1996), Hadorn's global QoL rating scale (Hadorn et al., 1995), Short-Form 36 (Jenkinson et al., 1993), HADS (Zigmond and Snaith, 1983). The SEIQoL-DW was used to provide an overall score for QoL (0-100), as well as to identify QoL domains of importance to individuals and how these may change. The Hadorn's scale gives a rating of QoL from 0-10. The SF-36 used the Physical Component Summary (PCS) and Mental Component Summary (MCS) which are standardised based on a population mean of 50 and standard deviation of 10. Both the Anxiety and Depression Subscales from the HADS were used (each with a total possible score of 21, scores >8 indicating there may be clinically relevant distress).
- Cognitive Screening: Telephone Interview for Cognitive Status (Brandt & Folstein, 2003). This was used to screen for participants with major cognitive impairment. A cut off score of <26 was used.

- Functional Outcome: Glasgow Outcome Scale – Extended (Wilson et al., 1998). This gives an indication of disability based on a structured interview.

In addition to current QoL, participants made a judgement concerning their QoL before TBI on both the SEIQoL-DW and Hadorn's scale; a retrospective judgement, comparable to that made in the 'then-test' (see Chapter 2). Participants were given the opportunity to nominate another five domains on the SEIQoL-DW if they felt that they had changed. This was done to ensure that participants continued to rate what was of importance to them as the nominated domains for their current life may not have been relevant before their injury. They were then asked to rate these domains in the same way for status and importance to reflect how they were before injury. Using a retrospective judgement, or the 'then test' procedure, allows the participant to report their perception of how QoL has changed. It is not necessary that retrospective judgements provide an accurate recollection of previous QoL, only that they reflect the person's current perception of previous QoL, and thus their perception of change. Change scores were calculated on both the SEIQoL-DW and Hadorn's scale by subtracting the score for past QoL from the score for current QoL; thus a positive number represents a positive change in QoL.

Medical records were accessed to obtain information about the severity of injury in the form of the Glasgow Coma Scale (GCS) and length of hospital stay. The initial GCS was noted where it was available on admission to hospital or recorded by paramedics at the scene.

Interviews took place at the hospital, and lasted around 40-60 minutes, of which 20-30 minutes was for completion of the SEIQoL-DW.

Statistical Analysis

Prior to analysis the distributions of scores were examined for levels of skew and kurtosis and histograms were plotted. Distribution statistics for the main variables used in the study are included in Appendix 3.3. Due to non-normal distribution on a number of variables non-parametric correlation analyses were used throughout the study. In addition to this Wilcoxon non-parametric signed rank tests were used to examine differences between current and retrospective judgements.

Two tailed tests were used throughout the study, unless effects were specifically predicted. In detecting a significant relationship between measures it will only be possible to detect effect sizes in the region of 0.5 or greater (a medium to large effect). With a sample size of 28 and a power of 0.8 a correlation of $\rho=0.485$ is required to be significant at $p<0.05$ (two-tailed) (G*Power 3.1; Faul et al, 2009). Correlations were conducted on 6 variables with each of two QoL measures. This gave a total of 12 correlations, as a consequence Bonferroni correction was used to control for multiple comparisons.

Results

Sample demographics and clinical characteristics.

The 28 patients in the study had a mean age of 42.14 (SD=13.97; range 22-65), and consisted of 19 males and 9 females. The mean time post injury was 57.53 months (SD=33.64), and ranged from 12 to 120 months. Fifteen patients had sustained their injury in an RTA (eight in cars, two pedestrian, two cyclists and three motorcyclists); six in falls; four due to assaults; and three in sporting accidents. The mean admission Glasgow Coma Score for patients in this study was 8.0 (SD=3.74), and ranged from 3 to 14. Patients had spent a mean of 89.46

days as an inpatient (including both acute and rehabilitation hospital treatment; SD=65.65, range 3 to 251 days). Outcome from injury assessed using the GOS-E is shown in Table 3.1.

Table 3. 1: Numbers of patients with each level of disability on the GOSE

GOSE category	Number of patients
Lower severe disability	2
Upper severe disability	5
Lower moderate disability	2
Upper moderate disability	4
Lower good recovery	9
Upper good recovery	6

Cognitive functioning

Cognitive Functioning, as measured by the TICS, ranged from 26 to 38, with a mean of 32.64 (SD=3.83). There was no significant relationship between the level of cognitive functioning as measured by the TICS, and the overall SEIQoL-DW score (see table 3.2), suggesting that the levels of cognitive performance in this sample did not impact on reporting on the SEIQoL-DW. A scatter plot of this data did not show any evidence of a non-linear relationship (see figure 3.1). All 28 patients appeared to understand fully the procedures when interviews were conducted.

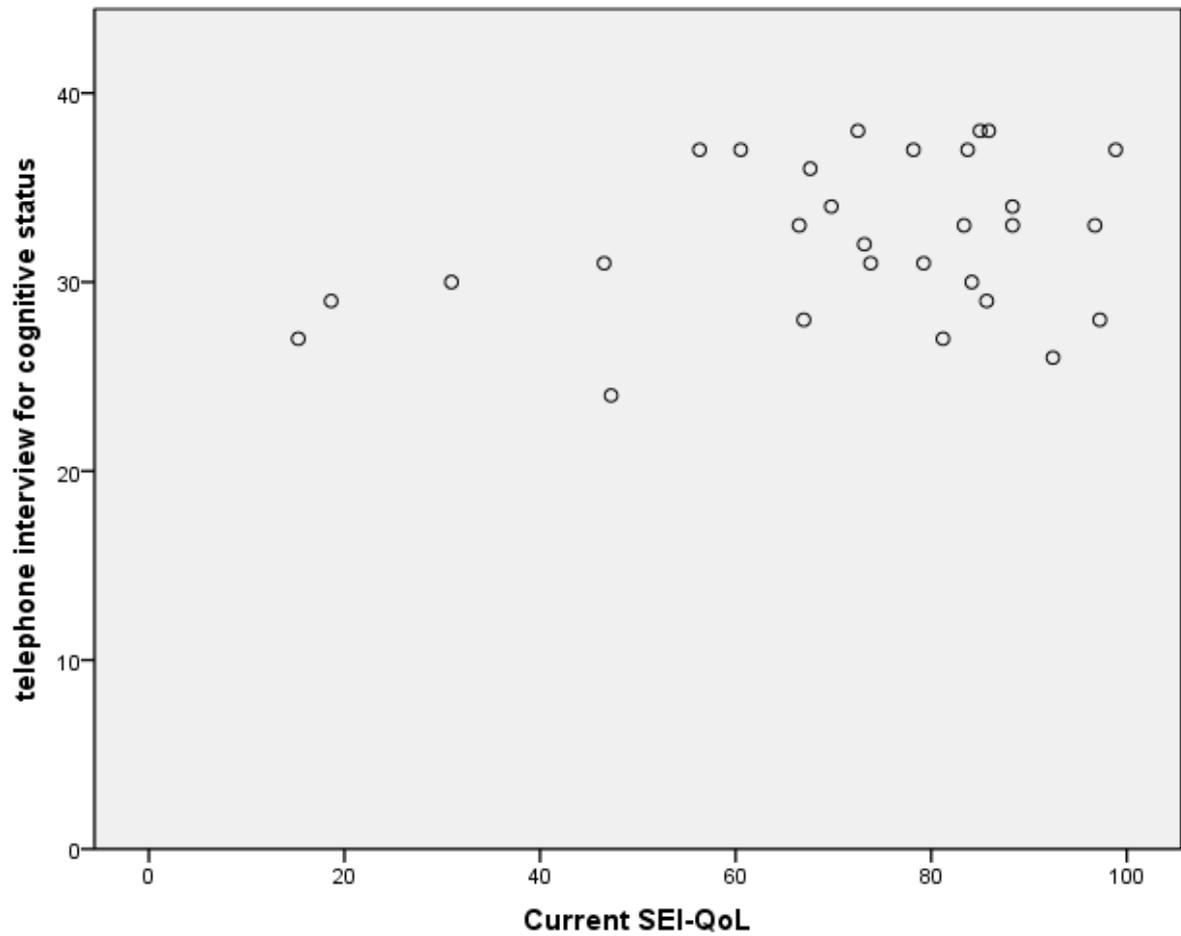


Figure 3.1: Distribution of the relationship between Cognitive Functioning as measured by the TICS and scores on the SEIQoL-DW

Table 3.2: Non-parametric correlations (Spearman's rho). Overall SEIQoL-DW and Hadorn's 1-10 scale correlated with SF-36 summary scores, HADS, GOS-E, and TICS. Tests are two-tailed. Significance is indicated after Bonferroni correction.

	Overall SEIQoL-DW	Hadorn's scale
SF-36: MCS	.348	.680*
SF-36: PCS	.103	.270
HADS: Anxiety	-0.287	-0.433
HADS: Depression	-0.553*	-0.786*
GOS-E	0.220	0.457
TICS	0.101	0.248

**p<0.0042(Bonferroni corrected significance level)*

SEIQoL-DW validity: Administration, relationship to other measures, and comparison with Hadorn's scale

Only two of the 28 participants required to hear the suggestion list for those unable to nominate five areas, and only after nominating two and three in each case independently. Thus only five out of 140 cues (3.6%) were nominated with the assistance of the list. Areas nominated are shown in Figure 3.2. Areas that were only nominated by one person are not included (these were: being sober, personal appearance, material things, fate, doing things to a high standard, and making a contribution to society). As might be expected, family, work and friends were the most commonly nominated. Where exercise and diet were nominated they have been grouped with 'health'. 'Mental States' include such things as 'happiness', 'appreciation', 'anger', 'guilt'; these were quite wide ranging in the way they were described by participants reflecting the different things that they meant to them and

the differing impacts they have on life. 'Time' might be having time alone, or time to get things done.

As expected, the relationship between the SEIQoL-DW and Hadorn's scale was significant ($\rho=0.514$, $p=0.003$, one tailed). Relationships between the SEIQoL-DW and other measures are shown in Table 3.2. Disability as measured by the GOSE, or the PCS or MCS of the SF-36, were not significantly associated with QoL as reported by the SEIQoL-DW. The Depression scale of the HADS was found to correlate significantly (negative correlation) with the overall SEIQoL-DW score. Thus, lower levels of depression were associated with greater quality of life. There was no significant correlation with the Anxiety scale of the HADS.

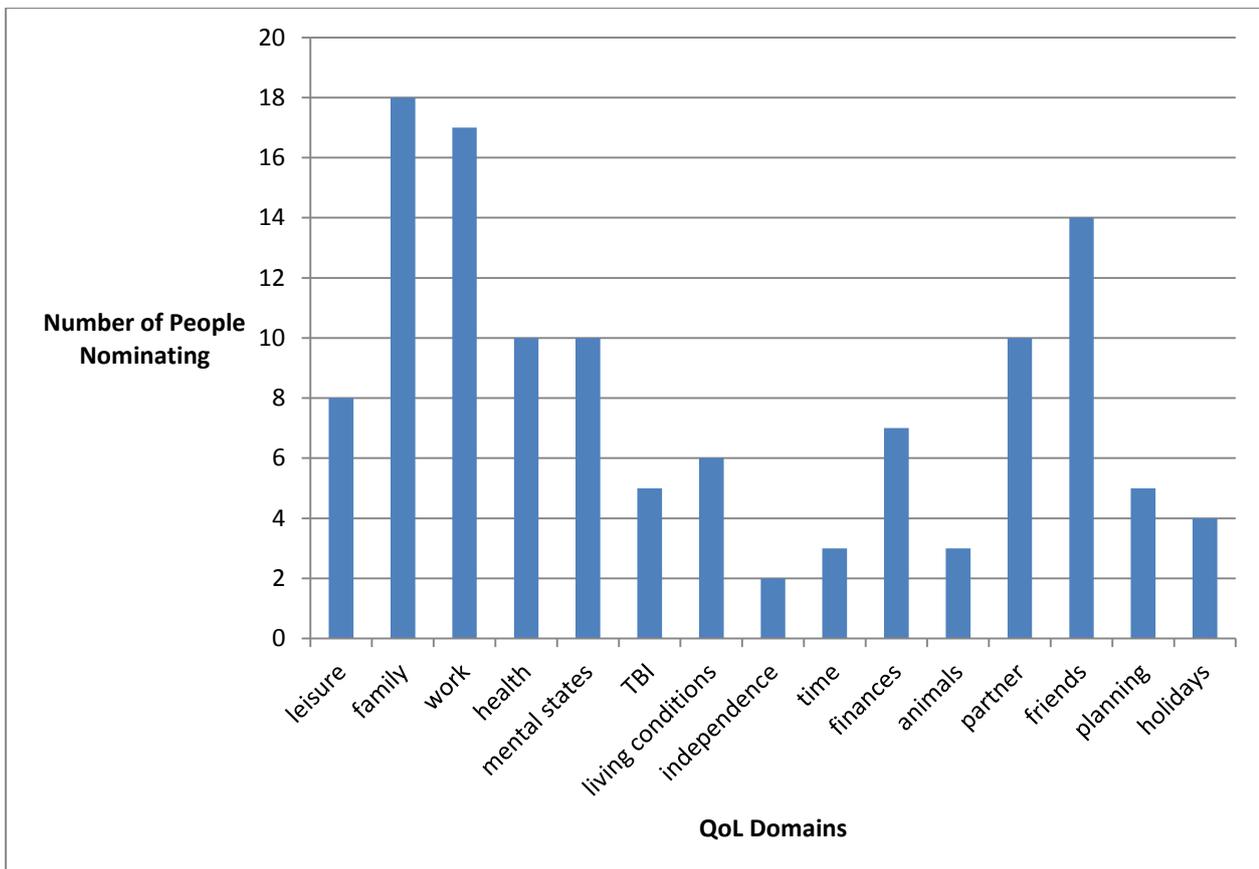


Figure 3.2: Areas of QoL nominated in the SEIQoL-DW; excluding those with only 1 nomination (n=28).

There were significant relationships between Hadorn’s scale and the MCS of the SF-36 and the Depression subscale of the HADS (see table 3.2). No significant relationships were found between the Hadorn’s scale and the PCS of the SF-36, the GOSE, or the Anxiety subscale of the HADS ($\rho=.433$). There was also no significant relationship found between the Hadorn’s scale and the TICS.

Table 3.3: Means and Standard Deviations of QoL ratings for past and current judgements (n=28).

	SEIQoL-DW	Hadorn’s scale
Past QoL	77.37 (SD=19.87)	7.71 (SD=1.85)
Current QoL	72.39 (SD=21.87)	7.31 (SD=1.79)

Perceived Change in Quality of Life: Evidence for response shift

Contrary to what might be intuitively expected there was no significant difference in the mean ratings of current and a retrospective judgement of past quality of life, on either the SEIQoL-DW ($z=-0.967$, $p=0.333$), or Hadorn’s scale ($z=-0.774$, $p=0.439$). Means and standard deviations are shown in table 3.3. One participant reported an unexpectedly large improvement in reported QoL as a consequence of their injury. To account for the possibility that this score was disproportionately affecting the results the analysis was repeated with the score removed and the differences remained non-significant.

Closer visual inspection of changes in QoL between the two time points demonstrates that the overall comparison masks substantial individual differences in responses of head injured participants. While some patients reported that QoL was better before their injury others reported that their QoL was worse. A similar pattern in the individual changes in QoL over the two time points is seen on both the SEIQoL-DW and Hadorn's scale.

Differences between the retrospective past and current judgement of QoL for each participant were calculated to provide a score of change in QoL, where a positive number indicates a positive change. This was done to examine individual patterns of change. The frequency of change scores are reported in figure 3.3. This shows that while the majority of participants reported that there was little change in their QoL from before injury, others reported either a positive or negative change.

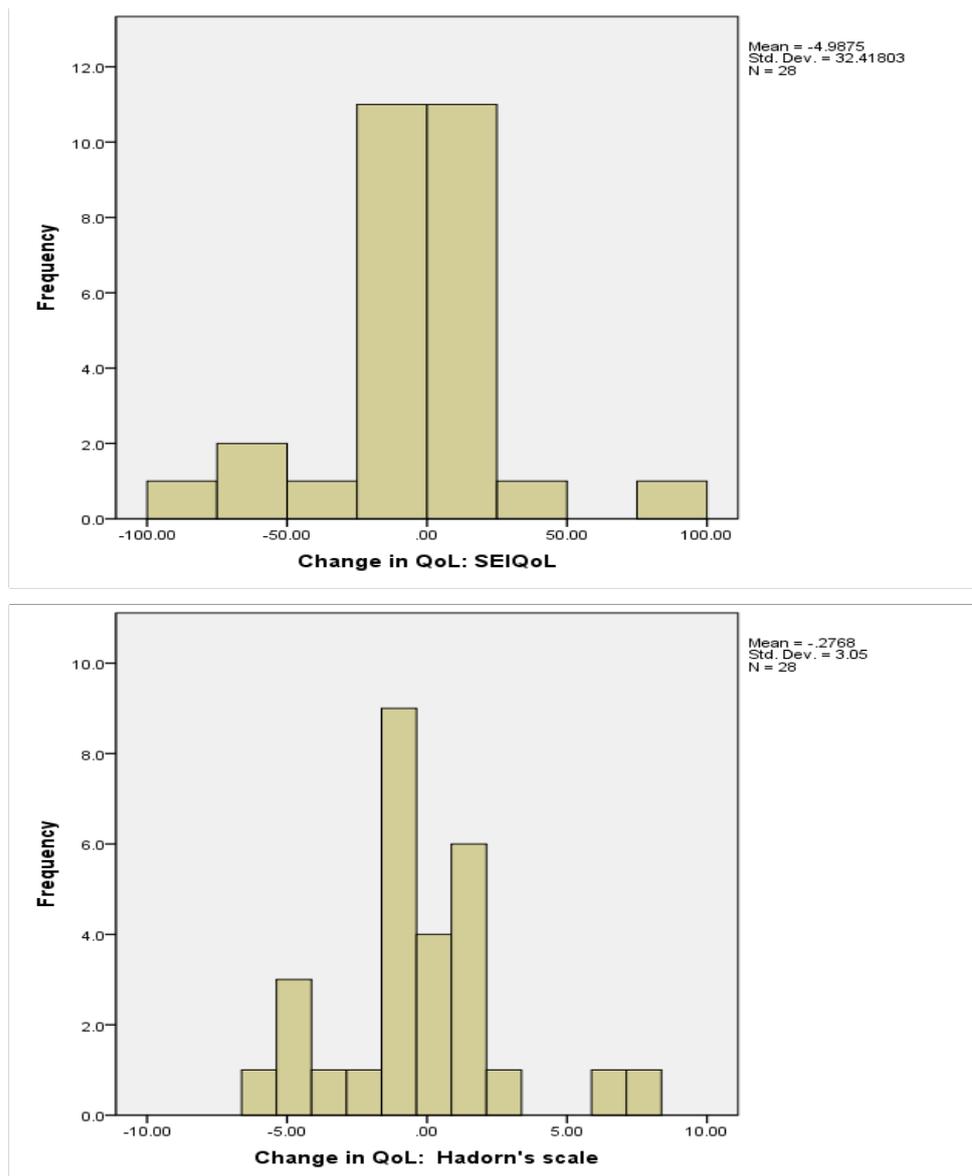


Figure 3.3: Frequency of reported change scores before TBI to the present time; as measured by the SEIQoL-DW and Hadorn's scale.

Areas nominated on the SEIQoL-DW as being most important before and after TBI are shown in Figure 3.4. The data suggested that aspects relating to family and well-being (such as partner, health, financial security and living conditions) become more important post TBI, while post TBI, work is nominated less often. Domains included as 'other', nominated by one person each, were 'drinking', 'being thin', 'myself', and 'time'. The domains 'being thin' and 'myself' were only nominated as being important prior to TBI, which may also indicate a change in focus as to what is important to QoL, with less evidence for the importance of

material goods and other people’s opinions. It should be noted that while this research was aimed at identifying how these factors change as a consequence of brain injury that they reflect a period of up to 10 years. It is not known, and there is not literature available to indicate, how these factors or changing perceptions may have altered over a similar time without the added complication of a brain injury.

Differences between past and current judgements of QoL for each participant were calculated to provide a score of change in QoL, where a positive number indicates a positive change. These change scores (QoL now versus retrospective QoL before injury) are similar to the adjusted time effects that are calculated as part of the ‘then test’ (see Chapter 2).

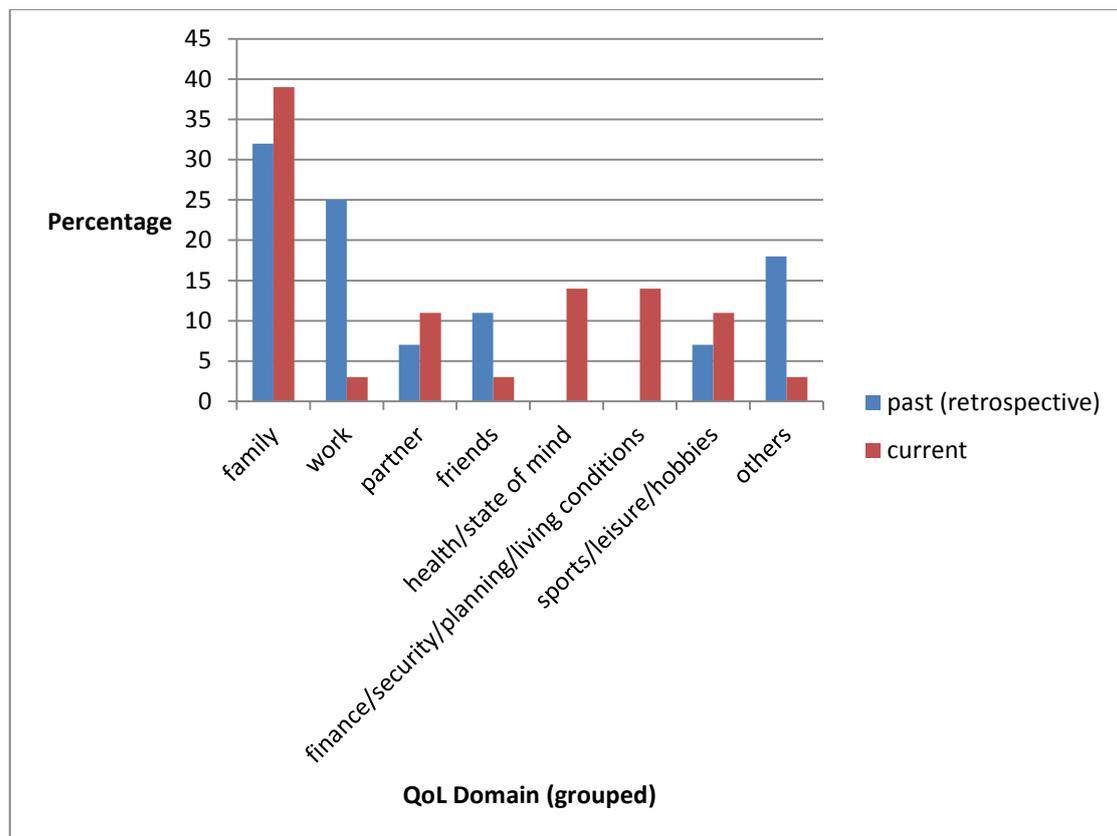


Figure 3.4 Percentage of people nominating specific domains as being most important to their quality of life before and after TBI (n=28)

Discussion

The results from this study indicate expected relationships between measures of quality of life and other assessments of outcome, but some seemingly paradoxical findings concerning perceived change in QoL since injury.

SEIQoL-DW validity and comparison with Hadorn's scale

During the interviews, the SEIQoL-DW was easy to administer with no notable difficulties in understanding. Of most difficulty was the practical manipulation of the SEIQoL-DW disc; however this was overcome with minimal assistance by all who initially had difficulty.

Nominating five QoL domains was done without assistance by most participants, the exception being two people, who independently nominated two and three domains unaided. This would not be unexpected in any population in which this measure has been used. Where level of assistance has been reported it has varied: In a study of diabetic children 21 out of 400 domains nominated by 80 participants (5%) were obtained with the assistance of the standard list, with all participants being able to nominate at least 2 (Wagner et al., 2004). In elderly patients 12 out of 60 patients were reported as needing the list or prompts (Mountain et al., 2004), whereas Waldron et al (1999) reported that 2 out of 80 cancer patients required prompting.

The relationships found between the SEIQoL-DW and the depression subscale of the HADS suggests a reasonable level of construct validity in this measure. Depression is the psychological factor that has been most consistently related to subjective QoL (Cicerone & Azulay, 2007) and good to moderate correlations were found with the overall rating and the depression subscale of the HADS.

Another indicator of the validity of the SEIQoL-DW is its relationship with the Hadorn's Scale. The concept of a simple "delighted" to "terrible" scale on which the latter is based has been widely used. It is also based on similar concepts to the SEIQoL-DW, in that quality of life is subjective and depends on individual evaluations (Bowling, 2005b). While the aim is to capture similar concepts using both the SEIQoL-DW and Hadorn's scale, they are by no means identical. This is indicated by the limit in the shared variance (25%). It is possible that the differences lie in the influence of emotional state that may be involved in making a judgement on Hadorn's scale (evidenced by the strong correlation between this scale and the HADS depression scale). In responding to the SEIQoL-DW participants are required to rationalise their decisions and make a judgement that is based on clearly specified and defined life domains, and it thus encourages more reflection than Hadorn's Scale.

There were no relationships evident between the TICS score and SEIQoL-DW suggesting that the level of variance in cognitive functioning did not impact on reporting on the SEIQoL-DW. It should not however be concluded that it is suitable for use in patients with more severe cognitive impairment.

Weaker correlations on SF-36 subscales were not statistically significant, although the correlation between the SEIQoL-DW and the MCS was moderate in strength at $\rho = .348$. With a larger sample it may be that this would reach statistical significance. In fact where SF-36 subscales have been correlated with overall QoL in previous studies relationships have not been particularly strong. Steadman-Pare et al (2001) compared physical functioning, mental health and health perceptions with Hadorn's scale in 273 TBI patients. They report a significant correlation with physical functioning of only $r = 0.30$. The strength of the relationship between the overall SEIQoL-DW and Hadorn's scale suggests that these measures do assess similar phenomena, and Hadorn's scale provides a simple and quick means of assessing QoL. However, stronger significant correlations with the HADS

depression, and with the SF-36 MCS suggest that Hadorn's Scale provides a rating more strongly related to these measures than the SEIQoL-DW. There were also non-significant relationships which were moderate in strength with the HADS anxiety ($\rho=-0.433$) and GOSE ($\rho=0.457$). It is interesting to note that the relationship between disability and both QoL measures is not significant as might have been expected. While the strength of relationship between Hadorn's scale and the GOSE is moderate in strength (and therefore the lack of statistical significance may be more easily explained by a lack of statistical power) the relationship between the SEIQoL-DW and GOSE is much weaker ($\rho=.22$). This would suggest that the conceptualisation of QoL that is made when responding to the SEIQoL-DW shows little or no influence of disability. Both the psychological and physical aspects of functioning may have a greater impact on overall QoL as measured by Hadorn's scale compared to when it is measured by the SEIQoL-DW. The Hadorn's scale is easier and quicker to administer than the SEIQoL-DW. Where more detailed analysis of individual aspects of QoL is desirable then the SEIQoL-DW would be of use.

Perceived Change in Quality of Life: Evidence for response shift

Surprisingly there was little overall difference between a current QoL judgement on the SEIQoL-DW and retrospective judgement of QoL before traumatic brain injury. However, there were substantial individual differences in patterns of change. Using a 'then test' judgement provides a measure of perceived change in QoL. As the participants in this study were between one and ten years post injury it is important to note that it is their perception of change that is of interest and it is not assumed that recollection is accurate. This reflects previous research which has compared a past judgement of QoL with a retrospective QoL judgement made at a later time (Rees et al., 2003; Korfage et al., 2007). In this previous work a retrospective judgement does not necessarily match that made at the time; rather it is the difference that indicates the occurrence of response shift. It has been argued that a

retrospective judgement allows for more accurate comparison of QoL over time as the participant will base their ratings on the same internal standards (Ring et al., 2005). These changes cannot however be conclusively attributed to a brain injury. It is not clear how these factors would have changed purely due to the passage of time. Further normative data would be required to fully understand how these factors change over time in a normal population.

Results suggest that family, partner and health were more important and work less so following TBI. This may help to explain the finding by Mailhan et al (2005) that patients with severe disability following TBI rated QoL as higher than those with moderate disability. Mailhan et al (2005) suggest this could be due to changes in interpersonal relationships, in that a person with more severe disability is out of necessity likely to have more social support, whereas someone with moderate disability is more likely to see a negative impact on their relationships. If these relationships become more important as an influencing factor when making a QoL judgement it is logical that any changes to relationships will have a greater impact on QoL itself.

Limitations of Small Sample Size

The size of the sample in this study is small, hence power is limited. Considering the limited power of the study is of particular relevance when examining the relationship between measures. A large effect is required for significance to be reached. For this reason, where there are relationships which do not quite reach statistical significance they have been included in the discussion of results. The lack of power means that exploration of the patterns and relationships is restricted to major associations. There is sufficient power to detect effect sizes that are of most interest when considering convergent validity.

Conclusions

Both the SEIQoL-DW and Hadorn's scale are valid methods for investigating QoL following traumatic brain injury, indicated by relationships with other QoL measures. Where an overall rating for QoL is required it is likely that Hadorn's simple scale provides a more useful means of measuring QoL, both in terms of practicality and validity. Where the SEIQoL-DW is likely to be of benefit is when an individualised assessment of QoL is required, which is likely to be of use when looking at changes in QoL or in clinical situations where an individual picture is desirable.

An apparent lack of overall difference between current QoL and a retrospective judgement of past QoL is consistent with influences such as response shift. Patterns of response on the SEIQoL-DW suggest that what is considered most important may change following TBI, with family and close relationships becoming more important and work less so. This provides evidence of a process of re-conceptualisation of QoL.

Individual differences in how QoL changes as a consequence of TBI provide a strong argument for further research into the factors influencing change. The results suggest that both of the measures investigated may be susceptible to response shift, and this should be kept in mind when interpreting QoL assessments.

Chapter 4: Changes in Evaluation of QoL after TBI: A

longitudinal study

Introduction

The study described in Chapter 3 presented evidence for changes in the evaluation of QoL after TBI that was consistent with the concept of response shift. Participants reported changes in domains that were most important to them thus providing evidence of re-conceptualisation. Response shift can also explain the rather paradoxical finding in this study that there was no overall change in reported QoL as a result of TBI. However, evidence for processes of response shift is rather indirect.

The theory of response shift (Sprangers and Schwartz, 1999; Figure 4.1) is based on the concept that a catalyst in the form of a change in one's circumstances leads to change in the way in which a subjective judgement of QoL is made. Response shift may occur through recalibration, reconceptualization, or reprioritisation. Recalibration occurs when the person making a QoL judgement changes the internal scale or standards on which they base their judgement; reconceptualization, when their concept of what QoL is changes; and reprioritisation, when the importance of different domains changes. Sprangers and Schwartz's model offers a number of explanations of how this may occur in the form of 'mechanisms'. Mechanisms include coping, social comparison, social support, goal re-ordering, reframing expectations, and spiritual practice. The type of mechanisms that are used will depend on 'antecedents'. These include sociodemographics, personality, expectations, and spiritual identity. Further discussion surrounding the term response shift

is provided in Chapter 1, with a detailed discussion of how it may be measured provided in Chapter 2.

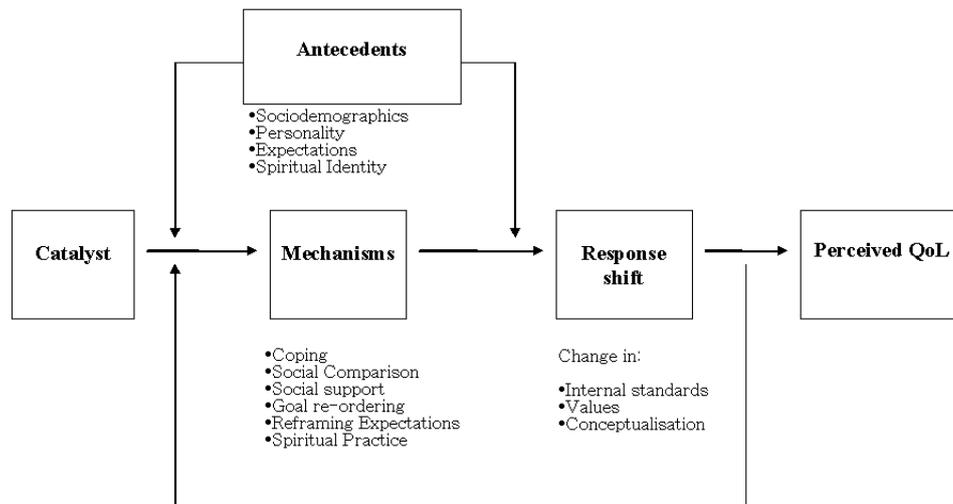


Figure 4.1: A theoretical model of response shift and quality of life (QoL). From Sprangers and Schwartz (1999).

The current study was conducted to investigate changes in evaluation of QoL directly by obtaining measurements at different time points. As described in Chapter 2 the ‘then-test’ has been used previously when looking at changing judgements of QoL (Ring et al., 2005; Nieuwkerk et al., 2007; Rees et al., 2005; Razmjou et al., 2006; Korfage et al., 2007), however the procedure has not been applied to TBI recovery. The then-test is designed to provide an estimate of how much of the change in reported QoL is due to alterations in internal standards, values and/or re-conceptualisation (i.e. response shift). It is argued that a then-test (retrospective) judgement reflect changes over time more accurately as the person is assumed to be using the same standards of measurement. In conducting and interpreting a then-test there should be some consideration of memory and the ability to accurately recall

situations in times past. The importance of this will increase when the population being studied is one in which people are likely to have memory problems, as is the case following a brain injury. In addition to this there is evidence to suggest that the inclusion of a then-test may alter responses on a post-test judgement (Nolte et al., 2012). The counter argument is that when making a subjective evaluation of QoL it is the individual's perception that is of importance and thus it is not the aim of a then-test to accurately portray the past, rather to gauge the level to which QoL is perceived to have changed.

While the clinical importance of response shift is often highlighted, in that it can have an impact on the accuracy and interpretation of self-report measure, the actual reported effect sizes tend to be small (Schwartz, 2006). For example the response shift effect size found by Korfage et al (2007) in their investigation of the impact of a diagnosis of prostate cancer ranged from as little as 0.01 on the SF-36 mental health 7 months after diagnosis; to as much as -0.43 on the EuroQoL. At 1 month post diagnosis the effects were less extreme; with the effect size for the EuroQoL being -0.26, and for the SF-36 mental health, -0.10. Both the timescale and the outcome measure used have been shown to have an impact on response shift. Schwartz et al (2000), in their meta-analysis, report that the general size of response shift effect for global QoL is around 0.30.

Schwartz and Sprangers (2010), elaborate on the importance of properly designed research in response shift. They suggest that with an increasing awareness of the likelihood of response shift occurring there is an increasing tendency towards null or negative results being explained as a result of a response shift process. As the other research presented in this thesis utilises a cross-sectional design this is clearly an issue which is important to address. Measurement of the importance of different QoL domains at different time points allows for investigation of the changes which occur in the way that a QoL judgments are made.

A further consideration should be the lack of data relating to the possibility of a response shift effect in the normal population. It is possible that these changes may occur as part of a normal process as people go through life. This ongoing change in perceptions should be kept in mind as a possibility when looking at specific change in response to a particular event.

Measures were included in the study to gain an understanding of influences on QoL judgements. Factors studied included variables proposed by Sprangers and Schwartz (1999) as part of their theoretical model of response shift (see Figure 4.1): Perceived social support (measured by the Multidimensional Scale of Perceived Social Support, MSPSS); social comparison (measured by the Iowa Netherlands Comparison Orientation Measure, INCOM); or looking for positives in a situation (Silver Lining Questionnaire) were measured. Factors specific to brain injury that were studied included cognition (assessed by the RBANS), awareness of deficits (measured using the Patient Competency Rating Scale, PCRS), and adjustment to the losses that occur as a result of brain injury (assessed with the Brain Injury Grief Inventory, BIGI). It was thus planned to study factors included within the response shift model and additional factors that are specific to brain injury. In the original design it was hoped to collect sufficient numbers of cases for multivariate analysis of these predictors. However, in the event this did not prove practical and this part of the study is essentially exploratory.

Study aims

The aims of this study are to:

- Investigate evidence for response shift during recovery from brain injury using a then-test procedure.

- Examine factors influencing QoL, including variables from the Response Shift model and brain injury specific factors.

Hypotheses

- Response shift predicts that baseline QoL rated at follow-up will differ from baseline QoL as originally rated at baseline.

Exploratory Questions

- Are the changes in test scores indicative of recovery?
- Are these changes in importance of QoL domains indicating reprioritisation?
- What is the relative importance of factors from a Response Shift model and brain injury specific factors in influencing QoL at follow up?

Methods

Design

This was a prospective observational longitudinal study. Patients were interviewed initially between 3 and 9 months post injury and were followed up 6 months later. Within group comparisons were made between different time points. A then-test was included in the assessment of QoL to investigate the possibility of response shift.

Ethical Approval

Ethical approval was obtained from the Tayside Committee on Medical Research Ethics A, and was given on the 27th April 2009 (reference number 09/S1401/19). The purpose of the study was explained to participants at the start of the interview, and they were reminded that they were free to withdraw at any time. Written consent was obtained from all participants at baseline. Information sheets differed slightly between health board areas due to differences in complaints procedure, but as an example the participant information

sheet for Glasgow is included as Appendix 4.1. A copy of the informed consent form is included in Appendix 4.2.

Participants

Twenty seven participants were recruited. Two of these did not attend for interview. Data is therefore available from 25 people at time point one. The sample included twenty two men and 3 women with a mean age of 38.4 (SD=15.21). Time since injury ranged from 88 to 278 days (2.9 to 9.2 months), with a mean of 179 days (SD=62.1; equivalent to 6 months). Mean NART scores were 21.16 (SD=11.82) indicating a pre-injury full scale estimate of an IQ of 105.

Twenty of the participants were followed up around 6 months after their first interview. Time between interviews was a mean of 6.9 months (208 days; SD=19.1), ranging from 174 (5.8 months) to 265 (8.8 months).

Inclusion Criteria: aged between 16 and 65; had a TBI in the past 9 months; had been discharged from inpatient hospital treatment; and were sufficiently well to take part in an interview and able to give informed consent, as judged by their responsible clinician.

Measures and Procedure

The following measures were used (described in detail in Chapter 2):-

- Quality of life: Hadorn's global QoL rating scale (Hadorn et al., 1995), Short-Form 36 (Jenkinson et al., 1993), HADS (Zigmond and Snaith, 1983). The Hadorn's scale gives a rating of QoL from 0-10. On the SF-36 the Physical Component Summary Scale (PCS) and Mental Component Summary Scale (MCS) were used in this study. Both the Anxiety and Depression Subscales from the HADS were used.

- Importance of QoL domains: Participants rated the importance of different QoL domains: family; work; partner; friends; health and well-being; security, finances, and living conditions; and Sports, leisure and hobbies. These were selected based on the results presented in Chapter 3. A visual analogue scale was used to provide a score from 0-10. Participants were asked to rate the importance of each area at the relevant time point (current, before injury, at time of first interview). If they felt that something was irrelevant to them it was rated as 0.
- Factors related to Response Shift model: Silver Lining Questionnaire (Sodergren & Hyland, 1997; Sodergren & Hyland, 2000), Multi-Dimensional Scale of Perceived Social Support (MSPSS) (Zimet et al., 1988), The Iowa Netherlands Comparison Orientation Measure (INCOM) (Gibbons & Buunk, 1999). The Silver Lining Questionnaire has 38 questions which are answered on a 5-point Likert scale ranging from 'strongly agree' to 'strongly disagree'. The overall total was used for analysis, which provides a score out of a total of 190. The MSPSS provides an indication of social support from 12 items answered on a 7 point Likert scale. There are three subscales (friends, family, and significant other) with a possible score of 28 for each, and a maximum total score of 84. Only the overall score was used for analysis in this study. The INCOM consists of 23 items; with 11 items looking at social comparison in general and 6 each looking at upwards and downwards comparison. The maximum score for comparison in general is 55. Only the comparison in general scale was used for analysis in this study.
- Brain Injury Specific Factors: Brain Injury Grief Inventory (Ruddle et al., 2005), RBANS (Randolph, 1998), PCRS (Prigatano et al., 1986). The BIGI consists of 11 items measuring loss and 9 measuring adjustment. The total score from each subscale was used for analysis in this study. The RBANS is a widely used measure of cognitive functioning which gives an index score based on a norm of 100. While scores for

subscales are calculated it is only the total index score that was used for analysis in this study. The PCRS is a measure of self-awareness which compares the answers given by the patients with those given by someone who knows them well on their ability to complete a number of activities. The difference is calculated between these scores with clinician-patient scores of <28 indicating mild or no self-awareness, 28-51 indicating moderate impaired awareness, and >51 indicating severely impaired awareness. The overall difference score was used for analysis in this study.

- Functional Outcome: Glasgow Outcome Scale – Extended (Wilson et al., 1998). This assessment gives an indication of disability based on a structured interview.
- Pre-morbid functioning: The NART (Nelson & Willison, 1991). This test provides an estimate of pre-morbid IQ based on the number of errors which are made when reading a list of 50 irregular words.

Patients with TBI were recruited from rehabilitation services in Tayside, Fife, Glasgow and Lothian. They were then interviewed between 3 and 9 months post injury and followed up 6 months after that. Participants were initially approached by a member of their healthcare team who provide them with information about the research along with a reply-paid slip to be returned to the researcher. Having registered their interest they were given further information and an appointment was made to see them for interview. Interviews took place at a hospital/healthcare setting familiar to the participants.

At each interview, participants provided background information, and completed each of the measures outlined above. Quality of life and response shift was measured using Hadorn's scale. This was selected because of its simplicity, thus allowing for retrospective and current judgements of QoL to be made. At the first interview participants were asked to rate their current QoL, and their QoL before their injury. At the follow up interview participants were

asked to rate their current QoL, their pre-injury QoL, and their QoL at baseline (i.e. 6 months earlier at the time of the first interview). Response shift was calculated as the difference between T1 and T2 ratings of baseline.

In addition to these overall QoL ratings participants were asked to rate the importance of different areas in their life. These areas were: family; work; partner; friends; health and/or state of mind; security, finances and living conditions; and sport, leisure and hobbies. These were selected as the areas most commonly identified by participants in the first study using the SEIQoL-DW. Ratings of set domains allow comparison of importance at different time points.

Statistical Analysis

Data were checked for normality and the distributions were found to be generally acceptable. The only measures with levels of skew and kurtosis which fell outside acceptable ranges were INCOM overall comparison and T2 pre-injury QoL rating on Hadorn's scale. The most extreme outliers were winsorised which brought levels of skew and kurtosis into acceptable ranges. This was done by replacing the value for outlying variables with one below the next lowest value. Distribution data prior to winsorisation of extreme variables is presented in Appendix 4.3 along with distribution histograms for the main measures at T1. Parametric statistics were used as appropriate for analysis. T-tests were used to examine differences in scores on the measures at different study time points, and differences in QoL ratings. Correlations were used to examine relationships between study measures and QoL ratings.

Related-Samples Friedman's Two way Analysis of Variance by Ranks is used in evaluating ratings of importance of QoL domains due to levels of skew in reported importance levels (particularly in the case of the importance of family). A test was conducted on each domain for the difference between the importance ratings for the three time points. These tests

indicate whether the difference between any of the three time points is significant for the domain being tested. These results are reported only as an initial description of the major patterns emerging from this data. Given the small sample size no post-hoc statistical tests were performed to examine specifically where the significant differences occur

A sample size of 20 and a one-tailed test will allow a correlation of 0.51 to be detected at $p=0.05$ and power of 0.8, for a two tailed test the correlation required will be 0.56. A one tailed test of within group comparisons with a sample size of 20, $p<0.05$ and power of 0.8 will allow for detection of a medium to large effect size of 0.59. Where a two-tailed test is used this will become an effect size of 0.67. This has clear implications for the size of effect that may be detected, however it will allow for major patterns to be identified.

Results

Sample demographics and clinical characteristics

Demographic characteristics are given in table 4.1. Three people had been injured in a road accident while in a vehicle, three as a pedestrian on the road and one as a cyclist on the road. Nine were injured through an assault. Six had had falls, two of which were from height. One had been involved in an off-road vehicle accident.

Two participants had PTA of more than 1 but less than 24 hours. Seven had PTA of between 1 and 7 days. Eight had PTA of between 1 and 4 weeks and eight had a PTA of greater than 4 weeks.

GCS scores were available for 14 patients; 8 had a score of ≤ 8 ; 2 scoring 9-12; and 3 scoring ≥ 13 . Time as an inpatient was available for 12 patients which gave a mean of 63.67 days (SD=31.42). Assessments at baseline and follow up are summarised in Tables 4.2 and 4.3. As part of characterisation of the sample assessments were examined for change over time.

GOSE scores, while showing some improvement at follow up, did not differ significantly

(Related Samples Wilcoxon Signed Ranks test=1.85, p=0.06)

Table 4.1: Education, injury type and employment status of participants in the study

		n at baseline	n at Follow up
Education level	Degree	7	
	College	9	
	School	8	
Type of injury	None	1	
	Road accident while in a vehicle	3	
	Road accident as a pedestrian	3	
	Road accident as cyclist	1	
	Assault	9	
	Falls	6	
	Off-road vehicle accident	1	
Marital status	Single	14	10
	Married	3	3
	Co-habiting	5	4
	Separated	1	1
	Divorced	1	1
Employment status	Widowed	1	1
	Employed full time	2	3
	Employed part time	1	1
	Self-employed	1	1
	Self-employed but unable to work	1	0
	Working towards returning to work	1	0
	Employed but signed off	6	1
	Unemployed	2	0
	Student	2	0
	Retired	2	3
	Benefits	6	9
	Other/Unknown	1	2

Table 4.2: GOSE scores at baseline and follow up

	GOSE at baseline	GOSE at follow up
lower severe disability	3	2
upper severe disability	8	4
lower moderate disability	7	6
upper moderate disability	3	1
lower good recovery	3	4
upper good recovery	1	3
Total	25	20

Scores on the measures used at baseline are reported in table 4.3, along with statistics for the difference between time points (t-test for paired samples).

There were few significant differences found between the SF-36 scores at baseline and follow up, although there is a trend for improvement on most dimension scores. Pain and general health were the exception to this trend. The two dimensions showing a significant improvement were role physical ($t(19) = -3.49, p = 0.002$), and energy and vitality ($t(19) = 2.18, p = 0.04$). PCS and MCS scores are shown in Table 3.

As with the SF-36, scores on the HADS improved from baseline to follow up. There was a significant change for the depression score, but not for anxiety.

Cognitive functioning also improved from baseline to follow up. However, this difference was only significant for immediate memory ($t(19) = -3.50, p < 0.01$) and for the Total Scale ($t(19) = -3.98, p < 0.01$). Attention also demonstrated a trend towards significance at $p = 0.07$.

Scores on the PCRS, INCOM, BIGI, MSPSS and Silver Lining Questionnaire did not differ significantly from baseline to follow-up and effect sizes were generally relatively small. For this reason only the scores at baseline were used when examining relationships between these measures and overall quality of life.

Table 4.3: Means and paired samples t tests for the measures used in this study.

Baseline means are calculated only from those cases that were followed up.

Measure	Subscale	Baseline		Follow up		Change statistics			
		Mean	SD	Mean	SD	t	df	P	Effect size (Cohen's d)
SF-36	PCS	-1.46	1.31	-1.31	1.72	-.64	19	.53	-0.10
	MCS	-.75	1.70	-.50	1.61	-1.25	19	.23	-0.15
HADS	Anxiety Score	7.90	5.70	7.00	4.52	1.24	19	.23	0.18
	Depression Score	6.90	5.06	4.20	3.89	3.34	19	.003*	0.60
RBANS	TOTAL SCALE index score	82.63	15.41	88	14.45	-3.98	18	.001*	-0.40
PCRS	difference from relative score (patient - relative)	4.81	15.78	3.92	14.10	-.99	9	.35	-0.06
	difference from clinician score	-3.50	20.29						
	difference from mean score	2.33	21.70						
INCOM	comparison in general	36.18	4.85	34.24	6.22	1.64	16	.12	0.25
BIGI	Loss	19.50	7.17	19.30	6.46	.36	19	.72	0.03
	Adjustment	21.80	3.14	22.30	3.61	-.70	19	.49	-0.15
MSPSS	Total	72.10	8.25	70.35	8.59	1.39	19	.18	0.31
Silver lining questionnaire		114.20	19.23	118.65	22.42	-1.11	19	.28	-0.21

*p<0.05; (Bonferroni corrections mean that a significance level of p<0.005 is required. This means that significant results flagged in this table remain significant when corrected for multiple comparisons)

Then-test and recalibration response shift

Figure 4.2 shows quality of life as measured using Hadorn’s scale reported at baseline and at follow up. Scores are shown in table 4.4.

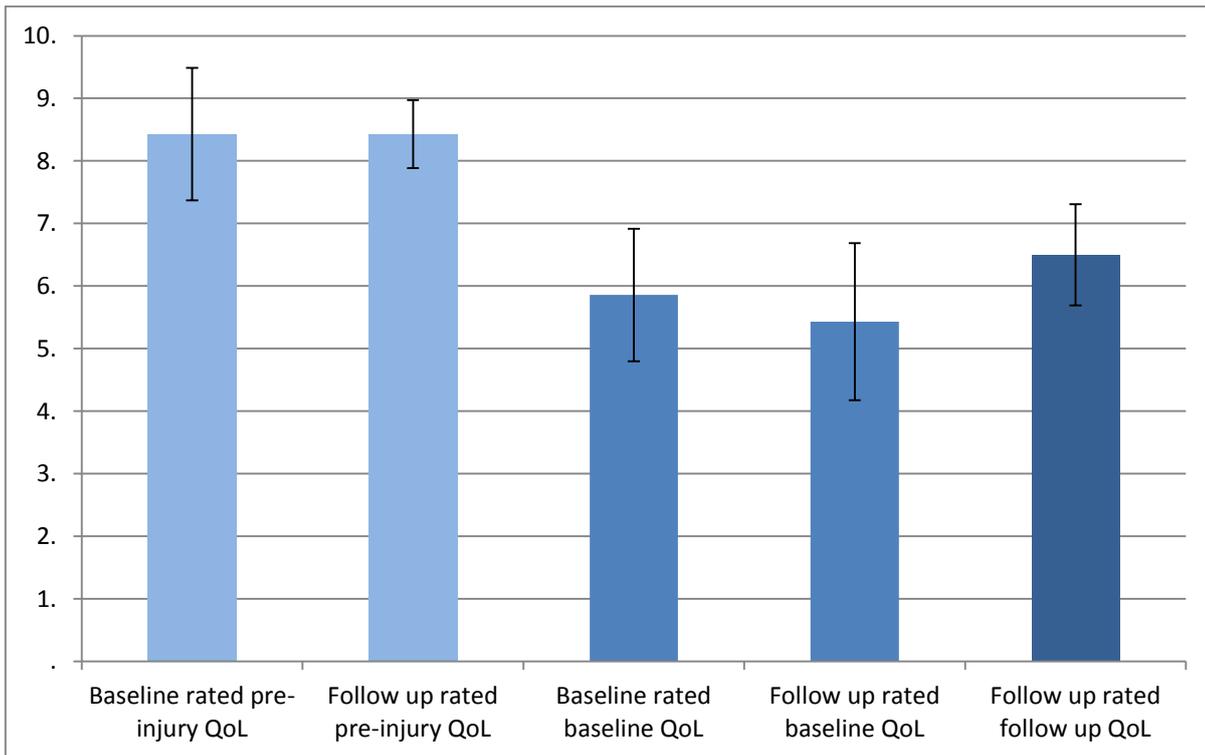


Figure 4.2: QoL ratings on Hadorn’s scale. Error bars show 95% confidence intervals

Table 4.4: Differences between overall QoL ratings (Hadorn’s scale)

			Diff	t	df	P
Follow up QoL differs from	Baseline QoL	Rated at baseline	0.71	1.16	16	.26
		Rated at follow up	1.06	2.50	16	.02

There is a significant difference between overall QoL at follow up and overall QoL at baseline when it is rated at follow up, but not when follow up QoL is compared to overall QoL as it was rated at baseline (figure 4.2 and table 4.4). A significant change in QoL is thus apparent when using the retrospective rating but not the original baseline rating. The pattern is consistent with response shift in that the adjusted time effect is significant. On the other hand there was no significant differences between the two ratings given for the baseline period ($t(16) = .89, p=0.20$, one-tailed). Thus the response shift effect itself does not reach statistical significance. As can be seen from Figure 4.2 the difference between the two baseline ratings is small. Means of the T1 test, T2 test, and then test are given in table 4.5, along with the calculated effect size as described by Schwartz et al (2006; effect size is calculated by dividing the mean difference between the two tests (then test and T1 rating) by the Standard Deviation of the T1 rating) in table 4.6, confirming that any effect present is small. Thus any evidence for response shift is limited.

Table 4.5: Mean scores on Hadorn's scale at 'pre-test', 'post-test' and 'then-test'

	Baseline QoL (pre-test)	Follow-up QoL (post-test)	Retrospective baseline QoL (then-test)
Mean	5.88	8.18	6.59
Std. Deviation	2.21	1.24	1.42

Table 4.6: Response shift effect size, calculated as described by Schwartz et al (2006; by dividing the mean difference between the two tests (then test and T1 rating) by the Standard Deviation of the T1 rating)

Then test minus pre test	Response shift effect size
-0.32	-0.16

Change in Importance of QoL Domains

In order to examine the possibility of reprioritisation from baseline to follow up the difference between the importance ratings given at T1 and T2 to each domain were compared. These differences are shown in Figure 4.3. No significant differences were found in the importance of different areas between T1 and T2. The results from this analysis are presented in table 4.7.

Table 4.7: Statistics relating to the change in the importance ratings given at T1 and T2

	Wilcoxon signed rank test	N	p
Family	-1.01	19	.31
Work	0.06	18	.95
Partner	0.17	15	.87
Friends	.95	19	.34
Health and State of Mind	.65	19	.52
Security, finances, and living conditions	.61	19	.55
Sport, leisure, and hobbies	.95	19	.34

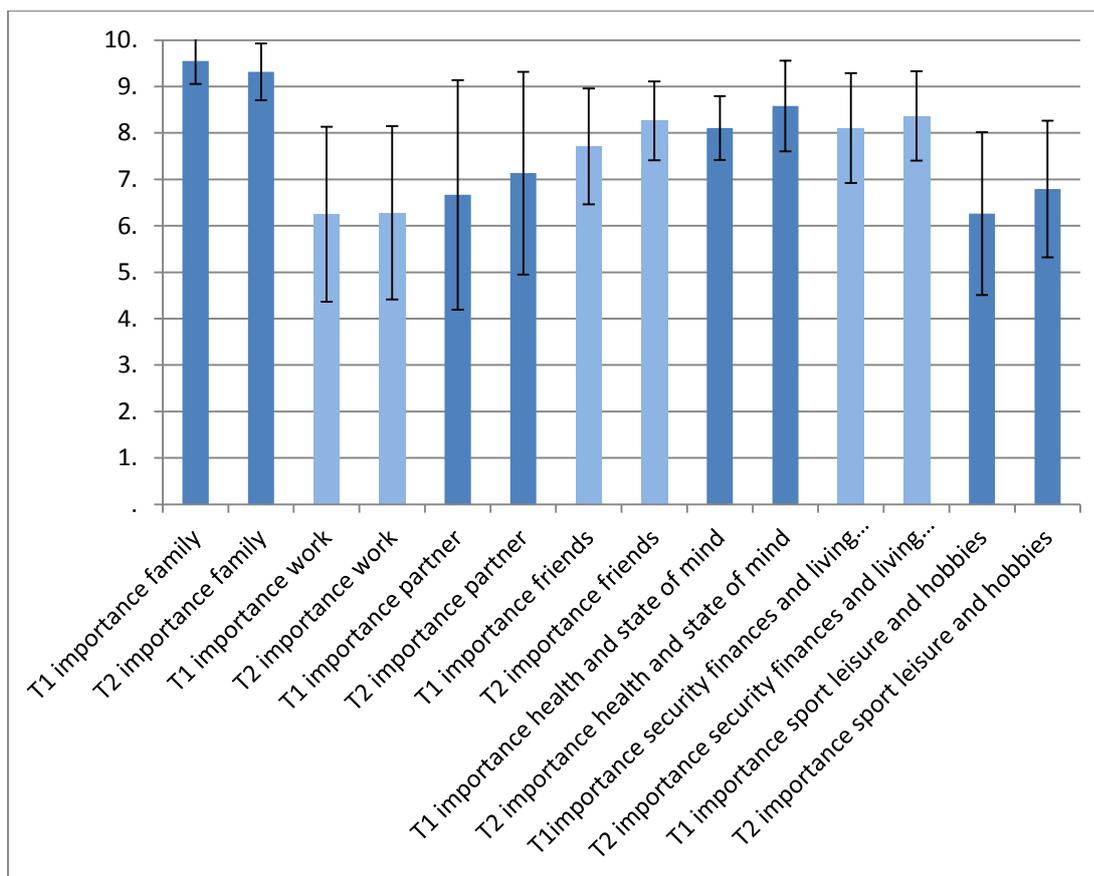


Figure 4.3: Importance ratings for QoL domains at T1 and T2. Error bars show 95% confidence interval.

The difference between T2 importance ratings was compared with the retrospective pre-injury importance ratings given at T2. These are shown in figure 4.4. The statistical differences between these scores are shown in Table 4.8. At follow-up participants rated family and security, finances and living conditions as being significantly more important than they were before injury, and work as being significantly less important.

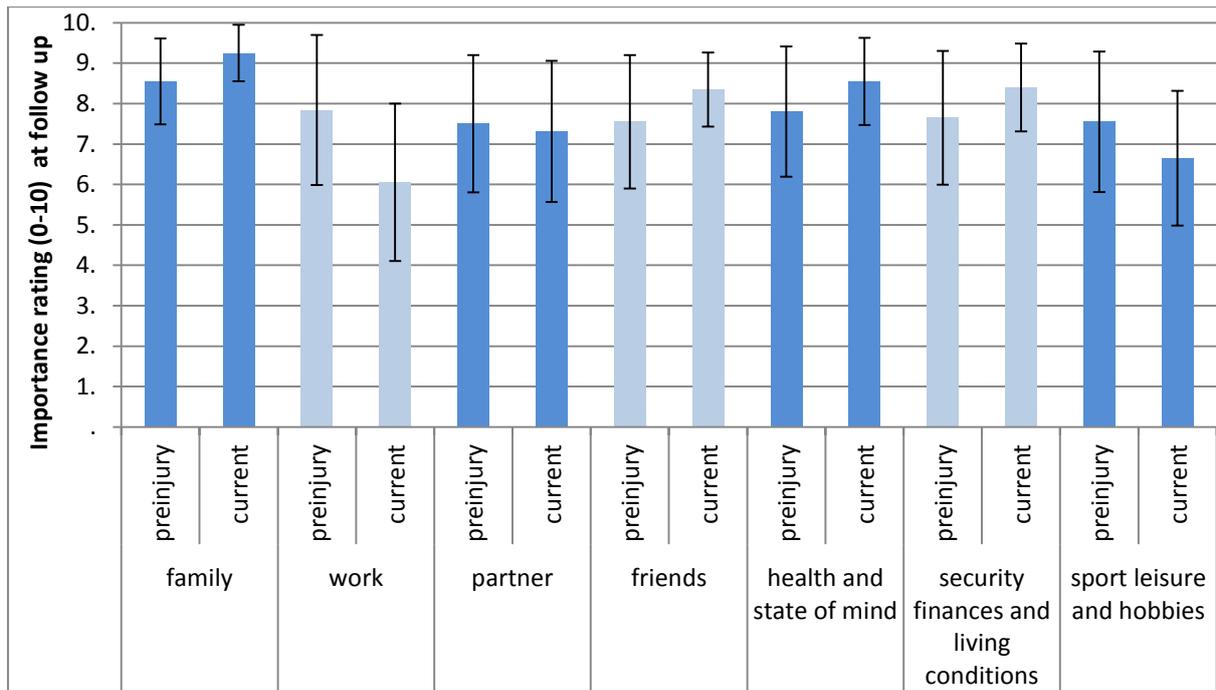


Figure 4.4: QoL scores at follow-up compared with a T2 retrospective rating of importance of different areas before injury. Error bars show 95% confidence interval.

Table 4.8: Statistical differences between T2 rating of QoL and a T2 retrospective rating of QoL from before injury

	Wilcoxon signed rank test	N	p
Family	-2.23	20	.03*
Work	2.37	19	.02*
Partner	0.08	16	.93
Friends	-1.26	20	.21
Health and state of mind	-1.23	20	.22
Security, finances, and living conditions	3.00	20	.03*
Sport, leisure, and hobbies	1.60	20	.109

Predictors and Associates of QoL

Analysis is confined to correlations with summary scales and totals where possible rather than individual sub-scales. Correlations were conducted between QoL at baseline (T1) and: the SF-36 MCS and PCS, the HADS anxiety and depression scales, the RBANS total scale, PCRS difference score, INCOM social comparison in general, the BIGI loss and adjustment, social support on the MSPSS, and the silver lining questionnaire. Correlations are shown in table 4.9.

Table 4.9: Correlations between QoL and scores on predictor variables at baseline.

	Pearson's r	P	N
GOSE	.360	.08	25
PCS	.385	.06	25
MCS	.744*	<.001	25
HADS - Anxiety	-.574*	.003	25
HADS - Depression	-.701*	<.001	25
RBANS – total	.424	.04	24
PCRS	.327	.14	22
INCOM - general	-.110	.64	21
BIGI – loss	-.707*	<.001	25
BIGI - adjustment	.516	.008	25
Silver lining questionnaire	.233	.263	25
MSPSS total	.476	.02	25

* p<0.05 after Bonferroni correction (p=.004 required)

There were significant relationships between QoL and the SF-36 MCS, both Anxiety and Depression on the HADS, and loss as measured by the BIGI. There were no significant relationships found on the three measures whose inclusion was motivated by the response shift model: the MSPSS, INCOM, and Silver Lining Questionnaire. Relationships with brain injury specific factors were stronger, although with the exception of BIGI loss not reaching statistical significance.

Discussion

This was a study of a group of individuals who were relatively severely injured and between the two assessment points changes were found indicating improvement in their condition. Cognitive performance improved, as indicated by scores on the RBANS; significant improvements were found in immediate memory and the total scale index. For the other dimensions while there were some improvements these were not statistically significant. HADS scores indicated less depression at follow up than at baseline. There was thus evidence of change over the period of follow-up though the effect sizes were generally quite modest.

Response shift: Recalibration and Reconceptualisation

The effect of response shift was not significant, with the analysis indicating that any effect was small. However, Quality of life was rated as being better at follow up than it was at baseline only when the retrospective rating of baseline was used. This is consistent with a response shift interpretation of changes in QoL evaluation, possibly due to a changing internal frame of reference. The size of the effect found here (-0.16), while small and not statistically significant, is within the range expected based on previous findings. A meta-analysis has described mean effect sizes (for 5 different QoL domains) ranging from 0.07 to 0.31, with the effect size for global QoL being 0.30 (Schwartz et al., 2006). The five domains measured (in order of effect size starting with the largest) were fatigue (0.31), global QoL (0.30), physical role limitations (0.23), psychological well-being (0.12), and pain (0.07). Schwartz et al (2006) describe a large variation in the effect sizes reported.

Evidence for response shift from reprioritisation evidence is also limited. There is little if any difference in the importance assigned to QoL domains at T1 and T2. There was more evidence for reprioritisation when the T2 ratings for importance at the current time and from before injury were compared. Here, family and security, finances, and living conditions were reported to be more important than they were before injury, and work was reported as being less so. This suggests that if changes are taking place then they are occurring earlier on in the recovery process than was

captured in the current study. There is also the issue of using a retrospective judgement when making this comparison and it must be borne in mind that it is only perceived change that is being measured and not an accurate representation of how these areas would have been rated prior to injury. A further aspect of relevance is that only 5 participants had returned to work at the follow up to this study. This indicates that a significant amount of time that would formerly have been spent at work is no longer. This will have implications on the way in which people evaluate their QoL. Equally this could apply to social and leisure activities; as people are less able to spend time participating in these activities they will factor less when judgements of QoL are made.

The study thus suggests that if response shift effects are present after TBI then they are relatively small. However, in this context it should be noted that the then test has some specific limitations applied to post injury TBI recovery. Ideally one would study changes in QoL ratings from before injury to after injury, but obviously this is impossible. The injury itself is the major catalyst for change in QoL evaluation, but it is not possible to study this directly using the then test procedure. The compromise design assumes that changes occur during the recovery period post injury that will potentially trigger a shift. It is also possible that changes triggered by the injury take a period of time to manifest which can be captured by this longitudinal design. However, such changes may be relatively small, and much smaller than the full effect of changes induced by the injury itself. Other problems with the then test include the difficulty identifying the T1 time point at follow-up, to which memory problems in the TBI sample will also potentially contribute. It would be of interest to investigate the way people rate these different areas before and after an intervention such as multidisciplinary rehabilitation. Given the results in the current study it seems unlikely that any effects relating to response shift purely due to the passage of time will be large enough to either detect statistically or to be of much clinical relevance.

Associates of QoL

Correlations were performed on summary scales to identify any major relationships. It was not possible to conduct multivariate analysis of predictors of QoL due to the small numbers recruited.

Significant correlations between QoL and the SF-36 MCS, and HADS depression confirms findings from Chapter 3 that these are variables most strongly and consistently related to reported QoL on Hadorn's scale. In addition to this HADS anxiety and BIGI loss also correlated significantly. These support the assumption that Hadorn's scale is influenced by emotional aspects of QoL. It is interesting to note that perceived loss (measured by the BIGI), specific to brain injury, is significantly associated with perceived QoL. Moderately strong relationships between QoL and the PCS, BIGI adjustment, RBANS, GOSE, and social support suggest that these factors have some influence on subjective QoL judgements. With a larger sample these may become significant.

From these results it appears that the most significant factors associated with QoL judgements are the SF-36 MCS, HADS anxiety and depression, , and loss as measured by the BIGI. This supports findings from previous research (Dijkers, 2004; Corrigan et al., 2001; Berger et al., 1999).

Awareness as measured by the PCRS does not seem to influence to an appreciable extent a QoL judgement when it is made on the Hadorn's scale, the relationship with the Silver Lining questionnaire also appears to be relatively small. The current results provide indication that brain specific factors (e.g. BIGI loss) have a stronger relationship with QoL than those indicated by the model of response shift (e.g. social support). However, it would appear from the strength of relationships that it is those factors related to psychological functioning that have the greatest impact on QoL as measured by Hadorn's scale. This may be explained at least in part by the nature of the scale and its susceptibility to influence from these factors (see Chapter 3 and 5 and comparison with SEIQoL-DW and QOLIBRI). It may be of interest in future to examine the relationship that these factors have with alternative methods for measuring QoL.

Limitations of the sample size

The study was relatively small scale, and this limited some of the analyses that could be conducted and also limited the power of the study to detect differences. Specifically power calculation indicates that for a significant difference to become apparent with a response shift effect size of 0.16 would require a much larger sample than was feasible to obtain. Recruitment was difficult throughout the study. This was partly due to difficulties in identifying suitable participants at the initial stages. Identifying participants who had been injured significantly but yet were well enough to be able to take part in the study was problematic. Recruiting through rehabilitation services limited the target population. It may have been beneficial to target patients through accident and emergency services to identify a larger number of people who had suffered a TBI but who were not deemed to require further rehabilitation. The logistic difficulties of doing this prevented it from being considered as a possibility in the planning stages but in future it may be of benefit to focus more attention on this patient group if a quantitative analysis is to be conducted.

Conclusions

This prospective study aimed to follow-up people with TBI during a period when they were recovering after injury; significant changes were found on measures of cognition and depression. Comparing a then test judgement with a baseline judgment of QoL on Hadorn's scale suggests that any effect of response shift over this period is small, as indicated by an effect size of -0.16. The study also examined evidence for reprioritisation to little effect. These findings suggest that there is little effect from response shift. Examination of associates of QoL suggest that brain-injury specific factors (BIGI loss) play a more important role in predicting QoL than those factors implicated by the response shift model.

Chapter 5: Investigation of factors influencing quality of life in people with Acquired Brain Injury attending a Headway group

Introduction

Conducting the longitudinal study reported in Chapter 4 over a relatively short follow-up interval allowed examination of changes that take place in the perception of QoL over this important period in the recovery process. It permitted the 'then test' to be used as a direct measure of response shift, and examined changes in the importance of different domains of QoL. Finally, influences on QoL ratings were explored. However, there are a number of issues that could not be addressed by this approach, and limitations in the number of participants recruited restricted the types of analysis that could be undertaken. The current study examines influences on QoL and specifically examines those included in the Sprangers and Schwartz (1999) response shift model. A questionnaire study was designed to allow collection of a larger sample of cases than the studies described in Chapters 3 and 4.

During the first year after injury patients with initial disability often make substantial gains (Lin et al, 2010). It is possible that response shift is more likely to occur at a later point as the individual comes to acknowledge persisting limitations. By studying individuals whose recovery from brain injury has been continuing for a longer period of time changes may be identifiable.

Sprangers and Schwartz's (1999) model of response shift (Figure 5.1) is a focus of the current study. In their model the initial part of the process is a catalyst, which typically takes the form of an illness or disability, or an intervention. A number of 'mechanisms' come into play that are determined to various degrees by 'antecedents'. Mechanisms are processes which change perceived quality of life (i.e. account for a 'response shift' process); for example, this can be by utilising different coping mechanisms, social support, or engaging in social comparison. In this study the catalyst is taken to

be the changes resulting from an acquired brain injury, such as disability and impairment. The model predicts various ways in which factors will impact on response shift and QoL outcome. The model proposes that the catalyst leads to use of mechanisms, which in turn influence response shift and QoL. The mechanisms in the model can thus be considered mediators of the relationship between the catalyst and quality of life. On the other hand the antecedents are factors which modify the relationship between the catalyst and QoL, and are thus moderators. Relationships predicted by the model can thus be tested by conducting an analysis of mediator and moderator variables (Preacher & Hayes, 2004; Preacher & Hayes, 2008).

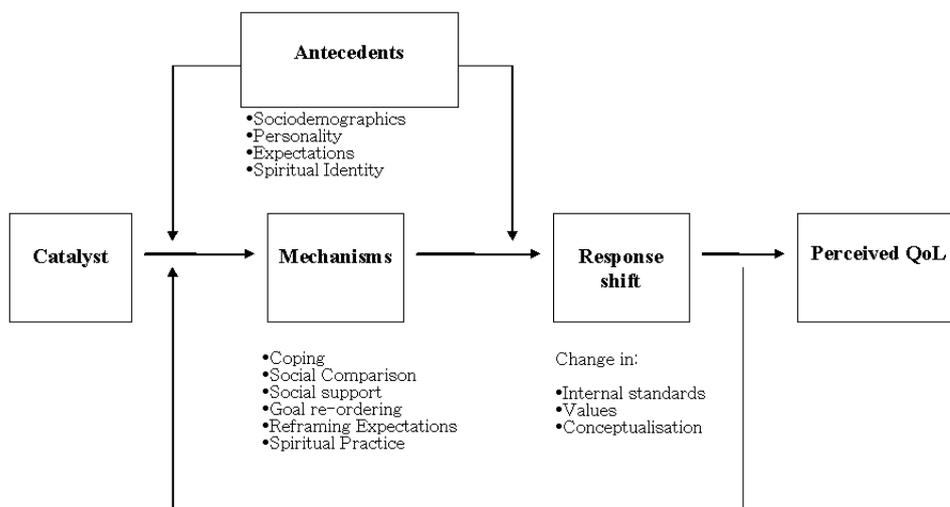


Figure 5.1: A model of response shift and quality of life (QOL). From Sprangers and Schwartz (1999).

For the current study the decision was made to examine aspects thought to act as response shift mechanisms or antecedents: social comparison, coping styles and social support (mechanisms) and optimism (antecedent personality trait). These factors were chosen for study on the grounds of evidence that they influence perceived QoL after brain injury (Steadman-Pare et al, 2001; Corrigan et al, 2001; Tomberg et al, 2007, Anson and Ponsford, 2006; Arenth et al, 2006).

Social Comparison has been highlighted in the past as a mechanism of response shift with evidence from a number of different medical conditions suggesting that it has an important role to play (Gibbons and Buunk, 1999). Investigation of social comparison in people who have had a brain injury suggests that it is used effectively in the early stages of recovery but that beneficial effects are short lived (Arenth et al, 2006). Patients in the study reported by Arenth et al (2006) were surveyed at either 1 or 6 months post injury. The current study will allow for consideration of the longer term impact of social comparison on the QoL of people after brain injury. Adaptive coping styles were emphasized by Richards and Folkman (2000) as ways that carers of patients with terminal AIDS enabled and maintained a response shift process through their caring and subsequent bereavement. Similarly utilisation of adaptive coping styles has been identified as improving emotional adjustment following TBI (Anson and Ponsford, 2006). Social support is also identified as being important both to response shift and to QoL in the aftermath of brain injury. With respect to response shift there is evidence that support is important, but that peer support may be of particular benefit (Brown et al, 2003; Schwartz and Sendor, 1999). In relation to QoL there is suggestion that quality rather than quantity of support is of importance (Tomberg et al 2005), and also that there is a complex relationship between availability of support and disability levels. Increased support that is available for people with greater levels of disability has been suggested as an explanation for a paradoxical finding that severe disability is associated with greater QoL than moderate disability (Mailhan et al, 2005). Finally, optimism is a personality trait which is likely to influence adjustment and perceptions of QoL and is one that has been used previously in connection with the theory of response shift (Dempster et al, 2009). Optimism has been shown to have influence on QoL and psychological distress after brain injury (Tomberg et al; 2005, Ramanathan et al; 2011).

The study also aimed to extend findings from previous chapters on reconceptualization and reprioritisation. As in the previous studies information was collected concerning both current QoL and retrospective ratings of QoL before injury. Ratings of the importance of specific life domains were also obtained in a similar way. In this study pre-defined domains for ratings of importance

were selected from two brain injury assessment instruments: the GOSE and the QOLIBR-OS. The authors of the QOLIBRI-OS make the claim that the domains covered are specifically relevant to the consequences of traumatic brain injury (von Steinbuechel et al., 2012). The current study thus examined whether these domains are perceived as being of more importance after brain injury than before, as evidence of reprioritization.

The aims of this study were:

- To examine factors identified by Sprangers and Schwartz in their model of response shift and the relationship of these factors with reported QoL.
- To investigate whether there is evidence for relationships predicted by the model (moderation and mediation).
- To study current and retrospective QoL ratings and perceived importance of life areas.

Hypotheses

- The theory of response shift predicts that the factors identified by Sprangers and Schwartz will be related to reported QoL (social comparison, social support, coping, and optimism). Based on previous literature it is hypothesised that social support (MOS-SS) and optimism (LOT-R, included as a measure of personality trait) will be positively associated with reported QoL. Emotional coping will be negatively associated with reported QoL whereas more active coping strategies will be positively associated with reported QoL. Downwards social comparison will be associated with better QoL, with the opposite true for Upwards comparison.
- Where significant relationships exist between these factors and reported QoL it is expected that those identified as 'antecedents' (i.e. personality) will act as moderators of the relationship between disability and QoL, and that those identified as 'mechanisms' will act as mediators on the relationship between disability and QoL.

Exploratory Questions

- Are there differences in current and retrospective before-injury ratings in the perceived importance of domains included in the QOLIBRI-OS and GOSE?

Methods

Design

This study was a cross-sectional questionnaire study. Participants were recruited through Headway support groups with questionnaires being completed either on paper or via an online system. Individuals with a range of ABI aetiologies were included.

Ethical Approval

Ethical approval was sought from and granted by the Psychology Department ethics committee at the University of Stirling. At the beginning of the questionnaire there was a statement providing information about the study and requesting that participants indicate their consent. A copy of the questionnaire, including this information is provided in Appendix 5.1.

Participants

A convenience sample of people with acquired brain injury was recruited through contact with Headway groups (n=46) (face-to-face meetings, e-mail, post and telephone) or through a posting on the Headway Facebook page (n=22). One person indicated that they had heard about the study from another source.

Inclusion criteria: Aged between 16 and 65; had a brain injury as an adult (>age 16); living in the UK.

Exclusion criteria: Aged over 65 (n=3), those missing QoL ratings (n=3), those injured as a child (age <16, n=4), those who did not report their age (n=1), or who did not indicate when their injury had occurred (n=7).

There were no specific criteria relating to cognitive, language, or behavioural function required due to the difficulties in screening for this as part of recruitment to this study. The nature of the questionnaire mean that there is some limitation in who will be able to participate given the cognitive demands but if an individual was able to complete the questionnaire (with or without assistance) their replies were eligible for inclusion.

Information given to potential participants offered a link to an online questionnaire or contact details for requests for a study pack. Where requested by Headway groups study packs were sent directly to group coordinators for distribution. Questionnaire responses were anonymous and were returned pre-paid either directly to the researcher or via Headway coordinators.

Fifty paper questionnaires were returned and 36 were completed online. Of the eighty six people who completed questionnaires eighteen were excluded, leaving a sample of 68. Reasons for exclusion were as follows: aged over 65 (n=3), missing QoL ratings (n=3), those injured as a child (age <16, n=4), those who did not report their age (n=1), or who did not indicate when their injury had occurred (n=7).

Measures and Procedure

The following measures were used (described in detail in Chapter 2):-

- Global QoL: Hadorn's Scale (Hadorn & Uebersax, 1995). The Hadorn's scale gives a rating of QoL from 0-10.
- Functional Status: GOSE, assessed using the questionnaire format for self-completion by participants (Wilson et al., 2002). This gives an indication of disability based on a self-report format.
- Health Related QoL: QOLIBRI-OS (von Steinbuechel et al., 2012). This is a 6 item scale addressing physical condition, cognitions, emotions, functions in daily life, personal and social life, and current situations and future prospects. Satisfaction in these areas is rated on

a 5 point scale. The resulting score gives a measure of QoL out of a total possible 100.

Outcome measure and retrospective judgements: Retrospective judgements were obtained on both Hadorn's scale and the QOLIBRI-OS to obtain a measure of QoL from before injury.

This allows an indication of how perceived QoL has changed

- Importance of QoL domains: Participants rated the importance of different domains. This was done on a 5 point scale from not important to extremely important. This was done for current and pre-injury importance.”
- The domains rated were based on the factors measured by the QOLIBRI-OS (physical condition; how your brain works; your feelings and emotions; your ability to carry out day to day activities; your personal and social life; and your current situation and future prospects), and those more closely related to functional outcome as measured by the GOSE (work; close relationships; and social and leisure activities). The question was worded: “How important are the following areas to your quality of life now/before injury?”, with areas and levels of importance given in a table format to be completed by the participant (see Appendix 5.1).
- Social Comparison: The Iowa-Netherlands Social Comparison Orientation Scale (Gibbons & Buunk, 1999). The INCOM consists of 23 items; with 11 items assessing social comparison in general and 6 each looking at upwards and downwards comparison. The maximum score for comparison in general is 55. The scale for upwards comparison and the scale for downwards comparison were used for analysis to allow direction of relationship to be examined.
- Coping: Brief COPE (Carver, 1997). The COPE inventory consists of 14 subscales answered on a 4 point scale; self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive re-framing, planning, humour, acceptance, religion, and self-blame. Scores for each subscale range from 0-8. Due to the large number of subscales in this measure principal components analysis was used to reduce the number of factors for analysis in this study (See Appendix 5.2).

- **Social Support:** Medical Outcomes Study Social Support Survey (Sherbourne & Stewart, 1991). The Medical Outcomes Study Social Support Survey (MOS-SS) is a nineteen item instrument that measures different types of support; emotional/informational, tangible, affectionate, and positive social interaction. Responses are on a 5-point scale from none of the time to all of the time. The total score on each subscale are: Emotional/informational, 40; Tangible, 20; Affectionate, 15; and Positive Social Interaction, 15.
- **Optimism:** Life-Orientation Test (Scheier et al., 1994). The Life-Orientation Test - Revised (LOT-R) is a widely used measure of optimism as a personality trait consisting of 10 questions answered on a five point Likert scale. This gives a total possible score of 50.

Questionnaires consisted of items relating to sociodemographic and background information, including questions relating to the injury (i.e. type of injury, PTA, whether they received inpatient rehabilitation) as well as the measures described above. A copy of the questionnaire pack is included in Appendix 5.1.

Statistical Analysis

Prior to analysis variables were examined for levels of skewness and kurtosis and histograms were plotted. Distribution statistics for the main variables used in the study are included in Appendix 5.3. Levels of skewness and kurtosis were within acceptable ranges with the exception of pre-injury QoL as measured by the QOLIBRI-OS. However, due to outliers on a number of variables and the inclusion of ordinal data either non-parametric tests were used or variables were transformed to ranks.

Relationships were examined between disability and QoL and between the factors identified by the model of response shift (social comparison, coping, social support, and optimism). Where significant relationships (after Bonferroni correction) were identified further analysis was conducted to identify whether these variables acted as significant moderators or mediators of the relationship between disability and QoL as predicted by the model of response shift.

For mediation it is necessary for there to be significant relationships between all three variables selected: the predictor (in this study disability on the GOSE), outcome (QoL), and the mediator. The aim of the analysis is to establish whether the potential mediator will account for the relationship between predictor and outcome. On the other hand a moderating variable is one which will influence the relationship between the predictor and outcome and need not have a significant relationship with the predictor variable itself. The aim of the analysis is to establish whether the relationship between predictor and outcome depends on the level of the potential moderator (i.e. whether there is an interaction effect). To examine mediators and moderators the Preacher and Hayes approach to mediation and moderation was used as implemented with PROCESS for SPSS (Hayes, 2013). PROCESS uses an ordinary least squares regression approach to examine direct and indirect effects in models of mediation and moderation. Bootstrap techniques are used to test significance of effects. Analysis was conducted using ranked variables. Two tailed tests were used throughout the study, unless effects were specifically predicted, in which case one-tailed tests were employed. With a sample size of 68 and a power of 0.8 a correlation of 0.33 is required to be significant at $p < 0.05$ (GPower 3.1; Faul et al, 2009).

Results

Sample demographics and clinical characteristics

Tables 5.1 and 5.2 show the clinical and demographic characteristics of the sample. The mean age of the participants was 45 (SD=9.62), and they had a mean age of 35 (SD=9.73) at the time of injury. Time post injury ranged from 3 months to 42 years, with a mean of 119 months (SD=98.68; equivalent to 9.9 years). Twenty four people had been injured five or fewer years ago (35%), 14 between 5 and 10 years ago (21%), 15 between 10 and 15 years ago (22%), and 15 more than 15 years ago (22%). In consideration of the wide range of time since injury that was represented by these participants independent samples median tests were conducted to identify any differences

between those who were injured <15 years previously and those who were injured >15 years previously. No significant differences were found between these groups (on Hadorn’s scale, QOLIBRI-OS, MOS-SS, LOT-R, importance ratings, INCOM, or COPE) and the decision was made to analyse the sample as a whole. Forty respondents were male and 28 female.

Table 5.1: Age and time post injury of the sample

	Mean	SD	
Age (years)	45	9.62	
Time post injury (months)	118.9	98.68	24 injured ≤5 years ago 14 injured 5-10 years ago 15 injured 10-15 years ago 15 injured >15 years ago

On the Glasgow Outcome Scale-Extended three participants had a lower good recovery, nine upper moderate disability, nine lower moderate disability, 35 upper severe disability and 12 lower severe disability.

Fifty of the injuries were TBIs; the other 18 were through other causes. These are shown in table 5.3. Sixty one participants reported being unconscious after their injury. All patients were hospitalised after their injury, with 43 reporting having received inpatient rehabilitation. Twenty three said that they did not receive inpatient rehabilitation and two were not sure. Length of PTA for patients with TBI is reported in table 5.4.

Table 5.2: Demographic and clinical characteristics of the sample

		N
Country	England	40
	Scotland	10
	Wales	7
	Northern Ireland	4
	Not specified	7
Ethnic origin	White	67
	Asian/Asian British	1
Marital Status	Single	20
	Living with partner	35
	Past partnered	13
Education level	Degree level	13
	College/vocational qualifications	23
	School qualifications	22
	No formal qualifications	9
	No response	1
Employment status at time of injury	Working	52
	Looking after family	3
	Studying	2
	Looking for work	7
	Other	2
	No response	2
Current employment status	Working full time	2
	Working part time	5
	Unable to work through illness or disability	39
	Retired (early retirement)	3
	Looking for work	1
	Not working but not looking for work	4
	Looking after family, but also looking for work	1
	No response	10
Injury type	TBI	49
	Non-TBI	18

Table 5.3: Causes of brain injury in the study population

Cause of Injury	N
accident while driving car	8
accident while passenger in a car	1
motorcycle accident	4
hit by vehicle while walking	4
hit by car while cycling	2
fall while cycling	2
Fall	14
Assault	12
Haemorrhage	2
Tumour	3
Aneurysm	5
Stroke	2
SAH	1
Encephalitis	1
Meningitis	1
Anoxic	2
Other (TBI)	2
Other (non-TBI)	2
Total	68

Table 5.4: Length of PTA of TBI participants

Length of PTA	N
5-60 minutes	2
>1 but <24 hours	2
>/=1 but <7 days	2
>/=1 but < 4 weeks	18
>/=4 weeks	26
Total	50

Quality of life ratings

Means and standard deviations on the QoL measures are shown in Table 5.5, and differences between current and retrospective judgements are shown in Figures 5.2 and 5.3. Comparisons were made using a Wilcoxon Signed Ranks Test for related samples. QoL was reported as being significantly worse at the current time than it was prior to brain injury on both the Hadorn's scale ($W(n=65)=5.02$ (standardized), $p<0.001$) and on the QOLIBRI-OS ($W(n=68)=6.61$, $p<0.001$).

Two statistical outliers were identified on the past rating of the QOLIBRI-OS, but given that non-parametric tests were used and that the results when these were removed were very similar to when they were included ($W(n=66)=6.64$, $p<0.001$) these cases were included for the purpose of further analysis.

Table 5.5: Scores on Overall QoL scale; the QOLIBRI-OS and Hadorn's overall

	N	Minimum	Maximum	Median
Hadorn's scale: current QoL (possible scores 0-10)	66	1.00	10.00	5
Hadorn's scale: pre-injury QoL (possible scores 0-10)	65	0.00	10.00	8
QOLIBRI-OS: current QoL (possible scores 0-100)	68	0.00	91.67	33.33
QOLIBRI-OS: pre-injury QoL (possible scores 0-100)	68	12.50	100.00	85.42

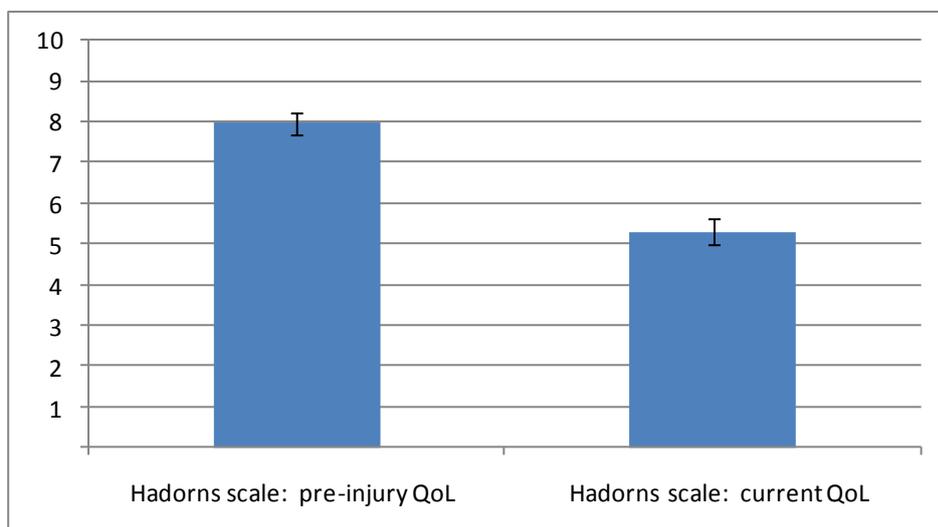


Figure 5.2: Mean QoL before and after brain injury on Hadorn's scale, bars show standard error

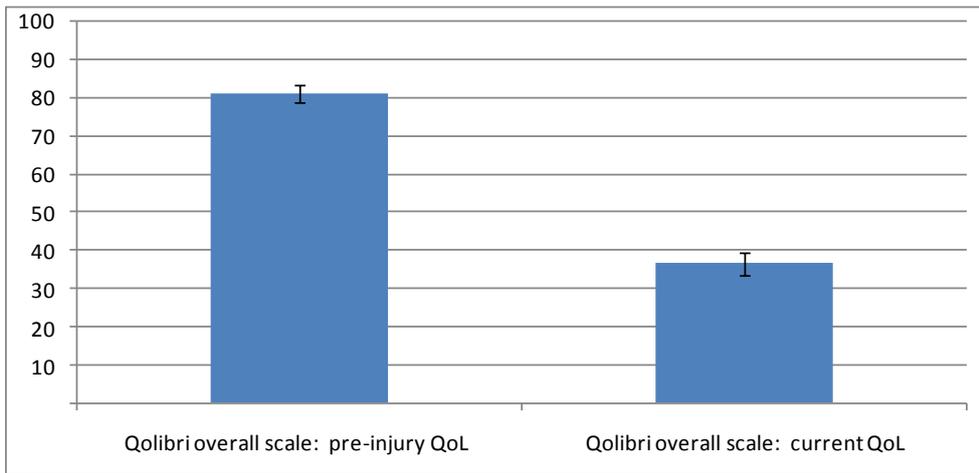


Figure 5.3: Mean QoL before and after injury on QOLIBRI-OS, bars show standard error

While in general life is worse as a consequence of brain injury, patterns of change are shown in figures 5.4 and 5.5. Here, change scores are calculated by subtracting pre-injury QoL scores from current QoL scores: a negative score indicates a negative change in perceived QoL while positive scores indicating positive change. Whilst many people report a decrease in their QoL assessed by Hadorn's scale others report an improvement. However there is less in the way of positive change when the QOLIBRI-OS is used as the outcome measure: it appears there is a clearer tendency for reported QoL to be worse post injury.

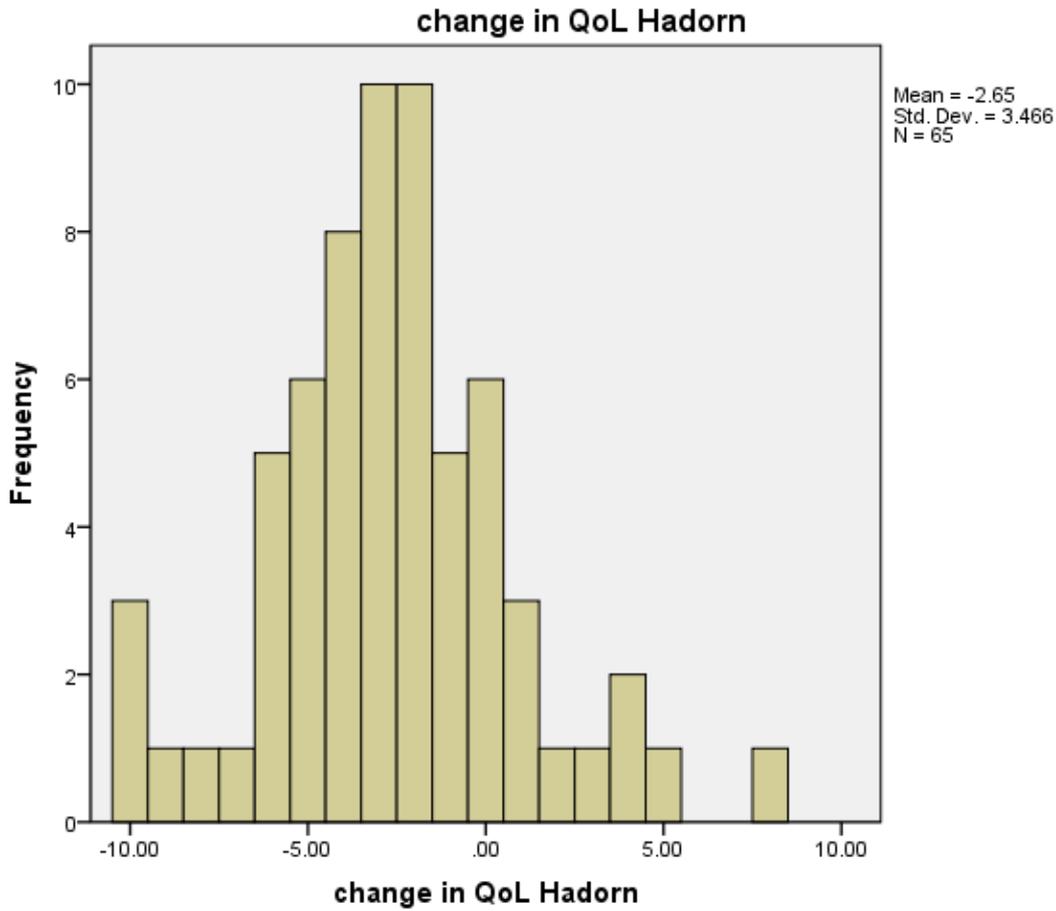


Figure 5.4: Distribution of change scores on Hadorn's scale. Change scores calculated by subtracting pre-injury QoL from current QoL.

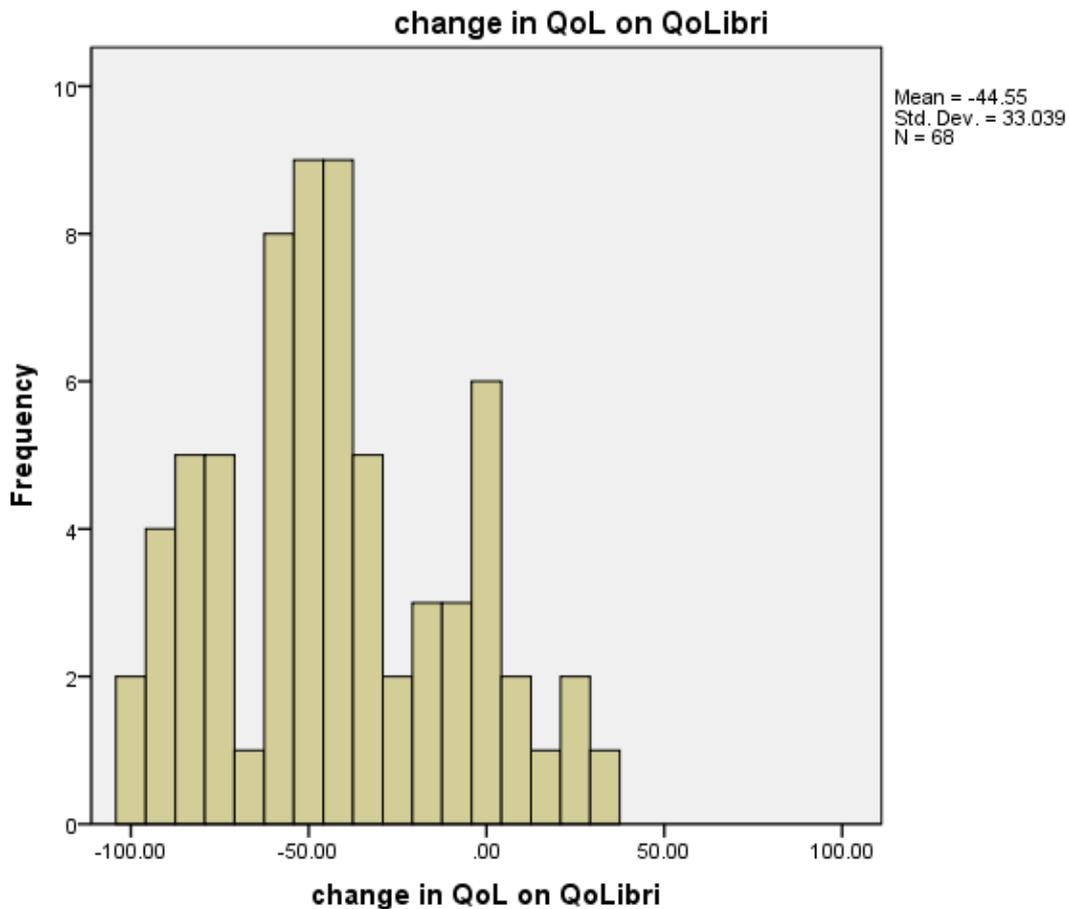


Figure 5.5: Distribution of change scores on QOLIBRI -OS. Change scores calculated by subtracting pre-injury QoL from current QoL.

Importance of different areas of life

Participants were asked to rate how important different areas were to their QoL. These results are shown in figure 5.6. With the exception of “personal and social life”, the mean importance given to each of these aspects differed significantly between the pre-injury ratings and those reported for the current time (see Table 5.6). The five remaining domains which relate to items in the QOLIBRI-OS were all rated as being significantly more important to the participants at the current time than they were prior to their injury. “Close relationships” were also rated as being more important after brain

injury, whereas “work”, and “social and leisure activities” were reported as being less so. Statistics for these comparisons are included in table 5.6.

Table 5.6: Pre-injury and Current importance of different areas of life

	Pre-injury mean importance (SD)	Current mean importance (SD)	Pre-injury median importance	Current median importance	Wilcoxon signed ranks test (standardized score)	N	P
Physical condition	3.54 (1.31)	3.90 (1.08)	3.5	4.0	-2.11	68	0.035
How your brain works	3.48 (1.31)	4.29 (0.95)	4.0	5.0	-4.29	67	<0.001
Feelings and emotions	3.31 (1.16)	4.03 (1.01)	3.0	4.0	-3.66	68	<0.001
Ability to carry out day to day activities	3.53 (1.32)	4.10 (1.02)	4.0	4.0	-2.98	68	0.003
Personal and Social life	3.65 (1.24)	3.60 (1.13)	4	4.0	.23	6	0.816
Current situation and future prospects	3.59 (1.32)	4.10 (1.12)	4	4.0	-2.38	66	0.017
Work	3.75 (1.24)	2.88 (1.52)	4	3.0	3.16	65	0.002
Close Relationships	3.97 (1.13)	4.32 (0.84)	4	4.5	-2.45	67	0.014
Social and leisure activities	3.82 (1.10)	3.50 (1.14)	4	4.0	2.05	67	0.041

Hypothesised Relationships

The scores and descriptive statistics for the sample as a whole on each of the measures used, along with Cronbach’s alpha statistic for reliability are provided in Appendix 5.4. The relationship between disability and QoL outcome was found to be significant for both QoL measures, but the relationship was stronger between the GOSE and QOLIBRI-OS ($\rho=.46$, $p<0.001$) than the GOSE and the Hadorn Scale ($\rho=.23$, $p=.03$).

Bivariate correlations were used to examine relationships between the QoL measures and factors that potentially influence QoL. These are presented in Table 5.7. Principal components analysis was used to reduce the number of Brief-COPE variables (see Appendix 5.2); for other measures total or mean scores were used rather than subscales wherever possible to reduce the number of comparisons being made. After Bonferroni correction significant correlations ($p < 0.003$) were found between Hadorn's scale and the LOT-R and the MOS-SS. The relationship between the QOLIBRI-OS and LOT-R was also significant.

Table 5.7: Bivariate correlations of the predictors with QoL measures (spearman's rho)

	Current Hadorn	Current QOLIBRI-OS
Brief COPE component 1: positive	.171 p=.088	.087 p=.244
Brief COPE component 2: avoidant	.048 p=.355	.008 p=.474
Brief COPE component 3: emotional	-.187 p=.070	-.253 p=.020
Brief COPE component 4: religion	.020 p=.436	.004 p=.487
Life Orientation Test – Revised	.355* p=.002	.345* p=.003
MOS-SS Mean of Subscales	.358* p=.002	.145 p=.124
IOWA-Netherlands Social Comparison Scale - upwards comparison	-.143 p=.135	-.204 p=.053
IOWA-Netherlands Social Comparison Scale - downwards comparison	.028 p=.414	.174 p=.085

* $p < 0.003$ (Bonferroni corrected significance level, one-tailed).

Mediator-moderator analysis

Where statistically significant relationships were identified with reported QoL further analysis was conducted to test whether the variables followed predicted moderating or mediating patterns.

There was a significant relationship between the MOS-SS and Hadorn's scale (Table 5.7), and the MOS-SS is a potential mediator of the relationship between the GOSE and QoL (Figure 5.1, Figure 5.2). However, there was no significant relationship between the GOSE and MOS-SS ($\rho = -.212$, $p = 0.05$, one-tailed). Since it is a requirement for mediation that there is a significant relationship between the predictor and the mediator no further analysis was carried out. The mediating relationship that was hypothesised and tested is shown in Figure 5.2.

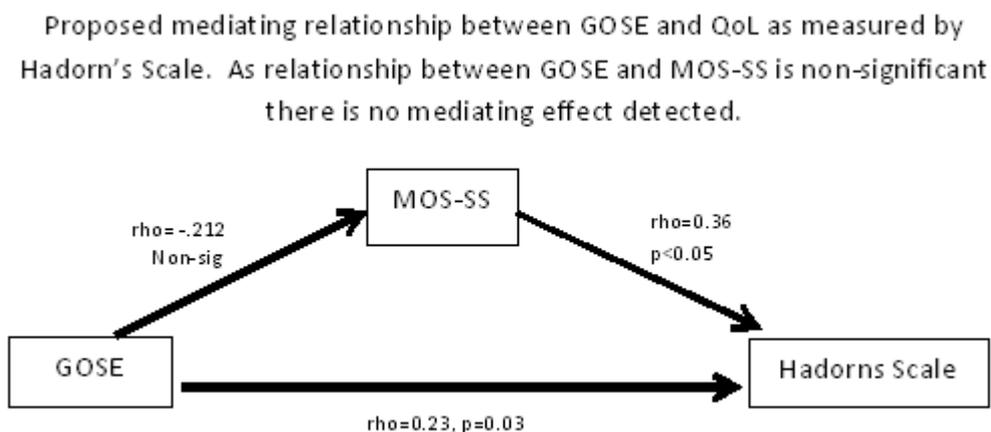


Figure 5.2: Hypothesised mediating effect of Social Support (as measured by MOS-SS) on the relationship between disability (as measured by GOSE) and QoL outcome (as measured by Hadorn's Scale).

The relationships between the LOT-R and both Hadorn's scale and the QOLIBRI-OS were significant. The LOT-R was tested as a potential moderator of the relationship between disability and QoL because personality is identified as an 'antecedent' in the model of response shift (Figure 5.1, Figure 5.3). In keeping with its possible role as a moderating variable, there was no significant relationship between the GOSE and the LOT-R ($\rho = -.21$, $p = 0.09$, two tailed). Results from PROCESS indicate that

there was not a significant moderating effect of scores on the LOT-R on the relationship between the GOSE and Hadorn's scale ($b=-.009$, 95%CI $[-.022, .003]$, $t=-1.546$, $p=.128$). While the moderating effect of the LOT-R on the correlation between GOSE and the QOLIBRI-OS was stronger it also did not reach statistical significance ($b=-.008$, 95%CI $[-.017, .001]$, $t=-1.731$, $p=.089$).

Proposed moderating relationship between GOSE and QoL. The LOT-R was not a significant moderator of the relationship between the GOSE and Hadorn's scale ($p=0.128$) or GOSE and QOLIBRI-OS ($p=0.09$).

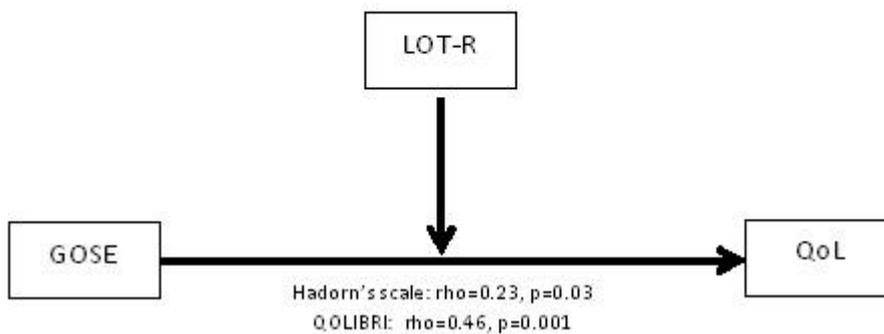


Figure 5.3: Hypothesised moderating effect of Optimism (as measured by LOT-R) on the relationship between disability (as measured by GOSE) and QoL outcome.

Discussion

The current study was conducted with people with acquired brain injury attending Headway. The group was generally more disabled than the cohorts studied in Chapter 3 and 4. People attending Headway are typically seeking help with problems related to brain injury, and thus it is not surprising that substantial morbidity is apparent in the group. In contrast to the results in Chapter 3 where little difference was apparent before and after injury, the group reported that QoL was substantially worse currently than before injury. This is not surprising given the greater morbidity in the current participants and the expected negative impact that brain injury may have on QoL. As in the previous studies there was evidence that the importance of different QoL domains changes after brain injury.

Change in QoL

Quality of life was measured on two different scales: Hadorn's overall scale and the QOLIBRI-OS. On both of these scales QoL was judged to be significantly worse in the sample as a whole at the current time than it was before injury. While the majority of cases reported that QoL was worse post-injury there are also a number of people for whom this is not true. This is demonstrated in the frequencies of different changes scores plotted in figures 5.4 and 5.5. This is particularly the case when the Hadorn's scale is considered. The clearer tendency for QoL to be reported as being worse post injury when the QOLIBRI-OS was used as the outcome measure is possibly due to the difference in the design of these two scales. The QOLIBRI was intended as a condition-specific measure, measuring areas of life that are of particular relevance following brain injury. Hadorn's scale on the other hand is more open to interpretation with the individual defining for themselves what is of importance to them.

Importance of QoL Domains

As part of the investigation participants were asked about the importance of QoL domains. The areas about which they were asked included the domains measured by the QOLIBRI-OS. In all but personal and social life these areas were rated as being significantly more important following injury than they were before. These results support the idea that domains assessed by the QOLIBRI-OS are of particular importance to people with brain injury. In addition to the areas measured by the QOLIBRI-OS participants rated for importance "work", "close relationships", and "social and leisure activities". These were selected as representing the areas assessed by the GOSE, and are thus particularly relevant to functional outcome. In relation to the GOSE; "work", and "social and leisure activities" were rated as being significantly less important following injury, whereas "close relationships" were more so. This finding that importance of areas differs between current and retrospective ratings provides further evidence for a direct re-evaluation of different domains of QoL after brain injury, and thus supports one of the main contentions of a response shift model. It also supports findings from Chapter 3 where evidence was presented that people change what is

important when making a QoL judgement. It should not be assumed that these are all of the QoL domains that may change as a consequence of a brain injury, but that those measured by the QOLIBRI are more important after injury than they were before. The changes that are reported in domains important to QoL are also likely to represent the time that participants are able to spend on the activities being rated. The majority of participants were unable to return to work and so this factors far less in their day to day routine. Equally the time they are able to dedicate to the pursuit of specific social and leisure activities may be reduced (especially if this category is interpreted as sporting activities).

Influences on QoL outcome

Unsurprisingly, disability as assessed by the GOSE is the variable most consistently correlated with QoL, a relationship which is stronger with the QOLIBRI-OS than it is with Hadorn's scale. This supports the use of the QOLIBRI-OS in the measurement of QoL after brain injury. It is also possible that it removes some of the emotional aspects associated with reporting QoL on Hadorn's scale (see associations reported between Hadorn's scale and SF-36 MCS and HADS Depression reported in Chapters 3 and 4). In addition to the demographic and clinical characteristics of patients, their coping styles, optimism, available social support, and use of social comparison were investigated as factors which may influence reported QoL. As outlined earlier, these were selected because of their relevance to Sprangers and Schwartz's (1999) model of response shift. It would appear from the results that the level of impact that these factors have on reported QoL is limited, however there is some indication that optimism and social support may have a role to play. The model of response shift predicts that the named factors are either mediators or moderators of the relationship between disability (GOSE) and QoL outcomes. While some significant relationships were identified between factors highlighted in the model of response shift and QoL the lack of mediating or moderating effects would indicate that the relationships are at least partially independent. Thus, while some relationships are apparent they are not specifically supportive of the model of response

shift. It should be noted again at this point that the small sample size of the study will only allow for detection of larger effect size and so there is a possibility that type 2 errors may be made.

Optimism as measured by the LOT-R was significantly correlated with current QoL on both Hadorn's scale and the QOLIBRI-OS, but there was no evidence that it plays the role of a moderator. Optimism was previously found to be associated with reported QoL on the SF-36 in a study of 85 individuals assessed 9 months to 3 years after TBI (Tomberg et al., 2005). However in a follow up of this patient group an average of 5.7 years later there were no significant associations between the LOT and reported health status or social well-being (Tomberg et al., 2007). The correlations initially reported by Tomberg et al (2005) with the SF-36 were moderate to strong ($r=.379$ to $.673$) and pass a Bonferroni corrected significance level of 0.002 ($N=85$, $r > .332$), while the correlations in the follow-up study were much weaker ($r .02$ to $.242$) (Tomberg et al, 2007). The current results support the earlier study and suggest that optimism is a factor worthy of further consideration in relation to reported QoL. Dispositional optimism has been shown to be associated with psychological distress (Ramanathan et al., 2011). Ramanathan et al (2011) identified significant relationships between psychological distress, cognitive ability, and dispositional optimism. More specifically, they identified that optimism was a significant mediator of the relationship between cognitive ability and psychological distress. While there are hypotheses and evidence relating to how dispositional optimism may influence recovery from and adjustment to brain injury there is less consideration given to how a life changing brain injury may influence a person's optimism levels. This point could be considered in future research as well as in the interpretation of current findings.

Social Support was related to the SF-36 in the studies conducted by Tomberg et al (2005; 2007), with perceived satisfaction with support rather than number of available supports being of importance. There is the consideration of multiple comparisons in these studies, but the strength of relationships ($r=.240$ to $.456$) indicate an influence worthy of further investigation. These results bear similarities with those found currently not only in the implication of these variables as potential

influencing factors, but in that optimism appears to have a greater role to play than social support. It would be of interest in future to investigate further the influence of optimism and social support on reported QoL.

Study limitations

This investigation was conducted using a self-report questionnaire format. This has several limitations. It is not possible to gauge how well people understood the questions. It is possible, for example, that some reports of atypical change in QoL were due to confusion over the rating scale. This problem was addressed in part by allowing assistance from family members, carers, or others, however this introduces the possibility that responses may be influenced. There were also some issues with missing data where questions had not been answered. Where current QoL measures were not available or there were significant missing responses then participants were excluded from analysis. While these issues will clearly have an impact on the quality of the data collected they did allow a wider population to be targeted which led to a larger sample size than it was possible to recruit in previous studies.

Other areas of weakness are that it was not possible to obtain an accurate indication of injury severity or of current cognitive functioning, and the injuries were of various aetiologies. Further consideration comes from the broad time range that was investigated. This ranged from 3 months to 42 years. This does have implications in that it is likely that the issues facing people at different stages after injury will be different, however analysis of the difference between people <15 years post injury and >15 years post injury did not highlight any significant differences and so the decision was made not to split the sample based on time post injury.

Conclusions

Little evidence was found to suggest that the factors proposed in Sprangers and Schwartz's (1999) model of response shift have predicted relationships with QoL. Two candidate variables were studied (optimism and social support), but neither showed the predicted pattern of relationships.

Nonetheless the study supports previous work indicating in influence of optimism and social support on QoL, and indicates that these warrant further study.

There were systematic difference between current and retrospective ratings of importance of domains. The level of importance given to the areas of life defined by the QOLIBRI-OS is higher after injury than before, with the exception of “personal and social life” for which there is no significant difference. The areas of life chosen to reflect that which is measured by the GOSE (“work”, “close relationships”, and “social and leisure activities”) are rated as less important with the exception of “close relationships”. These findings provide further support for the idea that QoL domains are re-evaluated after brain injury.

Chapter 6: Understanding the Subjective Experience of Recovery from TBI: An Interpretative Phenomenological Analysis

Introduction

Interpretative Phenomenological Analysis (IPA) is a qualitative method of data analysis that is increasingly used in psychology. Its aim is to develop understanding of people's experiences and may be especially useful in developing an understanding of the reactions to a significant life event such as a major illness or injury (Smith et al., 2009). Indeed there are many studies of life events using IPA (Griffiths et al., 2011; Dickson et al., 2007; Howes et al., 2005; Hunt & Smith, 2004). It has also been used in a number of studies with people who have some level of cognitive impairment (Howes et al., 2005; Shotton et al., 2007; Clare, 2003; Clare et al., 2008).

IPA is idiographic, in that it focuses on specifics, in terms of both the individual and the circumstance. Fundamental to IPA is the belief that it should involve an in-depth and thorough analysis to allow the understanding of a particular phenomenon as it is experienced by a particular individual (or group of individuals) in a particular context (Reid et al., 2005; Smith et al., 2009; Larkin et al., 2006). This differs from aiming to understand a phenomenon in a wider context, and the generalisability which is often the aim of quantitative research (a nomothetic approach). It also differs from other forms of qualitative research which may be more aimed towards development of theory (for example grounded theory) or examining how knowledge of the world is built up through interactions (discourse analysis). Different approaches to qualitative research often have slightly different philosophical underpinnings.

It was considered that IPA would allow an insight into phenomena related to adjusting to a brain injury not possible with a quantitative approach alone. An overview of IPA will be provided and a justification for its use in the context of this thesis.

Qualitative Research

Qualitative research, broadly speaking involves taking an in-depth look at content. Data often will take the form of language, either spoken or written, but could include visual data in the form of video recordings or photographs. The aim of qualitative research differs from that of quantitative research in that it is less about the generalisability of research findings (although by collating qualitative research from different sources this is increasingly possible), and more about capturing the subjective perspective or experience of participants. It may be used to complement quantitative research findings as the different focus allows a more in depth account of phenomena, with the possibility of picking up on details and individual differences that would be missed in a statistical analysis of a data set.

Qualitative research is a broad field and there are many different approaches that can be taken. Often there are differences in the philosophical backgrounds from which the approaches emerged. As in quantitative research, the usefulness of various approaches will depend on the question being examined. At a basic level, qualitative analysis may be 'thematic'; data is analysed and emerging themes are identified (Braun and Clarke, 2006). Braun and Clarke (2006) point out that the language of themes 'emerging' suggests that the role of the researcher is passive, when clearly this is not the case; themes are identified, selected and perhaps even constructed by the researcher based on the available data. There are a number of other approaches which are widely used that are also thematic in nature, but have more established and recognised aims. Perhaps one of the more familiar of these is grounded theory, which aims to develop theories based on findings from qualitative data analysis. The aim with this approach is to look for themes emerging from the data, and continue to do so until a point is reached where no new themes are apparent (known as 'data saturation'). At this point the data has provided all possible insight into the phenomena under investigation (Smith, 2007). Other approaches have different aims; Interpretative Phenomenological Analysis aims to understand the experiences of individuals and how they make sense of their

situation often following an event in their life that will have caused them to examine and rethink their position.

Mixed Methodology

IPA has been used beside other research methods; from combining it with different qualitative approaches (Smith et al., 2011; Smith, 2007)) to using it as a tool to complement quantitative approaches to research. Smith et al (2009, p192) suggest that mixed methods designs using IPA can be particularly useful as they allow a combination of insights into the research topic. They give the example of two papers published by Newton et al (Newton et al., 2005; Newton et al., 2007) and suggest that while the quantitative analysis provided in the first publication demonstrates that the cognitive behavioural group intervention for auditory hallucinations was effective, the IPA paper provides more insight into the complexities of the results. The IPA approach provides evidence for 'how' it works and allows for insight into the experiences of patients who did not follow the typical improvement that a quantitative analysis suggests. Smith (2009, p193) state that *"IPA can offer insights into experiences of events and processes, and the personal meaning of various 'outcomes', which can help researchers to interpret their quantitative findings and to illustrate them for a diverse audience"*.

A qualitative approach using IPA was felt to offer particular advantages in the current research because it became apparent at an early stage that the very individual nature of QoL judgements meant that a full understanding of the processes involved would not be possible from a purely quantitative approach.

Conducting IPA research

IPA emerged during the 1990's, developed with the intention of introducing a qualitative approach to data analysis that was based in psychology (Smith et al., 2009; Smith, 1996). In conducting an IPA study the focus is traditionally on finding a sample that will allow in depth study of the phenomenon under investigation. Therefore samples should be small, purposively selected so that they are able

to offer an insight to the phenomena under investigation (rather than probability sampling to allow for generalisability (Smith et al, 2009). Samples should also ideally be fairly homogenous, in order to build a detailed picture of the experience being investigated in a specific population: the idiographic nature of IPA. IPA does not aim to be able to generalise beyond the individuals studied and it is only with further research that it will begin to be possible to build a broader picture. The size of samples utilised in IPA studies vary, but they all tend to be relatively small in order to allow the in-depth analysis required by this method. Smith et al (2009) are strong proponents of small samples; they argue that a single case study can be especially powerful, although they warn of the complexities in conducting a single-case IPA study. They suggest that a sample of 3-6 will provide enough data to allow the identification of similarities and differences between cases without becoming unmanageable. Sample sizes that are too large, they warn, will make it increasingly difficult to meet the commitments of IPA. Published IPA research has used sample sizes ranging from single cases to 40+, although undoubtedly the numbers are typically at the lower end of this range. In 2005 the mean number was reported as being around 15; although 10 was stated as being at the higher end of recommended sample sizes suggesting that there was a general tendency to use sample sizes that were too large for the methodology (Reid et al., 2005). Smith et al (2009; p51) argue that sample sizes are decreasing over time as the method has become more established and there is better understanding of the aims of this approach.

Data collected for IPA research can come from a number of sources, but most commonly will take the form of an in-depth semi-structured interview. While interviews are usually conducted with a pre-prepared interview schedule, the aim of the interview is to elicit from the participant the issues that are relevant to them and their experiences. The interviewer encourages them to go into more depth about those issues which are relevant to the phenomena being studied. Allowing the participant to expand in depth about their experience potentially provides the researcher with a rich data set that can later be examined for the underlying issues of importance. The interview schedule

allows the interviewer to prepare for the interview and envisage possible topics which may arise; it is also there to act as a guide in the interview to ensure that conversation continues to flow.

Analysis is conducted on each individual and it is only after this is done that the researcher will begin to bring together the results. The aims of analysis are two-fold: to 'give voice' to participants and give an accurate account of their experience, but also to 'make sense' of their account in the context in which it is given. In this way it is interpretative and will go beyond just describing what the data contains, however any inferences that are made about underlying meaning should be strongly grounded in evidence from the data (Larkin et al., 2006; Reid et al., 2005; Smith et al., 2009). More detailed explanation of the processes utilised in this study are described later.

IPA as the method of choice in the current study

IPA was selected as the best method to utilize for this research as the aim was to examine the experience that people have when adjusting to changes in their life following a TBI. It has also been used before as a method for investigating coping and adjustment following TBI (Shotton et al., 2007; Howes et al., 2005; Muenchberger et al., 2008).

Shotton et al (2007) interviewed nine participants with moderate to severe TBI who were between 2 and 6 years post injury. A number of themes were identified in their data: 'Waking up':

Understanding TBI; 'I keep going': Coping after TBI; 'I knew I'd get better': Beliefs about TBI; 'The benefits have far outweighed the consequences': Searching for positives; and Non-adaptive adjustment. These themes suggest that those participants who adjusted well following a TBI, went through a process of 'waking up' after their injury as they emerged from a period of PTA, which they described as being surreal, disorientating, and detached from reality. Some participants reported not questioning this, whereas others were less accepting. Nonetheless none reported being distressed by the experience. They describe ways of coping which change as they go through their recovery process; starting in a structured way closely following the advice of professionals but adapting and changing to their own circumstances.

Participants utilised different ways of coping which changed as their recovery progressed. They were able to look at positive aspects of the situation in which they found themselves, and held positive beliefs about their long term outcome. They generally held a perception of having a consistent identity from before injury in that while things had changed they as a person had not. Also reported is optimism, the feeling that things would get better, even in the face of the knowledge that other people in similar situations did not recover. A tendency to compare with other people is also reported: either with people in general or others in a rehabilitation context. Social comparisons made in all cases were downward, that is, with people who were in a worse situation.

Shotton et al (2007) suggest that these processes are important as people cope and adjust, and cite as evidence the observation that one participant who was unable to do this had a less favourable outcome (non-adaptive adjustment). 'Margaret' did not describe 'waking up', she was unwilling to engage with rehabilitation. She felt that there was little point in following professional advice. She was pessimistic about her future, and while acknowledging that she could do something about it she did not adopt any strategies which may prove helpful. She showed a tendency to externalise blame.

Howes et al (2005) used IPA to investigate the experience of TBI in 6 women who were between 7 months and 15 years post injury. They identified four main themes; 'Awareness of change', 'Emotional reactions', 'Struggle to make sense', and 'Adaptation and acceptance'. 'Awareness of change' is described as being a general awareness of being different as a person to before injury which is gradually replaced by insight into how and why these changes have occurred. The reasons for change are broadly broken down into cognitive changes (e.g. mental slowing, tiredness); physical changes (e.g. vision, hearing, physical awkwardness, clumsiness, weight changes, the 'hidden' nature of the disability related to TBI); and changes in experiences as a social being (decrease in social interaction with the loss of work, routine, and friends, also the changes in the dynamics of personal relationships, feeling like 'children' in needing looked after). 'Emotional Reactions' manifest in a

variety of ways; with anger, anxiety, diminished ability to deal with others, and social phobia (with some justification as a consequence of negative experiences) all featuring as important issues. 'The struggle to makes sense' is described in a number of ways, as participants have difficulty visualising their future selves, finding it difficult to plan for the future. Differences are described between their own experience and the reality as seen from the point of view of others. Turning to experts as a source of information, as well as listening and more general social support are reported as being important to this process of making sense of the situation. Under the theme of 'Adaptation and acceptance', reconstruction of identity is described, along with the way in which people have changed the way they look at what is important to their QoL, and being able to see positives in the situation.

The aim in the current thesis was to use IPA alongside the quantitative methods described in earlier chapters to examine whether the mechanisms proposed in the response shift model would correspond with the experience that individuals have of adapting to the consequences of TBI. It is important to note that IPA should be approached and conducted in a way that is open and exploratory to elicit as accurate a representation of the participants' experience as is possible. However, there is the possibility of using IPA research to address a secondary research question, which may have its basis in established theory. In this way data may be used as a 'lever to evaluate existing theories' (Smith, 2009; p.48). So, in the case of this research, the aim was to investigate the experience of adjusting to changes in life following TBI with the secondary aim of using these experiences to further understand the legitimacy of response shift as a relevant theory in this process.

To address these questions the decision was made to investigate the experiences of those people who had suffered some level of disability as a consequence of their TBI. This was to allow investigation of the experiences in a group of people who were likely to have faced substantial changes in their day to day life and who are most likely to have had to go through an adjustment

process. IPA has been used previously as an effective way to gain an understanding of the experiences of people who have cognitive impairment (Howes et al., 2005; Shotton et al., 2007; Clare, 2003; Clare et al., 2008). For example, Clare (2003) used IPA specifically to investigate the awareness that people with Alzheimer's had of their condition and their experiences relating to this. Clare (2003) indicates that one of the strengths of IPA is that results can be interpreted in the context of other information. In order to provide some understanding of the validity of the information provided by participants in the current study the PCRS was included in the interview. This was to give an indication of the level of self-awareness that participants had. The ability of the participants to accurately recall information or the impact that their behaviour has on those around them is acknowledged only in the context of their own perception. This provides a representation of life after brain injury that is true to the current subjective perception of participants. The implications of this are that results can only provide an understanding the experience of these men (a key aim of IPA). As reflexivity on the part of the researcher is considered an important aspect of the IPA process it is worth bearing in mind that there was an underlying secondary research question from the start of the project. The researcher had an interest in the theory of response shift and the impact it has on the adjustment process. In order to minimise the impact of this the effort was made to use only minimal prompts during the interview allowing the participant to volunteer as much information as they were able without being influenced by specific questions. Prompts addressing specific issues were purposively kept towards the end of the interview. Unless the participant brought the issue up themselves they were not brought into the interview until the participant had exhausted the topics and experiences that they volunteered. This was done to give the participant as much freedom as possible to explore the issues that were of importance to them. Pauses in the interview were used to encourage the participant to continue and expand on what was being said, with general prompts and encouragement rather than asking a specific question. The interview will undoubtedly be influenced by the interviewer; when they nod encouragement, how they ask the participant to continue, when they make the decision to ask a question; which

lines of enquiry they decide to pursue. Fundamentally, the relationship that is built up between the participant and interviewer will influence the quality of data collected in a far greater way than it would in an interview aimed at collecting quantitative data. An awareness of this on the part of the interviewer is important in structuring the interview to ensure that the views of the participant are paramount; however subjectivity is clearly an unavoidable issue. This is not necessarily a problem, since it is an aim of the IPA process to acknowledge and understand the influence of the researcher, but to aim for the focus to be on the participant. Nevertheless it is acknowledged as part of the methodology that the researcher plays an active part in the construction and interpretation of the data.

As part of the process of reflexivity the researcher must understand the part they play in constructing the outcomes from an IPA study. The differences of reflexivity have been described on a continuum, ranging from '*benign introspection*' to '*radical constitutive reflexivity*' (Shaw, 2010). The difference here ranges from positivism and making an 'accurate' account of the participants experience to a post-modern approach which assumes that reality is a construct and assumes the equal contribution of both participant and researcher in understanding particular phenomena. It is the latter that is of relevance in IPA: the researcher should engage in reflexivity and have an awareness of the influence that they have over creating an understanding of the participant's experience. It is with reflexivity that the '*double hermeneutic*' often referred to in relation to IPA comes into play. Hermeneutics is concerned with the theory or art of interpretation. Having a focus on hermeneutics allows for an interpretation of the data. An important part of IPA is the 'double hermeneutic', that is; the researcher making sense of the participant making sense of the experience (Smith et al., 2009). As part of this is the process of 'bracketing' where the researcher acknowledges his/her preconceptions and attempts to move away from these and focus entirely on the participant (Smith, 2007; Smith et al., 2009).

Reid et al (2005, p21) say that '*In keeping with the broad premise of positive psychology (e.g. (Seligman & Csikszentmihalyi, 2000), there is scope for IPA research to become less disease and deficit focussed, and for participants to be given the chance to express their views about strength, wellness and quality of life*'. This perhaps reflects the most important potential benefit of including a qualitative approach. It gives the possibility of understanding the adjustment process at an individual level, providing a complementary approach to the other methods utilised in this thesis.

Study Aims

The aim was to study the processes of recovery and adaptation after TBI from the perspective of the individual.

Methods

Design

This study was designed as a qualitative investigation utilising Interpretative Phenomenological Analysis. Participants were selected based on their level of disability with the aim of recruiting a sample that was similar in that they had experienced substantial change in daily life as a result of TBI.

Participants

Participants were recruited through a community rehabilitation service. Participants were screened for suitability for inclusion in three ways. (1) By the judgement of the responsible clinician in the rehabilitation unit; (2) By contacting their GP; and (3) by initial interview with the researcher.

Patients were identified in September 2010 when back-dated records were examined by a member of the rehabilitation team. All individuals who had a GOSE score of 3, 4, or 5 (lower severe, upper severe, or lower moderate disability) on discharge from the centre were considered for inclusion.

As potential participants had been discharged from the service potentially a number of years ago General Practitioners were contacted to ensure that it would not be inappropriate for the researcher

to make contact. If GPs did not raise any objections to contact individuals were sent a letter asking if they would be willing to take part in the research.

Six individuals responded to the information about the study. On meeting with one of these it was apparent that they did not understand the purpose of the study and so was not able to offer their informed consent; a full interview was not conducted. Due to technical difficulties one interview did not record and was not available for analysis. This meant that the final analysis was conducted with the transcripts from interviews with four participants. All identifying information was removed from the transcripts and participants were given an alias for ease of identification. All participants had sustained severe brain injuries, 3 in road accidents and one as a consequence of an assault. The PCRS was completed by the participant at the start of the interview; with the relative's part of the form being given to them to pass on to someone close to them. This was returned by post. The form was completed by a family member with the exception of James, whose form was completed by his support worker who knew him well. Difference between the scores provided by the participant and their relative were compared to provide an indication of levels of awareness of their deficits. Clinician-patient difference scores of <28 indicate mild or no impaired self-awareness, 28-51 indicate moderately impaired awareness, and >51 indicate severely impaired awareness (Sherer et al, 2003).

Inclusion criteria:

- Aged 21-65 at time of study
- Severe or lower moderate level of disability
- Referred to rehabilitation services within last 6 years
- Able to provide informed consent and give consistent and appropriately detailed responses in an interview setting.

Interviews

Interviews were conducted at the community rehabilitation unit during October and November 2010. They ranged in time from 50 to 80 minutes. The purpose of the interview was explained to the participants at the beginning, in particular that it was their experience that of interest, so that while there were some questions the main purpose of the interview was to learn about their perspectives and experiences in general. They were also reminded that they did not have to answer any questions that they did not wish to, they were free to withdraw at any time and they were could take breaks if they wished. During the interview a schedule of 11 questions or prompts were used. These were used as a flexible basis for the interview, but were not adhered to rigidly as participants were free to describe experiences that were relevant to them. Questions were only referred directly to if it was felt that the interview was drifting too far away from the topic, or when the participant was unable to offer any more information. In general, once the interviews began they ran smoothly with topics being covered without direct reference to the interview schedule.

Interview Schedule:

1. Can you tell me what your life was like before the injury?
 - a. Relationships
 - b. Work/occupation
 - c. Like/dislike
 - d. Hobbies
 - e. Personality
2. Can you tell me about your injury?
 - a. Date
 - b. Cause

- c. Circumstances
 - d. Loss of Consciousness
 - e. Hospital Care
 - f. PTA
3. How did your injury affect you?
- a. Emotionally
 - b. Physically
 - c. Cognitively
 - d. Behaviourally
 - e. Relationships
 - f. Personality
4. Do you feel you have adjusted to life after brain injury?
5. Has there been anything in particular that was helpful to you in adjusting to the consequences of the injury?
6. Would you say your quality of life is any different now to how it was before your injury?
7. Are the same things important to your quality of life as before your injury?
8. Do you think that having a brain injury has changed the way you look at QoL in general?
9. When you are thinking about your life do you ever compare yourself with other people?
- a. Who would you compare yourself with?
10. Looking back, is there anything that you would change about your recovery?
11. Do you have any advice or suggestions for the professionals working with people who have experienced brain injury?

Analysis

Analysis was conducted based on the guidelines set out by Smith et al (2009) which involve a 6 step process. This is summarised below:

1. Reading and re-reading: The analyst immerses themselves in the data and becomes familiar with the interview transcript.
2. Initial noting: The transcript is read through and comments made line by line regarding the content of the text. These can take a variety of approaches, ranging from the descriptive to the interpretative, taking into account the language used by the participant and the potential meaning reflected in what is being said. This process provides an additional level of data that is used in the next stage of the process.
3. Developing emergent themes: The exploratory comments made in the previous stage of analysis are further analysed to identify emergent themes.
4. Searching for connections across themes: Connections, similarities, differences and other relationships between the emergent themes are identified and then used to group them into different thematic levels. Superordinate themes are developed under which the emergent themes are grouped. Not all emergent themes are kept at this stage, only those that make a meaningful contribution to the overall analysis.
5. Moving onto the next case: The process is repeated for each case individually.
6. Looking for patterns across cases: Connections between cases are identified, as are any recurring themes. In some cases there may be superordinate themes that are shared by individual cases, in others similarities will allow the development of concepts that more readily apply across the different cases whilst still incorporating the superordinate themes that were of importance on an individual level.

In the current research transcription was completed by the researcher. This allowed the development of familiarity with the content of the interviews. Transcripts were read a number of times along with the voice recordings to build up this familiarity. The initial exploratory coding was conducted on hard copies of the interview transcripts. It was felt that this allowed the researcher to continue to increase familiarity of the content of the transcript; and perhaps more importantly at this stage, ensure a continuing awareness of the context in which issues arose. Transcripts were formatted with double line spacing and wide margins to allow space for comments to be made. Initial comments were made to the right hand side of the transcript. All aspects of the interview content were considered, and commented on, with the aim of developing understanding of both the content and meaning of the transcript.

Following the exploratory comments the next level of analysis was conducted. This involved re-reading the exploratory comments and identifying the themes that were emerging. Initially this stage of analysis was also conducted on the hard copy of the transcripts. This allowed a clearer structure to emerge from the analysis and themes could begin to be combined into meaningful units.

The following stage was conducted by inputting the emerging themes into a table. These were included along with supporting statements from the text to ensure that the meaning of the themes remained as close as possible to the original. Using a table in this way allowed similar themes to be grouped. Connections between themes were identified allowing for grouping under superordinate themes. This in turn allowed reconsideration of the groupings of emergent themes. On completion this gave a table which presented the superordinate themes along with lower level themes and supporting quotations from the interview transcripts. Linking themes back to the original quotations allowed reconsideration of the validity of the themes by ensuring that they held a close relationship to what was originally said by the participant.

Once this process had been followed for each participant the four analyses were combined to give an overall picture of the experiences of the four men. This was done by identifying themes which recurred across the interviews. Recurring themes were then entered into another table in a similar way to the individual analysis, but including evidence from each of the participants. Where a theme did not appear to be relevant for a particular participant this was noted, and possible reasons why this might be the case were identified. In some cases the identification of themes led to reconsideration of the original data and corresponding themes to see if they would make more sense when considered in the context of the other data.

Results

Participant characteristics and background

All participants had a lower moderate level of disability according to the GOSE. That is, they were independent in daily life, but restricted in their ability to participate in roles such as work, and social and leisure activities, and may have difficulty in maintaining close relationships. Differences in scores from the PCRS indicate that some participants were not fully aware of the level of their deficits, something that should be kept in mind when interpreting the results. Table 6.1 provides a summary of the information relating to participants. James and Andrew had little or no problems with self-awareness, whereas John had moderately impaired awareness, and Robert had severely impaired awareness. For further illustration of levels of impaired awareness Figure 6.1 shows that Robert had impaired awareness in regards to all areas of functioning, John had impaired awareness in regards to interpersonal, cognitive, and emotional functioning, but not ADL. James and Andrew showed a reasonable levels of awareness on all areas of functioning based on 1.2 difference points (1SD) indicating impaired awareness (Sasse et al., 2013).

In addition to this the PCRS scores as reported by the participant's relative (or support worker, as in James's case) are plotted in Figure 6.2. It is assumed that these represent a more realistic measure of ability than the ratings given by the participant. These provide an indication of levels of disability and difficulty in functioning experienced. All participants experienced some level of difficulty in all areas of functioning.

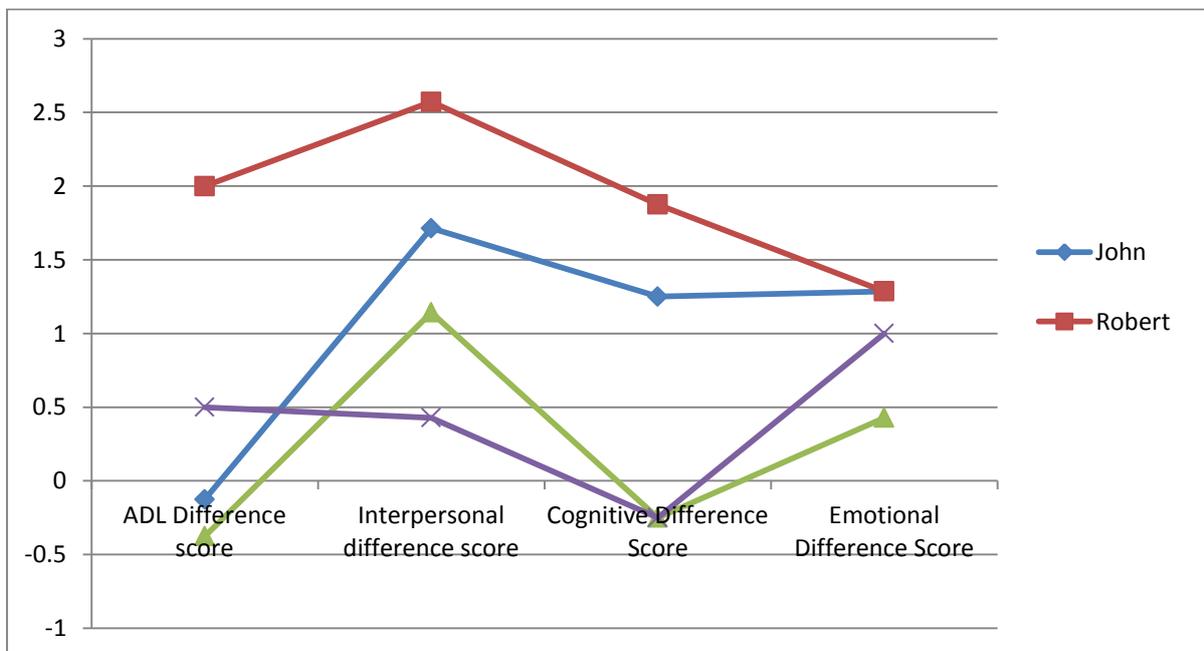


Figure 6.1: PCRS difference scores on different areas of functioning. A cut off score of 1.2 difference points (1SD) has been used to indicate impaired self-awareness (Sasse et al., 2013).

Table 6.1: Participant information

Participant	James	John	Robert	Andrew
Age	44	47	38	48
Time post injury (years)	12	7	18	3
PTA	6 weeks	5 weeks	6 weeks	5 weeks
PCRS (difference in scores)	5 (mild or no impaired awareness)	32 (moderately impaired)	60 (severely impaired awareness)	12 (mild or no impaired awareness)
PCRS relative form completed by	Support worker	Wife	Mother	Son
GOSE	5	5	5	5
Current living circumstances	Supported accommodation	Living with wife and son	Lives alone	Lives with adult son and teenage daughter.
Pre-injury living circumstances	Living with family (brother)	Living with wife and son	Living with family (parents)	Living with his partner and children.
Cause of injury	Assault	Car accident	Car accident	Car accident
Problems relating to injury	Lack of motivation. Experiences fatigue and anxiety. Spent some time homeless. Has lost contact with his family.	Increased Aggression. Difficulties with speech and with information processing. He finds these problems frustrating.	Increased aggression. Difficulty interacting with other people.	Physical disability in one arm, vision affected. He also reports increased levels of aggression, difficulty with information processing, and memory problems.
Current employment status	Not working. Not able to work	Not working. Not able to work	Supported volunteering	Not working. Not able to work
Pre-injury employment status	Employed	Employed	Employed	Self-employed
Available support	Relies on support workers	Supportive wife	There is little mention of family support, although his mum does live nearby.	His adult son is a source of support to him and helps with household chores.

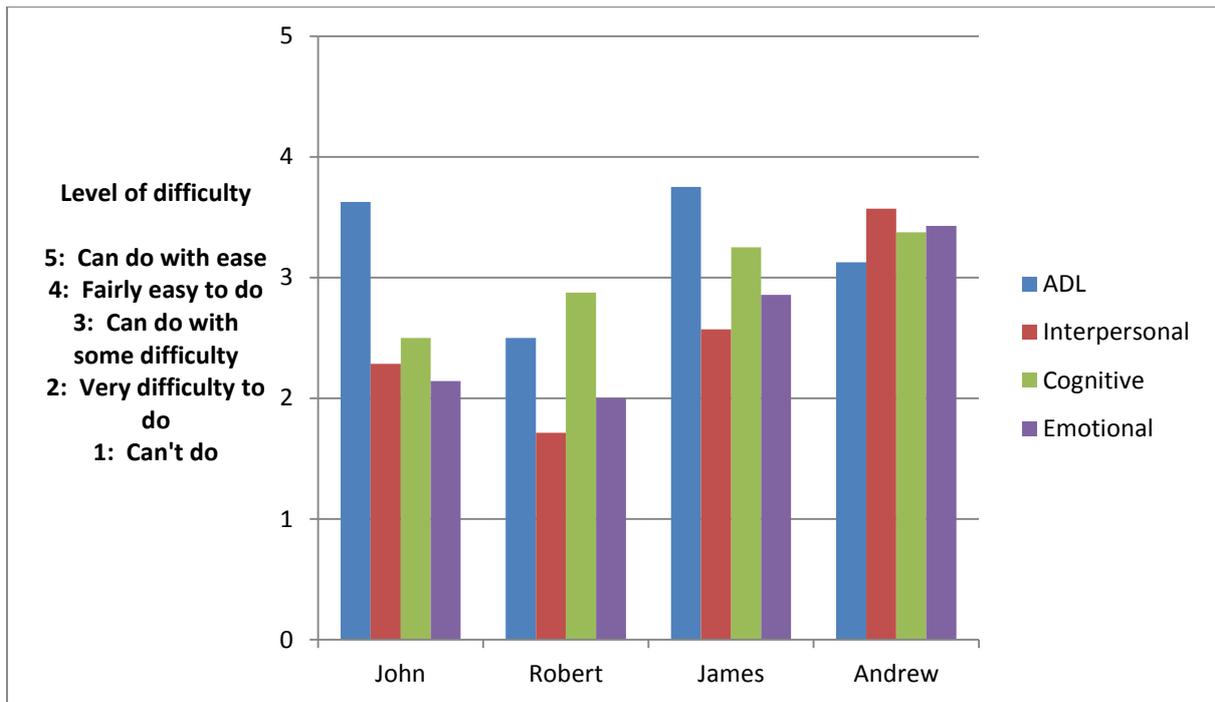


Figure 6.2: Levels of Difficulty in Areas of Functioning for each of the four participants: as described by their relative/carer on the PCRS.

General themes and views of outcome

Combining the ideographic analyses of each of the four participants in this study provided a broader picture of the experiences that these four men have had in living their lives after having had a TBI.

Figure 6.3 gives a schematic diagram of the themes emerging in this study which are discussed here in more detail.

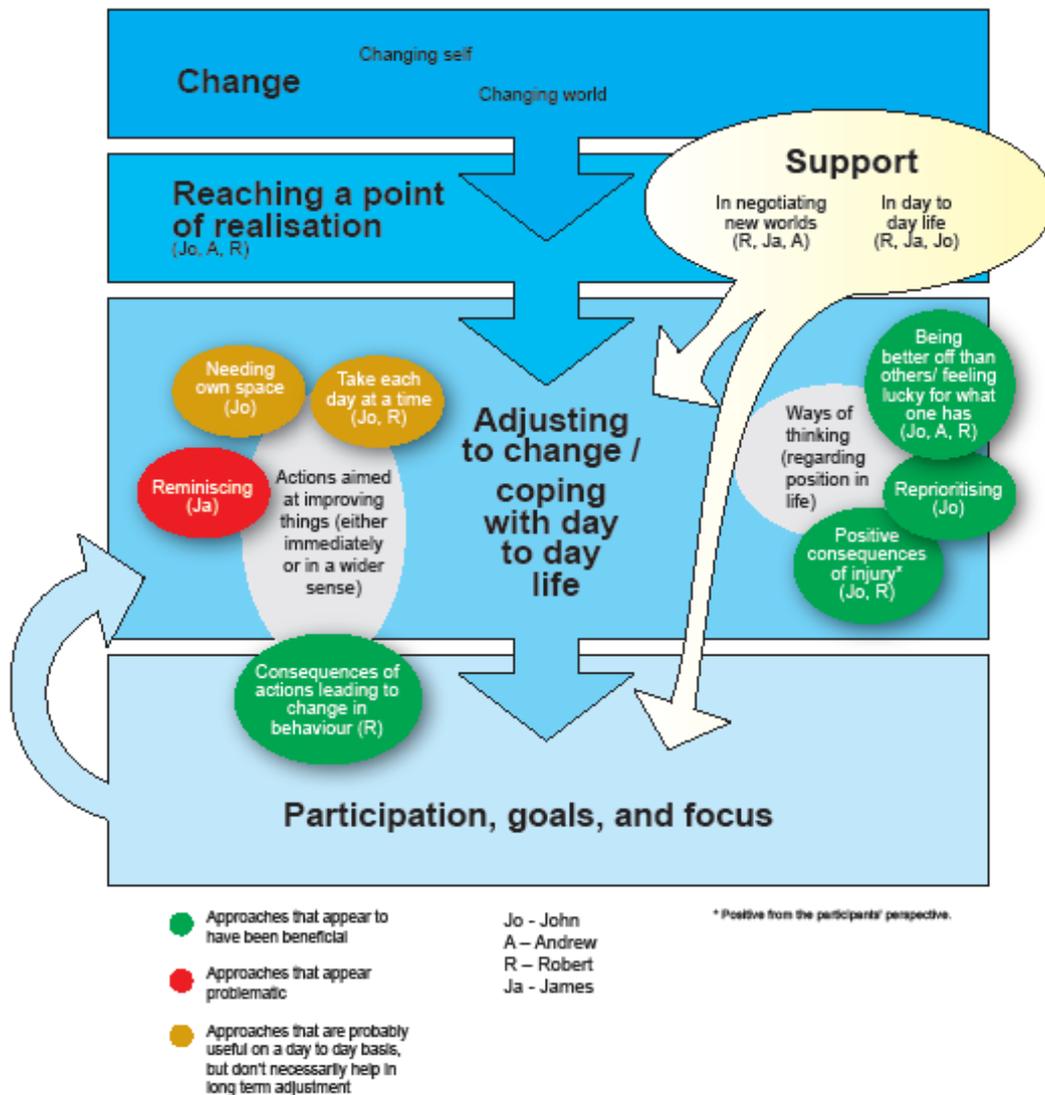


Figure 6.3: Schematic Diagram of the themes emerging from the analysis. The figure shows a schematic diagram of processes and influences described by participants (initials given in brackets). This is organised in a way which illustrates how these processes and influences may interact.

Each of these four men has a level of disability resulting from their injury that makes it very unlikely that any of them will be able to return to paid employment. In terms of maximising their adjustment, and consequently quality of life it would appear that the most important thing for them

would be having the opportunity to feel involved. This may result from the opportunity to participate in activities and to have a focus in what they are doing. Of these four men, two seem to have achieved this. Robert, although facing uncertainty about the future of his volunteering opportunity had found something that gave him satisfaction and the sense that he is doing something useful with his life. Andrew talked in less depth about his need for something to focus on, but is heavily involved in the lives of his children giving him a clear focus in his life. The reason that Robert talked in great depth about his experience with volunteering may be that for him it is a fairly recent occurrence. He indicated that for many years his involvement in a support group was purely due to the lack of a better option rather than it being something that he felt was important to his life. Andrew, on the other hand did not go through an equivalent period. Andrew's children make up a large part of his life, in a way they always had. He talked about them in detail, but does not draw any attention to the influence that they have on his life. This is perhaps because for him that is just the way it is and therefore he gives it little thought. Neither John nor James spoke of anything in their life that appeared to carry the same importance as Robert's volunteering or Andrew's family. John talked about missing the sense of purpose that he got from his work before his injury; specifically saying that he misses having targets and something to work towards. While John mentioned on a number of occasions the importance of his family he did not appear to be involved in the practical day to day running of family life, apparently very much the responsibility of his wife. During James's interview he reflected on the need to make an effort to become more involved with the activities and groups that had been suggested to him by his support workers. From the experiences of each of these four men it seems that it is that feeling of purpose, of having goals and doing something useful is an important factor indicating a good outcome following a TBI.

Robert: *"I could very easily sit in the house every day like my friends husband, but I couldn't do that, it would drive you up the wall."*

Robert: *"There was nothing else until the gardens came up. That's the only thing I've done since my crash that's been worthwhile."*

Robert: (talking about what is likely to be helpful to people after a brain injury) *"Volunteering, I found that personally a big saviour, myself, it gave me belief back again. Don't let them sit in the house just fester in their thoughts (pause) encouragement and trust in them."*

James: *"I know I do need to get myself motivated and get involved with something. So I'll see that, I'll go to that drop in centre some day, go sometime this week"*

John: *"I suppose what I do miss, I suppose, having something to get up for in the morning. You know where you know just say I had a problem with a contract, I'd get up in the morning right I need to go there get that sorted, targets if you like ... you know I need to get that sorted, something to aim for if you know what I mean"*

Beyond this indication of what may be helpful to people following a TBI the themes emerging from interviews with these four men indicate that the issues influencing them surround changes in both themselves and the way in which they have to negotiate the world around them; and then the ways in which they are able to deal with and come to terms with these changes. Support seemed to be the most important influencing factor for this; in both enabling these men to come to terms with the initial changes to their lives but also in negotiating their day to day life. This is discussed in more detail later.

Change: In self and in the world.

Changing self: Participants described change in a number of ways. Perhaps most noticeable is the changes that occurred in themselves. As would be expected much of this relates to the direct consequences of their injury (e.g. impulsivity, increased aggression, loss of motivation, reduced cognitive abilities, inability to focus, poor executive functioning, etc). These normal consequences of TBI are spoken about by the participants in the context of what they as a person are like and comparing this to how they were before their injury.

Robert: *"I would be more impulsive after my injury."*

James: *"I seem to have lost interest in a lot of things as well ... there's a lot of things I want to do but I just don't seem to have the energy to do it."*

Andrew: *"I talk more, a bit more of a temper. I don't pick up on things so quick what I say if I get any paperwork or whatever it was um I'd read it once and that would be it I wouldn't need to look at it again but now it's like that (indicating paperwork relating to study) I read that a couple of times just to make sure I took it all in you know."*

John: *"you know I'm a lot better than I was, but I don't see it like that I know I'm different to how I used to be."*

These changes are perhaps in some ways the expected consequences of their brain injuries, but spoken about by the participants in this study they reflect fundamental changes in the people that they are. Perhaps most eloquently put by John when he said *“how I’ve got it in my head, I see the old John, the old John’s gone, he’s not here no more this is a new John you know”*.

Changing world: While the above changes reflect those occurring in the individuals themselves, but as would be expected these then lead onto changes in the person's life. This is reflected in changes in role, status and relationships. As a consequence of this the worlds in which they conduct their life change dramatically. Both John and Andrew went from positions of responsibility in the companies for which they worked (or in the case of Andrew ran) to being unable to work and provide for their family. Robert had been working prior to his injury doing something he clearly enjoyed. James was less secure at the time of his injury in that he did not have a job and was living with his brother; however he describes his ambitions towards a new career and the efforts he had made to pursue this.

Personal changes also manifest themselves in changes in the individual's ability to do the things that they used to do prior to injury. All four participants talk of things that they did before their accident; whether that is work as it was for Robert, John and Andrew, and indeed for James, although he spoke in more depth about his interests than the work that he had done; or if it is changes in ability to do things in terms of leisure activities. Andrew talked of not being able to travel in the way he was prior to his injury, and James talked about rambling and nature watching which he is unable to find the energy or motivation to do since his injury.

No less important, are the changes that occur in life for reasons unrelated to the injury. This is something that is most noticeable with Andrew, for he talked in great detail about his family and problems arising with his ex-partner which he feels were not related to his injury but have had a very

significant impact on his life. John also discusses a number of problems that have arisen recently in his family life which have had a significant impact on him. Unrelated changes occurring in life were not spoken about as directly by James or Robert but they require some consideration. A number of years have passed since injury for each of these four individuals, and in the case of Robert this is 18 years. Such a long period of time gives plenty of opportunity for other events to occur changing the course of these individuals' lives. While it is entirely possible that all aspects of their life have been affected in some way by the consequences of their injuries it would be naïve to assume that this must be the case, or to discount the influences of other events. Considering whether his life would have changed in the same ways had it not been for his injury, Robert says *“who knows what would have happened if it had never happened”*.

In addition to the personal changes that have occurred there is the significant issue of finances and living circumstances which for all four participants were an issue at some point post injury. Both James and Robert returned to live with family after their injuries but ended up being asked to leave. James spent some time being homeless and while currently housed, he is in supported accommodation and relies on help from support workers. Robert spent time living in bed-sits after being asked to leave his parents' home, which continued until he received financial compensation from his accident which allowed him to buy his own home. While Robert admits to squandering a proportion of his compensation it has provided him with the security of owning his own home.

Robert: *“it's a lot better now I own my own house eh saying that I squandered the rest of my compensation but the house is still there eh ... I've got a better life now I think”*

Andrew talked in some depth about his reliance on benefits and his gratitude for the help that he receives. In some ways he sees this as a positive thing in that he does not have the same pressure

on him that he did before his injury regarding financial worries. He does however report being much worse off financially than he was before his injury.

Andrew: *"I'm on it permanent now (incapacity benefit) ... so there's money to pay for things, I haven't got my worries like beforehand ... having said that I had more money before this happened I had money in the bank which is all gone"*

John does not really talk about his living circumstances or the financial impact of his injury suggesting that it is perhaps not such an issue for him (perhaps because his wife is working and supporting them), although he does mention the fact that he is unable to provide for his family (*"to provide for the family like I say I haven't done that for seven years"*).

Reaching a point of realisation

Three of the four participants describe a point where they came to some realisation of what their brain injury actually meant for them. In some ways this seems to be important for them in coming to terms with the changes that they were facing in their lives. For John this meant discovering that he would not get back to normal; his hope that he would return to work was unrealistic and he would have to come to terms with his decreased abilities in this respect. For Andrew it involved realising that his loss of eyesight due to damage to the brain was permanent. For a long time he was under the assumption that both his eyesight and the physical damage to his arms which happened in the same accident could be repaired, on learning that it couldn't he was forced to come to terms with the long term implications. Robert was faced with an understanding of what brain injury means, recognising that it is different from other types of injury by meeting people who were worse

affected than himself when he attended a support group. This realisation of how bad things could have been allowed him to reassess the consequences of his own injury.

John: *"I did try voluntary work ... I mean I was enjoying it don't get me wrong and there was one day I'd done something wrong I'm just trying to think now what it was I'd put a wrong number ... I told the supervisor she says right leave it as it is I'll check ... then me being me I'm trying to sort it out by myself ... I'm just making it worse and worse and I just got that frustrated I wanted to sit in a corner curl up and cry my eyes out because as far as I'm concerned I've never cried I've never shed a tear over this you know what I mean and that's what I felt I just felt like sitting in a corner curling up and crying my eyes out that's how bad I got and then it brought it home to me I'm not ready for work you know I probably never will be you know but then that's what I'm saying that's what it comes into it that I'll never be better I'm going to be like this I've accepted it I'm going to be like this for the rest of my life"*

Andrew: *"I just thought okay it'll get better or they'll do whatever operation and then ... then eventually they did another they tested everything again then they just turned round and said that's it it's permanent and that did me in I said what ... because I really thought that whatever problems I had whatever damage that I had was fixable they said no it's permanent you are lucky you can see at all, so that was it, that was that, really hit that did, know what I mean"*

Robert: *"you went in there my god look at this ... my god look at half of these man half of their bodies couldn't work or nothing I thought my god how lucky are you ..."*

Robert: (realising that head injury is) *“different from any other injury I think that point came when I went to that Headway I thought my god it kind of frightened me kind of something”*

James does not describe a similar experience, and in many ways he does not seem to have come to terms with the way his life is. He reports spending a lot of time thinking about things. He says that he reminisces a lot as a way of trying to remember things. He is very concerned about the consequences of his injury but does not seem to fully understand the implications of his injury. This is not a lack of awareness that he has difficulties; of the four men the scores on the PCRS suggest he has the greatest level of awareness; it is more that he lacks the knowledge relating to the nature of brain injury. He worries about going senile as a consequence of a comment made by a friend some time ago. He spends time doing crosswords in an attempt to keep his brain working, but says that he worries over whether or not he has got the right answer, and whether or not he ‘should’ know the answer. While James recognises that things are worse in his life than they were before his injury he does not seem able to pin point directly why this is (*“I know things were alright before the injury and after the injury there were a lot of difficulties”*). It is possible that it is this lack of understanding that James seems to have of what his brain injury actually means to him that causes him to spend time thinking and worrying over speculations made by a friend. Perhaps not having reached a point of realisation in the same way that the other three men appear to have done bears some relation to this. Of course, equally it could be that his tendency to ruminate and worry over things has prevented him from coming to a point where he realises the full impact of his injury on his life.

Support

In negotiating new worlds: Related to the changes that these individuals faced in their life and in their way of looking at the world was their need to renegotiate and relearn how to deal with the world that they find themselves in. For Andrew this involved support from people who were

involved with helping him shortly after his injury; support which he spoke highly of as being instrumental in helping him to find his way around both submitting benefits claims and dealing with the housing problems that he faced. James, on becoming homeless, managed to secure assistance from homeless support services which enabled him to regain a level of security in his life that he was unable to do by himself. Robert has been a long term user of support services provided for people with brain injury. While for a long time he did not find this to be particularly helpful it was the only opportunity that he felt was open to him. It was through this service that he obtained the volunteering opportunity that has been such a positive influence in his life in recent months. John does not appear to have had to renegotiate the world in the same way that the other three participants have, but he appears to rely heavily on the support he receives from his wife which may protect him from having to face changes to his life in quite the same way that the others have.

Andrew: *"he applied to the DLA (Disability Living Allowance) for me cos I'd never heard of the DLA I didn't know you know didn't know any of these things"*

Robert: *"the ... project I found useful that was to get you back into society again I found that useful but the rest they were just telling me things I already knew and I shouldn't have been there ... there was nothing else until the gardens came up that's the only thing I've done since my crash that has been worthwhile"*

James: *"I got a support worker for homeless people ... they got me housed"*

James: *"they've been pretty helpful they've introduced me to lots of courses"*

The difficulty described by three of the participants in learning how to negotiate the world in a way new to them highlights the need for support. Perversely, it may also be the support and tolerance of John's wife that prevent him from having to make major changes in either his behaviour or his living circumstances (and hence having to renegotiate the world in the same way as his fellow participants). He openly admitted that his behaviour towards her can be quite aggressive, and that his knowledge that she will always be there for him allows him to continue to act the way that he does. While clearly John's wife is important to him, he recognises that his wife's tolerance for his behaviour will allow him to 'get away with it'.

John: *"I'll turn round to her and say I wish you'd piss off to work like I say I like my own space but I suppose I say that because I know she's going to come back ... I know she's going to come back so I'll probably get I don't know what word I'm looking for I'll probably get away with saying it (laughs)"*

"I love her to bits you know what I mean um all the relationships I've had in the past not one of them would have stood by me but she's still there you know she was there before my accident and she took me back after you know and that's good on her part it really is cos she must you know I eff and blind at her all the time call her stupid bitch dick head all sorts but she's so you know what I mean she really is I mean she's worth her weight in gold she must be to put up with me (laughs) I don't think I could put up with me know what I mean"

In day to day life: The support that John's wife provides for him appears to be important to him in his day to day life. He seems quite reliant in a number of ways; she will remind him about things

that he needs to do and he seems to expect her to (in that he says he doesn't look at the calendar), he would prefer her to make decisions about things on a day to day basis so that he does not have to face the pressure of coming to a decision (he gives the example of deciding what to have at meal times). John also suffers from depression, but states that this is not something he is particularly aware of and that it is his wife who notices a difference in his mood if he does not take his anti-depressant medication.

The other three men also reported needing support in their day to day life. For Robert this comes from his mother, for Andrew it is his son. However, it is James that seems most reliant on the support that he has from his support workers. Beyond the day to day help that they provide with practical issues they also appear to provide him with encouragement to get out and do things.

James: "I got a support worker for homeless people they do a lot for them they got me housed and housing support workers they come up and help with the house and that make sure I'm keeping up to date with all my bills and that help with the cleaning and all that"

James: "they've been pretty helpful they've introduced me to lots of courses ... and all that but I've just not got round to seeing about it these are drop in centres and that mostly just people with brain injuries"

Adjusting to change / Coping with day to day life

This analysis raised a number of possible ways in which these participants seem to cope with their day to day life, and indeed adjust and accept the changes that have occurred in their life. For example both John and Robert talked of the importance of taking each day as it comes.

John: *"There's a lot of frustrating things in there you know but like I say I just take each day as it comes"*

Robert: *"I just try to get through every day as it comes"*

Beyond this, however there seems to be two main approaches that these men have utilised in trying to come to terms with the changes that have occurred in their life. Firstly, there are ways in which they have changed their way of looking at life and their position in life, and secondly there are things that they do to make things easier on themselves or to improve things in a wider sense. The variation that is evident between these four men gives some indication of the many ways that individuals may go about adjusting to change and coping with day to day life. It is likely that there may be both positive and negative ways that people use approaches under both of these broad categories.

Actions aimed at improving things: Here there is the example of Robert who by facing up to the consequences of his actions managed to gain a greater control over his temper. He stated that the guilt he feels over the way in which he treated his parents as well as the time that he spent in prison were the precipitating factor in helping him to control his aggressive temper.

Robert: *"my dad's passed away now but my god the hell I put that wee guy through"*

Robert: *"I've not really done something about it (his anger) it was the jail done that for me there's no way I'm going back in there again"*

John likes to have his own space and this seems to be his way of avoiding problems. He prefers when his wife is at work as this allows him space to do things in his own time and avoids the possibility that she might ask him to do something. It is unclear whether this is something that is of much benefit to him other than avoiding immediate confrontation and stress that the pressure of being around other people brings to him; although by doing so it is undoubtedly a useful coping mechanism.

John: *"I just don't like being told what to do or when I can do it it's like I say I like to go at my own pace do what I want when I want"*

John: *"I'll turn round to her and say I wish you'd piss off to work like I say I like my own space"*

James spends time reminiscing as by doing so he hopes to ensure he does not lose his memory. James is quite clear in his reasons for both reminiscing and doing crosswords; he wishes to keep his brain working. Despite his intentions it seems unlikely that James's approach to coping with his

injury is benefiting him in any way. He came across as being rather depressed, and gave no indication that he expected this to change.

James: *"I've been doing a lot of crosswords and there's times I'm thinking do I know the answer and I don't know the answer or should I know the answer just to a lot of simple questions you know"*

James: *"I think back a lot I do do a lot of reminiscing hoping not to forget..."*

Ways of thinking (regarding position in life): Three different ways in which the participants changed their way of thinking about their own situation in life emerged during the course of this analysis. All of these appear to be beneficial to the individual; although as we will see with regards to the way John views his increased aggression as being a positive consequence of his injury it may be that what he views as positive effects may be negative, or even harmful to those around them. This may be in part to a lack of insight, however John freely acknowledged the way in which his aggression impacts on his wife and son. It appeared that while he is aware that his temper does have negative effects on those around him it is of more benefit to him to maintain the level of respect, fear, and perceived control that this elicits. In the same way that the examples emerging in this analysis reflect positive changes in the thoughts of the men in this study it is equally plausible that they could work in a negative way. For example, seeing other people as being better off than oneself or only looking at the effects of injury as being negative. This analysis does not however provide evidence for this. One explanation for this is that there is a level of self-selection bias in the sample, as participants who agreed to take part may be the ones that in general felt more positive about their experience.

The most notable example emerging from is the perception of being in a better situation than other people and feeling lucky for what they do have. The only participant who does not mention this is James. Andrew in particular gives many examples of how he is lucky. He feels lucky that things aren't worse for him, he feels lucky that he has had the opportunity to see the world, he sees himself as being lucky in that even though he can no longer travel abroad Scotland is a good place to be, and he feels he is lucky for all the support he had in helping him to adjust to his post injury life. Both John and Robert also recognise that things are worse for other people.

Robert: *"you went in there my god look at this ... my god look at half of these man half of their bodies couldn't work or nothing I thought my god how lucky are you"*

John: *"there's worse people, off than me, lost more than me"*

Andrew: *"I miss travelling but at the end of the day I've done it I've done a lot of it and here the Highlands is better than any of it anyway that's the way I look at it anyway that's the way I look at really I only got to get on a bus or get on a train and I go to a better place pretty much than anywhere ... so yeah things aren't perfect for me but they could be a lot worse"*

Andrew: *"I'm lucky I've done all that really that's the way I look at it"*

Andrew: *"it could be far worse ... at the end of the day I'm very lucky because I didn't lose my left arm and I'm not completely blind so I'm lucky I'm grateful really cos it could have been worse"*

Andrew: *"I'm lucky I'm here I look at what I could have been like and I look at other people and the sorts of lives other people have I'm quite lucky I'm quite happy at the fact I can walk about and I look perfectly normal I'm lucky there cos it could be far worse for me couldn't it I mean it is for other people yeah I'm happy enough"*

Another example emerging in this analysis is that of seeing positive consequences to the injury. Both Robert and John give examples of this. For Robert this is the financial compensation that he received following his accident which he sees as providing him with a better life. For John there are two possible examples of seeing positive consequences to his injury. He sees his temper as being a positive thing, although he does acknowledge that there is a down side to this, mostly in the way that it impacts on his family. This is a positive consequence from his perspective, despite the negative wider social implications. He sees his aggression as being a positive thing as it prevents other people from taking advantage of him

John: *"Getting angry means that people don't walk all over me you understand what I mean you know especially good neighbours and good friends they do understand what I'm like so they sort of there's a line there that they know not to cross you know what I mean"*

Another positive aspect that John sees in his injury is related to the third way in which he changed his way of thinking; reprioritisation. In terms of seeing this as a positive consequence of his injury John does not express his feelings about it being positive in the same way as he does about as his temper, but he does suggest a level of regret that it took him having his accident to take a more

realistic look at his working life (in that he wasn't indispensable and that relationships with his colleagues were just that; relationships with work colleagues). It took him having his accident to see that family should come first.

John: *"Unfortunately it took something like this for me to realise you know um... but now I'm just not interested in work, family comes first that's how I look at it you know, work can piss off."*

John: *"Before it was always work, work, work, but now I suppose after having the accident it's brought home to me you're just a number know what I mean. Like I say I've not worked for 7 years but the company is still there, know what I mean. The job I used to do is somebody else's, well they've lost the contract but my position is, somebody else has got that, know what I mean so nobody's, what's the word, indispensable."*

Participation, Goals and Focus

From what was said by each participant it seems to be the possibility of having a level of social integration with personal goals and focus that is particularly important in determining whether or not they consider they have a good outcome. This is described in more detail at the beginning of this section. The example of Robert gaining so much satisfaction from his voluntary work (which appears was supported specifically in order to help people with brain injury) suggests that this does not have to be a return to paid employment and may be possible in the context of support services. The key here appears to be in finding the most appropriate activity, as Robert's experiences with brain injury support groups was far less positive.

While intuitively it seems that the way in which people cope will be linked with their perceived outcome the relationship between these two themes is likely to be complex. The examples obtained in this analysis of the ways in which people adjust and cope can only be a snap shot of possible influences, even just for these four participants. While enabling successful adjustment and the implementation of coping strategies will be important in reaching a point where participation and social integration is possible it is likely that both support and opportunity will be key to this final part of this process. Robert's concern about the future of his volunteering project is a reminder of this; without the support available to him he is unlikely to be able to continue with his work. In addition to this combination of coping, support, and opportunity, the continuation of a state in which the desired level of participation is possible will rely on continuation of effective coping strategies. It is possible that for many it will remain an ideal that cannot be realised under the constraints of their post TBI disability. This is reflected in John's wish to be like he was before, and his acceptance of his post injury life while still holding onto the hope that things will improve.

John: *"the more it goes on and on it gets easier and easier but like I say even now I wish I was back to what I was before although I've accepted it'll never happen but you've always got that hope I suppose haven't you"*

John: *"the only time I'll ever think I've recovered is when I get back to where I was before which is never going to happen so no I don't think I've recovered and I know I never will be"*

Summary of Main Themes

A schematic diagram of the themes emerging in the analysis is shown earlier in Figure 6.3 providing an illustration of the way in which the themes emerging from this study may fit together. 'Change' is the first part of this; change in the self and in the way the world is experienced. 'Reaching a point of realisation' is another important factor as individuals report a specific event that caused them to

realise the extent of the consequences of their injury. 'Support' is of importance as it enables individuals to negotiate the changes in the world that they experience, as well as facilitating coping on a day to day basis. An important theme was 'adjusting to change/coping with day to day life'. This has many aspects; those which appear to be beneficial to the individual as part of a long term adjustment process; those that appear to be beneficial in terms of coping on a day to day basis; and those that while engaged with in an attempt to improve the situation appear to be harmful in nature. 'Participation, goals and focus' seems to be an important factor indicating a favourable outcome for participants; however the likelihood of achieving this is likely to be a complex relationship between ability to cope, available support, and opportunity. The arrows in the diagram indicate possible lines of progression as part of a recovery process representing the general overriding themes which emerged in this study. Clearly there may be other patterns of recovery process, and other influences not captured. The possible relationship between themes is only inferred from the available data. Despite this, the general patterns seem to bear some resemblance to the work of Prigatano, and colleagues (Prigatano, 1999; Prigatano, 1987); in that coming to awareness is an important part of a rehabilitation process. Part of this process will involve individuals engaging in rehabilitation and become aware of their problems as a way of enabling them to be addressed. This is reflected in the current findings in that reaching a point of realisation appears to be an important part in the adjustment process of at least three of the four participants.

Discussion

The themes which became apparent in this analysis were related to change, adjustment to change, support, and the need for meaningful activity. With respect to change this related to change in both the self, and in the world, in that all four men described how they were different in some way since their injury. In addition to this there are changes that have occurred in life both as a consequence of

their injury, but also just as a consequence of life moving on. Three out of the four participants described reaching a point of realization about their injuries; which seems to be an important point in their process of adjustment. James, who does not describe a similar experience, seemed to be the least well-adjusted of the participants in that he describes repeatedly reminiscing about the past without making much in the way of visible effort to change the way things are. His mood appeared to be lower than other participants, and he appeared to be less involved with activities or people. James recognised that there were things he could be doing to improve his situation, but due to his lack of motivation had been unable to do so. While acknowledging ways in which things might be better the other participants seem to be relatively content with their current situation. Each of the main themes (Change in self and world; reaching a point of realisation; support; dealing with change and coping with day to day life; and involvement in activities and having a focus in life) will be discussed in turn. They all represent to some extent findings in previous literature. The aim here is to set these findings in the context of other research and current understanding of the adjustment process following brain injury.

Change in self and world

Change in the way people perceive themselves has been described extensively in the literature, with experiences relating to changes in the self-featuring prominently (Nochi, 1998; Nochi, 2000; Gracey et al., 2008; Cloute et al., 2008). Reports of personality change are a well-established consequence of brain injury, going back as far as brain injury has been reported: Phineas Gage being the classic example (McMillan, 2000). Yeates et al (2008) review the literature surrounding personality change, highlighting the changes in both physicality and personality that will make the individual seem different to others. This is quite clearly stated by John in the current study when he says “the old *John’s gone, he’s not here no more this is a new John you know*”. Personality changes are well documented following brain injury; with aggression, impulsivity, lack of judgement and insight, and inappropriate behaviour being examples of the way this manifests (King & Tyerman, 2003; Santoro & Spiers, 1994). There is a long history of investigation of the factors surrounding personality change

and the impact it has on outcome (Max et al., 2006; Brooks & McKinlay, 1983; Brooks et al., 1987). More recent qualitative studies have sought to understand this further. Cloute et al (2008) used discourse analysis to examine the way in which people build up their self-identity, specifically in the context of their relationship with a significant other. In the context of the analysis there is discussion of disempowerment, as the individuals with TBI became almost passive in their telling of their experience with their family member taking on the role. They also discuss the way in which medical references are made perhaps legitimising unemployment and making it more socially acceptable possibly further disempowering the individual. It is possible that in the context of Cloute et al's (2008) study that the effects of disempowerment are particularly salient as those close to an individual with brain injury are rarely given the opportunity to voice their experiences. However, it is also likely that it represents a shift in power, and a change in the way that relationships work which is something to which adjustment will be required. In the current study John talked in some depth about the changing relationship he has with his wife; that he feels he has less freedom; he is unable to support his family; and he doesn't have a defined role.

In Howes et al (2005) IPA of the experiences of TBI of women, changing self is reported (*"I just feel different somehow and I don't know why or how I'm different but I just know I am"*; 51 year old woman, 1 year and 5 months after a severe TBI). One of their themes is labelled specifically 'Awareness of Change' which bears much resemblance to 'change in self and world' in the current study. In addition to the changes in self that are reported, in terms of both cognitive and physical changes, they also describe changes in the self as a social being. This has some similarities with the changes in the world in that it represents the changes in the way the individual has to interact with their surroundings and the situations in which they find themselves.

The 'self' is described in some detail by Nochi (1998). Here, the experience of brain injury and the beginning of loss of self-knowledge is described as occurring during periods of memory loss following injury, this combined with difficulty understanding what they have become, and

understanding how they are now in relation to how they used to be come together to create an overall experience of change following brain injury. This difficulty understanding the changes in themselves is particularly apparent with James and his constant self-reflection. He uses reminiscence as a way of holding onto the way he used to be as he struggles to come to terms with what his brain injury means to him. He lives with the fear that ultimately his injury will result in him becoming demented.

This idea of changing self fits in to some extent with the use of the term grief in relation to adjustment. People must come to terms with the fact that a previous self has 'gone' before they can start to rebuild a new sense of self. This has been described in relation to schizophrenia (Wittman & Keshavan, 2007), but also forms the basis for the development of the Brain Injury Grief Inventory (Coetzer et al., 2006; Ruddle et al., 2005; Coetzer & Corney, 2003) which enables a quantitative measurement of loss and adjustment following brain injury.

Reaching a point of realisation

A point of realisation was described by Shotton et al (2007) in their IPA study. They describe this as 'waking up' and coming to terms with having a TBI. There are differences evident between the current study and that of Shotton et al (2007) in the way this manifests. The experiences described by participants in Shotton et al's (2007) study were more related to the early stages, perhaps more closely related to forming an awareness of circumstances in general rather than coming to a realisation of the actual consequences of their injury. Shotton et al (2007) link it specifically with the period of PTA and suggest it serves a protective function for individuals as they felt detached from reality. The authors suggest that there does not appear to be any sense of distress as people come to this awareness. This is clearly not the case in the current research where participants describe it in terms of a shock; something that required them to come to terms with and to think about the negative connotations of their realisation. The participants in this study do not describe their realisation coming during their period of PTA and it is not without difficulty. John in particular talked about his acute distress: that he cried for the first and only time following his injury as he realised

that he was not able to work and probably never would be. *"I just got that frustrated I wanted to sit in a corner curl up and cry my eyes out because as far as I'm concerned I've never cried I've never shed a tear over this you know what I mean and that's what I felt I just felt like sitting in a corner curling up and crying my eyes out that's how bad I got"*. Nonetheless there are similarities between the experiences in this study of people coming to a realisation about their condition and the "waking up" described by Shotton et al. (2007). In particular they describe one participant who does not appear to go through a "waking up" process and as a consequence does not utilise coping strategies, made no use of social comparison, and saw no beneficial consequences to their injury. This person demonstrates a very similar experience to that of James in the current study. James does not describe reaching a point of realisation and, as with the participant described by Shotton et al (2007) does not seem to have made a positive adjustment to the consequences of injury. There are however some differences in that James seems to be aware that things are different for him and he is making some effort to deal with this. The similarities between James and the participant described by Shotton et al (2007) are in the lack of effective strategies that are put into place. However, given his general lack of motivation and general demeanour it should be considered that depression may play a role in the difficulty that James has in implementing effective strategies.

In addition to 'waking up', the point of realisation described by John, Robert and Andrew bears a resemblance to the way in which Shotton et al (2007) describe changes in the way that people coped (under the theme 'I keep going: Coping after TBI'); they describe how people lose hope and come to recognise and accept their limitations as part of their adjustment process. It should also be acknowledged that it cannot be concluded from the results that realisation was found in a clear dichotomous manner defined by a single event. While these participants describe a specific moment when they became aware of their situation it is may be that reaching awareness was a dynamic process happening over a period of time, perhaps as part of rehabilitation, and that it is only in recollection that it becomes something more specific. This process indicates a way in which they

have made sense of their injury and subsequent recovery process rather than necessarily offering an accurate description of the process itself.

Support

Support is repeatedly reported as being an important factor in the recovery processes of people following a brain injury; with higher levels of support and greater satisfaction with support repeatedly being associated with QoL, depression, and adjustment in general (Glover, 2003; Leach et al., 1994; McCauley et al., 2001). In particular it has been suggested that this is a reason for unexpected findings in relation to self-reports of QoL where individuals with more severe disability report higher levels of satisfaction with QoL than those with moderate disability following a TBI (Mailhan et al., 2005). In the current study practical support seems to be of particular importance. Social support is often identified as a factor that is of importance to people following brain injury (Tomberg et al., 2007; Steadman-Pare et al., 2001; McCauley et al., 2001). However, often when social support is measured a number of different aspects are taken into account; for example emotional support, financial support, informational support. These types of support may be very different in nature and the differing impact that they may have is poorly understood. For example the Social Support Questionnaire (Sarason et al., 1987) used by Tomberg et al (2007) measures the number of sources of support and the quality of these sources. Steadman-Pare et al (2001) measured social support based on the availability of financial support, emotional support, help with ADL, and availability of information relating to injury. Marital status was also used as an indication of greater social support. It is possible that the broad way in which social support is defined might mask the benefits of specific ways in which support is given. The practical aspects of support which are described by the men in the current study are perhaps those which are more easily identified and implemented (for example; help with obtaining benefits, or help in the house). It may be of

benefit for future research to investigate this further as positive identification of things that are of specific benefit will allow for a clearer understanding of what may be done to improve adjustment and recovery from injury.

Howes et al (2005) describe support as being important in their IPA study. Under the theme 'The struggle to make sense' both the knowledge of professionals and the importance of having someone there to listen are described as being important in the quest to make sense of the changes that have occurred since injury.

Dealing with change and coping with day to day life

In dealing with change and coping with day to day life two main themes are apparent: changing the way of thinking about things; and actions aimed at improving things. This was also reported by Shotton et al (2007), to the extent that they use a quote from one of their participants in the heading for the theme "I keep going": Coping after TBI'. However, there are differences in the motivation for continued effort. Shotton et al (2007) report an inbuilt drive and determination to get better. The quote that they use to support this is *"I keep going at things, not because I have to but because I want to"*. This seems to be more positive than the impression from the participants in the current study for whom it appeared to be more something that they had to do (*"There's a lot of frustrating things in there you know but like I say I just take each day as it comes"* (John)/*"I just try to get through every day as it comes"* (Robert)). One reason for this is that some of the participants in the current study are a longer time since injury, at 3, 7, 12 and 18 years; compared to those in Shotton et al's (2007) study who ranged from 2 to 6 years. The comments quoted here from John and Robert who were 7 and 18 years post injury, and it is these two participants who comment on the need to take one day at a time... It is possible that hope for improvement decreases as time goes on and individuals become accustomed to the way that things have become. It is also probable that there are personality differences at play.

Changing ways of thinking have been reported in the literature; as in both Shotton et al (2007) and Howes et al (2005) describing how their participants looked for positives in the situation. Participants may compare themselves with others (Shotton et al., 2007), or change the way they look at life in general (Howes et al., 2005). Often described is how participants talk of how things could be worse (Nochi, 1998; Gibbons & Buunk, 1999); a comparison that is made in the current study by three out of the four participants. Reprioritisation is described by John, and this fits neatly in with the theory of response shift where it is described as a way in which people adjust to changes. Also described is ways in which they see positive consequences to their injury; also reported by Shotton et al (2007) and Howes et al (2005) in IPA studies of experiences after TBI.

Involvement in activities and having a focus in life

In the discourse analysis conducted by Cloute et al (2008) they also identify progression and productivity as being key life-defining features. This reflects closely with the findings here in that there was a need for that feeling of 'usefulness'. A particular characteristic of their research is that they interview participants with a family member. They report a weight of reflection and expectations both of the individual and on the opportunities that will be available to them. They give an example of a father talking of his son being 'put on the scrap heap' as an example of the complex nature of difficulties, as the father's perception of an external being with control over outcome which when put in such an emotive manner is difficult for his son to disagree with. Cloute et al (2008) also report one participant talking about making papier-mâché heads: "I'd say the same as it is now you've gotta get on with it it's no good arsing about is it (. . .) urm I'm I'm not a sit sit round (..) in a (.) in a hall (.) making papier-mâché heads and so on (.) I mean (.) these 'ead injuries I mean (.) you get on (.) doing by yourself (.) the system holds you back (.) they let you down.". This reflects the experience reported by Robert who attended a brain injury support group but found it unsatisfying, it did not provide him with the focus he needed in his life. His volunteering post on the other hand allows him an important focus in his life and provides a feeling of fulfilment and purpose

in his life. Of course, this is not without problems as at the time of the interview his volunteering programme was facing funding difficulties and its future was in some doubt, thus highlighting the importance of structure and support in enabling a productive lifestyle. These issues can only serve as a reminder to the individuals involved of the limitations they face.

Limitations of the study and Methodological considerations

The IPA approach adopted here has both strengths and weakness as a tool to study psychological processes (Brocki & Wearden, 2006). A well-recognized limitation of the approach is the difficulty in generalizing results. Subject samples are relatively small and there are also likely to be sources of selection bias in participants who agree to participate in research. This means that findings cannot be generalized to wider populations in a straightforward way. Nonetheless, this does not mean that the research simply consists of re-stating the accounts of particular individuals. The approach is designed to give insights which can potentially be applied in other contexts, and which might be further investigated by systematic studies with representative samples; for example, the observation here that hope for improvement decreases over time.

There are also limitations that apply to the way in which the data are collected. The information gathered in interviews will be subject to difficulties in accurate recollection and to response bias in the way in which they are influenced by their perceptions of researcher expectations. These are issues that are relevant to qualitative research in any setting. When conducting research with people who have had a brain injury there is the added consideration of memory and cognitive impairments, and the possibility of impaired awareness. The principle focus in IPA is on the individual's experience as communicated by them (Smith et al 2009). The PCRS scores of John, Andrew, and in particular Robert suggest that they do not have a full awareness of the nature of their difficulties. This may have impacted on how they report their situation in life and the influence

that their brain injury has had on their life in general. For the purposes of this analysis what is reported by the individual is recorded, reported, and interpreted in the context that it is found.

A further set of issues arise from the subjective way in which analysis is conducted. As part of the IPA process the researcher attempts to make sense of the participants' experience. This subjective aspect is part of the nature of IPA research and reflects its dynamic and interpretative nature. On occasions identifying themes allowed for a reconsideration of the original data set which led to some re-evaluation of the original themes. This is an accepted part of the IPA process as looking for connections between cases and themes leads to understanding of a 'higher order concept'. In the words of Smith et al (2009) this can be a '*particularly creative task*'. While it is imperative that evidence is provided to support any conclusion drawn it is in combining cases in this way that the subjective nature of qualitative data analysis is particularly evident. Evidence and extracts from interviews are provided to support any conclusions drawn, but nonetheless this is a process that the researcher is actively involved in, becoming part of the interpretation process. Finally, the researcher brings theoretical preconceptions to the data which may affect, for example, identification of particular themes. Good practice is to take particular care that themes are actually represented in the data (Brocki & Wearden, 2006). Nonetheless the researcher inevitably has an interpretative role in this research approach.

Conclusions

Examining the experiences of four men who have had a TBI provides an insight into the way in which they adjust to the consequences of their injury. The coping strategies used by the participants varied, but in general involved ways of thinking and ways of acting. The techniques described by the participants in this study are representative of those reported in previous literature.

As might be expected support is also an important factor reported by the participants and is likely to be of importance in both day to day coping and in providing opportunities where they might

otherwise be unavailable. Practical support appeared to be of particular importance which may indicate the need for a better understanding of the ways that different types of support can be beneficial.

In terms of a satisfactory outcome the fact that participation and social integration are of importance may suggest that functional abilities are of particular importance after brain injury; a factor which, while traditionally a key indicator of outcome, might not be expected when considering only a subjective report. The results show different ways in which this may be achieved, with family involvement and supported volunteering identified. This suggests that there may be a number of ways in which participation and social integration may be supported that allow for a meaningful contribution to communities and family life.

Chapter 7: Integrating perspectives on QoL

The aim of this research was to investigate judgements of QoL after TBI, what influences these judgements, and the role of response shift. The response shift model (Sprangers & Schwartz, 1999) provides a structured theoretical explanation of ways in which people may adjust to the consequences of TBI, a topic that has typically been approached descriptively in the past. Using response shift as a theoretical basis from which to investigate QoL allows different aspects that may influence QoL to be brought together.

The Sprangers and Schwartz (1999) model of response shift (figure 7.1) identifies a number of variables which may have an impact on the way in which people evaluate QoL. Many of these have individually been investigated within a brain injury population; however they have not been brought together, and this may allow a more comprehensive explanation of the ways in which people change the way they perceive QoL after a brain injury.

Under the Sprangers and Schwartz (1999) model a catalyst (in the case of the current research assumed to be disability relating to a brain injury) leads to changes in the way people perceive their own QoL: A 'Response Shift' Process. The way in which a response shift occurs will be influenced by 'mechanisms'. A number of these have been implicated previously as being important factors in relation to quality of life after brain injury. As was described in Chapter 1, social support and interactions are often reported to be important to QoL following TBI (Kalpakjian, 2004; Steadman-Pare et al, 2001; Corrigan et al, 2001). Different coping styles may influence reported QoL. Social Comparison has also been investigated in people with TBI (Arenth et al., 2006).

The aim of this chapter is to evaluate findings from the current research to better understand whether response shift occurs following a brain injury. It will examine a combination of evidence to support whether or not there is evidence for response shift, and in particular whether there is

evidence for the underlying processes associated with response shift (reconceptualization, reprioritisation, and recalibration). It will also examine the relationship between factors implicated in the Sprangers and Schwartz (1999) model to gauge the level of influence they may have on QoL judgements. Following this the different ways of measuring QoL will be evaluated and the implications for research and practice considered.

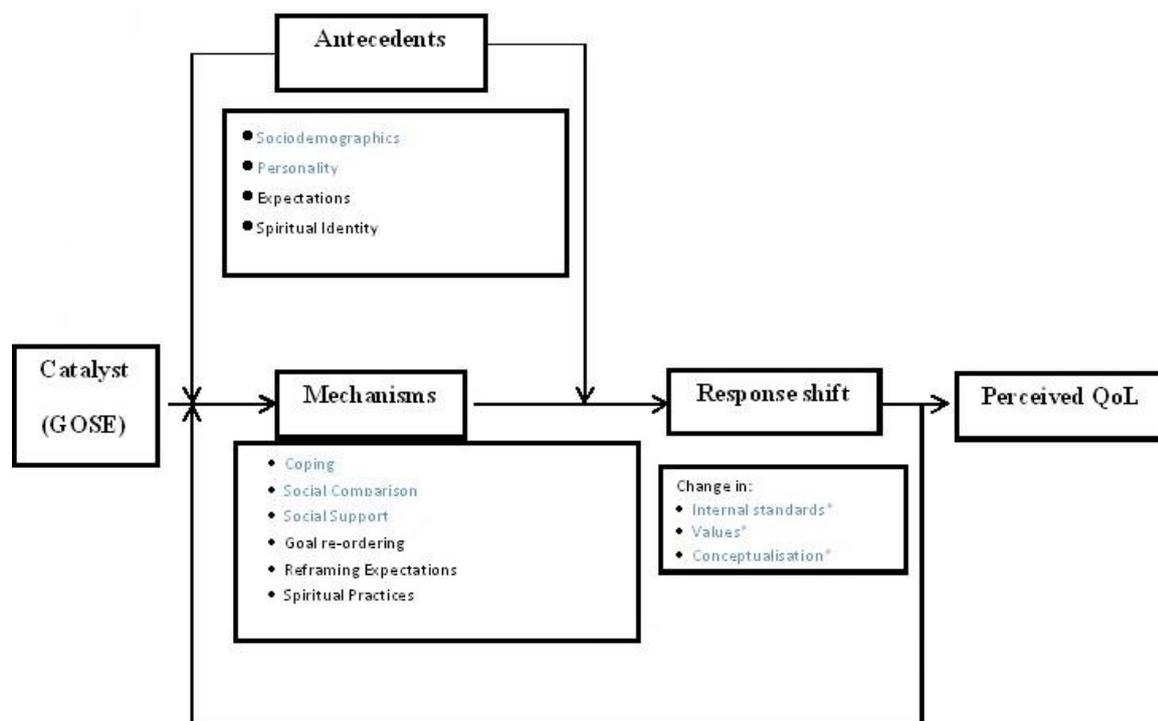


Figure 7.1: Sprangers and Schwartz (1999) theoretical model of response shift, with variables tested in this thesis highlighted in blue.

What is the evidence for response shift?

Then test

The 'then-test' provides the classic test of whether or not response shift occurs, and specifically whether there is evidence of recalibration; the procedure is described in detail in the longitudinal study in Chapter 4. Figure 7.2 shows a graphical representation of the then test as shown in Chapter 2, reproduced here for clarity. The overall change between T1 and T2, "the adjusted time effect", was significant, while the "reported effect" between baseline and follow-up was not. The difference between the reported effect and the adjusted time effect is that the adjusted time effect provides a comparison that uses the same internal standards. On the other hand the reported effect will reflect changes between judgements that are made using different criteria due to changes that occur over time or between different circumstances. The pattern of results is consistent with a recalibration effect, but the results are considerably weakened by the fact that the response shift effect was not itself significant. The effect size for the difference was -0.16 ($t(16) = .89$, $p=0.20$, one-tailed).

Although recalibration effects of this size are not unexpected based on previous research (Schwartz et al., 2006) it means that the results of the study described in Chapter 4 are indeterminate. It must be concluded that there is little evidence from these findings to support the hypothesis that response shift takes place in the recovery period after brain injury.

The study has some important limitations, which should be borne in mind when interpreting the results. Most obviously, given the small sample size, it is possible that a real effect is present but is not being detected (i.e. a type II error). A much larger sample size would be required to be confident of detecting an effect of the estimated size and logistically this was beyond the scope of the present study.

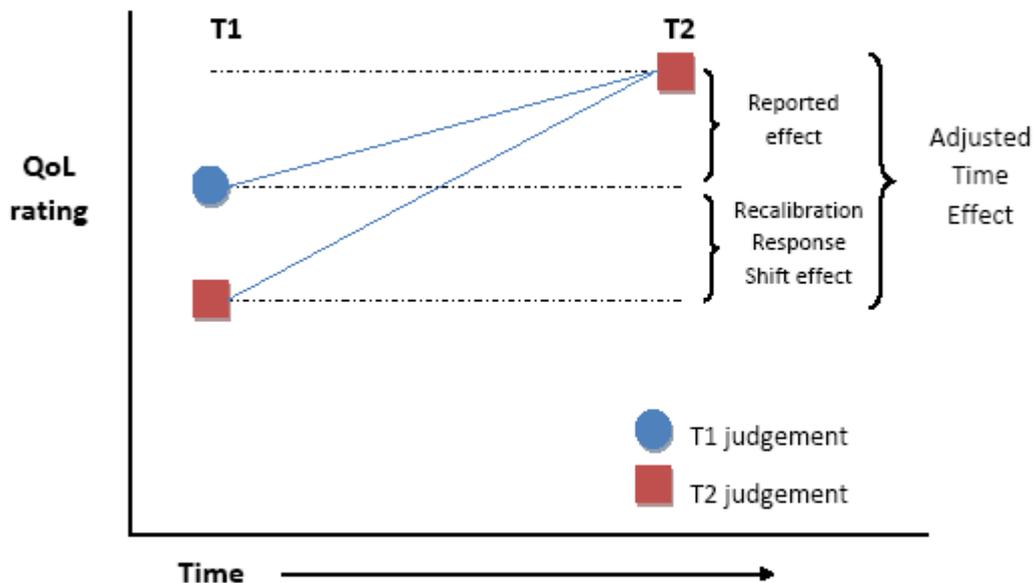


Figure 7.2: The Then-test (based on figure from Sprangers and Schwartz, 2010). The “then-test” involves administering QoL questionnaires at baseline (T1) and at follow-up (T2). In addition to assessing QoL at T2 respondents are asked to think back to how they were doing at T1 and to answer the questionnaire retrospectively (“then”). Recalibration response shift is estimated by computing the difference between the original QoL rating at T1 and the retrospective rating made at T2. The adjusted time effect is estimated by computing the difference between the QoL rating at T2 and the T2 retrospective rating of QoL at T1.

Furthermore, using a then-test judgement in general is not without its problems (e.g. in terms of recall bias or in retrospective judgements influencing post-test judgements; (Schwartz et al., 2006; Nolte et al., 2012). Of particular note in the current research is the fact that the response shift process under investigation is limited to that occurring post injury. It would however, be of interest

to use a then test to investigate whether response shift takes place in a setting where patients may be expected to change their perceived QoL. In a multidisciplinary rehabilitation setting for example it would be of interest to identify how much improvement is down to functional gain as opposed to changing expectations or perceptions.

There is also the consideration of the long time period that recovery from a brain injury can involve. There is the possibility that effectively understanding and adjusting to the long term consequences of injury may take months or even years. By focusing on the first 12-15 months post injury the aim was to capture the optimum time for detecting changes as this is the time when most improvements to functioning are likely to be made. However, it could be that adaptation in particular will continue for a much longer period of time. An adjustment process is likely to begin early in recovery; at a time when other factors such as being in PTA and remaining a hospital inpatient will have a significant impact on the individuals' ability to make a subjective evaluation of QoL. There is the likelihood of being unable to appreciate the impact of any limitations on their life if they are in a hospital setting and awareness levels may be low. This has implications for conducting research at this point in recovery. It would be of interest to obtain normative data relating to changes in QoL and any response shift process in the general population over a similar time period as the brain injury participants. This would act as some control for what is a difficult data set to interpret given the number of variables that will be at play. Such normative data are not currently available.

This was the first use of a "then-test" to study post-injury changes in TBI, and there are two main lessons learned for future research seeking evidence of a recalibration effect. One is that such studies should be powered to detect small effect sizes. The other is that the test should be conducted over an interval when change is likely, either before and after a specific intervention, or over a longer time interval. The results are reassuring from the perspective of longitudinal quality of life measurement after injury since they suggest that any effects of recalibration are relatively limited.

What is important to QoL: Evidence for the occurrence of response shift

Another way in which it is possible to consider whether response shift occurs is in the investigation of the processes of reconceptualization and reprioritisation, and here there was consistent evidence of changes both in selected domains and the importance assigned to individual domains.

In Chapter 3 where participants were able to nominate the domains that were important to them both before and after injury evidence for reconceptualisation comes from the fact that these have changed. Differing levels of importance also indicates that reprioritisation is taking place. More people nominate family or partner as being most important to their QoL after injury, with less nominating work. Health and state of mind, and security, finances, and living conditions are only nominated as being of particular importance after injury. This is possibly because these had previously been taken for granted.

Chapter 4 provides evidence for reprioritisation, in that participants' were asked to rate pre-defined QoL domains, based on the results from Chapter 3. Thus, it is the way in which the importance of these areas changes that can be identified, rather than the way in which they conceptualise QoL per se. There is little difference in the importance ratings given to these QoL at the baseline and follow up periods suggesting that there is little in the way or reprioritisation occurring in the period over the time being investigated in Chapter 4. There is however differences when the ratings given at the follow up period are compared with those given at that interview retrospectively for before injury. Here, similar patterns to those identified in Chapter 3 become apparent. Family is significantly more important to people after injury. Work is significantly less important to people after injury. Security, finances, and living conditions are significantly more important. Again, this could be because these aspects of life are taken for granted before a brain injury.

Similarly, Chapter 5 indicates that there are changes in the way people prioritise different areas of their life when making a judgement of QoL. Again, work is rated as being less important after injury and close relationships rated as being more so. Interestingly social and leisure activities are also

rated as being less important after brain injury, a result which is not apparent in Chapters 3 and 4. Ratings are also given in this chapter for the importance of the areas of life that are addressed by the QOLIBRI-OS. All of these with the exception of personal and social life are rated as being more important post injury than before. This provides support for the use of this measure as one which addresses areas of life that are of particular importance after brain injury.

There is also some indication from the qualitative findings in Chapter 6 of the increased importance of family and lesser importance of work, when John says: *“now I’m just not interested in work, family comes first.”* However, the results obtained from this approach to investigation do not clearly support the findings from the quantitative chapters as it appears that finding purposeful activity is important to the lives of the participants.

Re-conceptualisation suggests that individuals are redefining what QoL is, and reprioritisation suggests that different domains become important as the way in which QoL is subjectively assessed changes. The evidence from Chapters 3, 4, and 5 indicates that these processes do occur.

Similarities were found with the results in Chapters 3, 4 and 5, in that work was rated as being less important after injury whereas close relationships were rated as being more so. In Chapter 5 social and leisure activities were rated as being less important after injury; this differs from the Chapters 3 and 4 where trends indicate that this might be more important. It is unclear why this might be, but could be related to the way in which it is evaluated. One possible explanation for this is that there is less time dedicated to certain activities; specifically work and leisure. Many of the individuals who participated in the research had been unable to return to work and many had suffered some reduction in their ability to participate in activities that they would previously. This will have impacted on rating, and may have resulted in them being rated as holding less importance.

Work has been indicated as being significantly associated with QoL after brain injury (Seibert et al., 2002; Dijkers, 2004; Brown et al., 2000; O’Neill et al., 1998); which shows that it does in fact continue to be of importance to people after a brain injury. While work is rated as less important

after injury than it was before the ratings given indicate that it remains an important contributor to overall QoL. Results from the qualitative study reported in Chapter 6 would support this in that at least 3 of the 4 participants made some comment on either their ability to undertake paid employment or on their ability to participate in similar activities

In sum the studies provide evidence for reconceptualization and reprioritization as forms of response shift after TBI. However, the findings have some important limitations. The judgements are retrospective and are thus subject to the same caveats as the retrospective quality of life ratings. Perhaps the most significant limitation is that the influence of these reported changes on overall quality of life have not been quantified. The expectation is that changes in importance are adaptive, and serve to promote adjustment and quality of life. However, there is no direct test of this hypothesis, and it remains for future research. In practice the size of the influence may be small when quality of life is measured on scales such as the QOLIBRI-OS, where ratings of the importance of domains do not play a role in scoring.

Evaluation of the Response Shift Model

The following section will consider the evidence for associations and whether they are consistent with the model of response shift (Sprangers & Schwartz, 1999). Factors related to the response shift model include social support and social comparison (Chapters 4 and 5), coping strategies and optimism (Chapter 5). The Glasgow Outcome Scale was used in Chapters 3, 4, and 5 to allow the influence of disability to be assessed.

The study described in Chapter 5 aimed to test specific hypotheses derived from the response shift model. Both social support and optimism were related to reported quality of life, as predicted by the model. However, there was no evidence that social support acted as a mediator of the relationship between disability assessed on the GOSE and quality of life, nor was there any evidence that optimism acted as a mediator of this relationship. Thus specific predictions of the response shift model were not supported. The model also predicts that social comparison and coping strategies

will act as mechanisms of response shift, but these factors were not found to have a significant relationship with quality of life in this study. On present evidence it appears that although some of the factors identified in the Response Shift model are important to quality of life after TBI they do not exert an influence through the predicted mechanisms.

There are a number of possible reasons for the lack of support for the response shift model. The numbers in each of the studies were small and corrections were made for a relatively large number of comparisons thus requiring a much stronger effect before statistical significance can be concluded. This meant that the power to detect a significant relationship was small, with only medium to large effects becoming statistically significant. This is sufficient in identifying overriding patterns within the data, but does limit the conclusions that may be drawn about null results. It is also quite plausible that factors such as social support and optimism exert an influence on quality of life that is independent of mechanisms such as response shift.

To answer the question posed at the outset, the evidence from the current studies for response shift is relatively limited. There was no convincing evidence of recalibration using the then test. The most consistent evidence found in the studies was for processes of reconceptualization and reprioritization, but it is not clear how much these changes influence reported quality of life. Finally, the response shift model did not provide a good fit to relationships between variables and quality of life.

Factors influencing QoL judgements

In addition to the focus on response shift, the studies examined a range of factors influencing quality of life in an exploratory fashion. The following sections provide commentary on the main findings.

The impact of disability on post injury QoL

Disability is consistently found to be a factor influencing reported QoL in both the current research and previous literature (Lin et al., 2010; Kosty et al., 2012; Bullinger, 2002; Corrigan et al., 2001).

While some relationships between QoL measures and GOSE were found to be moderate in strength ($\rho=.46$ with Hadorn's scale in Chapter 3; $r=.36$ with Hadorn's scale in Chapter 4) these were not statistically significant. It is possible that the lack of a significant correlation is due to a combination of a small number of participants and correction for a relatively large number of comparisons (i.e. lack of statistical power). Nonetheless it does suggest that while disability may be a factor influencing reported QoL it is not always as strong as might be assumed. The implication is that disability and QoL represent separate aspects of outcome that can have stronger or weaker associations depending on the circumstances.

Social Support

Findings in the qualitative study reported in Chapter 6 suggest that support is an issue of some importance. The results from the quantitative chapters also suggest that support may have a role to play in the way that QoL judgements are made. In Chapter 4 the relationship between support and the Hadorn's scale was moderately strong ($r=.48$) but fell short of statistical significance. Equally in Chapter 5 a correlation of $\rho=.358$ was bordering, but not quite reaching the required level of significance. Social support is also a recurring theme in the literature as a factor which has an impact on quality of life, or satisfaction with life after injury (Neugebauer et al., 2002; Corrigan et al., 2001; Berger et al., 1999; Brown et al., 2000). At the most extreme, it has been credited with being the reason for paradoxical findings of QoL; where people who have had more severe injury or more

severe disability report their QoL as being better than those with a lower level of disability (Mailhan et al., 2005; Jones et al., 2010).

Previous research has identified that different types of support are important; for example Steadman-Pare et al (2001) identify the need for emotional support; whereas Ponsford et al (1995) highlight the importance of practical support. However, where social support is investigated the identification of the underlying meaning is not always clear. It may be that as in the current research it is used as an over-riding definition for a combination of factors, or it may be that it is used as a term to describe something more specific. Recognition of this is important as a more specific understanding of what is meant by social support will allow for a clearer understanding of what may be implemented to bring about positive change. An example to illustrate this comes from Kolakowsky-Hayner et al. (2001) who investigate the support needs of families and caregivers of people who have had a brain injury. They identify a perception that instrumental and professional support needs are not being met for a significant number of participants. This is important in that it highlights a specific way in which services may be improved. It may be of benefit in future research to look specifically at different types of support to help identify how these may be put into place to best support those who have had a brain injury. The apparent way in which practical as opposed to emotional support is identified in Chapter 6 may indicate that specific types of support have a greater impact on individuals.

Personality Factors

Optimism was identified for study in Chapter 5 as it reflects a personality trait which may influence response shift processes. It is also been documented to be of importance in reporting perceived QoL (Kostka & Jachimowicz, 2010; Scheier & Carver, 1992). Evidence relating specifically to brain injury is inconclusive: Tomberg et al (2007) report that while levels of optimism increase over time it is not associated with well-being; while Tomberg et al (2005) found that optimism was positively and significantly correlated with all of the SF-36 subscales. The evidence from Chapter 5 indicates that

optimism is significantly associated with QoL as reported on both Hadorn's scale and the QOLIBRI-OS (at $\rho=.355$ (Hadorn) and $\rho=.345$ (QOLIBRI-OS)). Further analysis did not indicate that it was a significant moderator of the relationship between GOSE and the QOLIBRI-OS. The strength of relationships between optimism and the two QOL measures (at $\rho=.355$ (Hadorn) and $\rho=.345$ (QOLIBRI-OS)) suggests that the strength of association of the LOT-R with these different measures is similar. Thus optimism seems to have a modest but consistent relationship with QoL no matter how it is assessed.

Brain Injury Specific Factors

Evidence from Chapter 4 indicates that factors specific to brain injury may have an impact on reported QoL. The BIGI, which provides an indication of perceived loss and adjustment related to the consequences of brain injury, had a significant relationship with reported QoL. There is also the suggestion that the GOSE and RBANS are of some importance. These findings highlight the diverse range of factors which influence QoL and thus indicate to some extent the limitations the response shift model in explaining the influences on QoL after brain injury. The results from the BIGI suggest that this specific avenue would be worth further exploration.

Impact of cognitive ability

In Chapter 3 participants with more severe cognitive impairment were excluded due to the cognitive requirements in understanding the SEIQoL-DW, but in the following chapters there was no formal cut off in terms of required cognitive ability. It was a requirement that they were able to provide informed consent and participate in the interview or complete the questionnaire (possibly with help). This means that in all chapters there was a possibility that memory problems or otherwise impaired cognitive abilities would have an impact on reporting. Where possible this was investigated statistically: no significant relationship was found between the TICS and SEIQoL-DW in Chapter 3 or between the RBANS and Hadorn's scale in Chapter 4. The lack of statistically significant

relationships does not imply that there is no impact of cognitive ability, only that the significance of this is limited in the current results.

The nature of the study excluded those with more severe impairment or disability who were unable to participate in an interview or to complete the questionnaire. This means that the applicability of these results is specific to those with a level of functioning that allows them the physical and mental ability and stamina to participate. While there was undoubtedly some level of both disability and of cognitive impairment it does not fully represent that found in the wider context of all survivors of brain injury. It would be of benefit in future research to use less demanding measures and include participants with more severe impairment and thus allow representation of a broader population.

Comparison of QoL measures: Hadorn's scale versus the SEIQoL-DW and the QOLIBRI-OS

During the course of the thesis different ways of examining QoL have been utilised. Most consistently, Hadorn's scale has been used, a simple global overall measure of QoL where participants rate their overall QoL on a scale of 0-10. Hadorn's scale was found to be a particularly useful way of looking at QoL due to its ease of use and continued demonstration of strong associations with other QoL measures used. It correlated with the SEIQoL-DW though perhaps not as strongly as might be expected, and demonstrated relationships with subscales of the SF-36 that were as strong, if not stronger than those found with the SEIQoL-DW. It was also related to the GOSE. These findings support the validity of this measure, as a meaningful and useful way of assessing overall QoL. They also support the findings of Steadman-Pare et al (2001) who used Hadorn's scale with people with brain injury; finding disability to be an important influence on QoL scores.

There are however, some issues regarding this simple measure. One is that it provides no detail about QoL or how it is conceptualised by the participant. It is not possible to identify what it is that

contributes to making such a judgement of QoL. This issue will not always be relevant depending on the circumstances in which it is used, but it means that results do not give information about domains affected.

Another issue relates to the impact of emotional status on ratings. In Chapter 3, correlations were found with Anxiety ($\rho=.43$), but particularly depression seemed to be having a large impact on ratings ($\rho=.79$). This correlation is stronger than that found with the SEIQoL-DW for which the concept of QoL is more clearly defined ($\rho=.55$). It should perhaps be noted that the correlations were in general stronger between Hadorn's scale and the other measures (all SF-36 subscales, with the exception on pain; HADS anxiety and depression; GOSE; and TICS) than they were with the SEIQoL-DW. This provides some support for the use of Hadorn's scale; suggesting that the way in which individuals define QoL for themselves on this simple global scale resembles the concept that is being measured by more traditional QoL/outcome measures. A strong relationship between a measure of QoL and these subscales may suggest that the QoL instrument is measuring something closer to psychological distress than QoL. It is possible that to some extent individuals are responding on Hadorn's scale based on their current affective state rather than conceptualising and rating QoL.

Conclusions

The evidence for recalibration response shift is limited, with only a small non-significant effect found on the then test over the initial recovery period post brain injury. There are methodological difficulties in measuring response shift due to brain injury itself, since it is not possible to get a baseline measurement of QoL prior to the injury taking place. This has implications for the usefulness of the then test in measuring directly the effect that brain injury has on QoL. Nonetheless it may be of benefit to use the then test in the future as a way investigating changes that take place as a consequence of a specific intervention.

In support of the model of response shift there is evidence from the current research that reconceptualization and reprioritisation take place after brain injury. Most notably importance ratings change systematically; for example, work is consistently reported as being less important after brain injury and family more so.

On the other hand little evidence is found of predicted relationships between the factors identified in the model of response shift and reported QoL. The complicated nature of the model and the numbers of participants that were recruited may have contributed to this due to a lack of statistical power. Identification of trends in the current data may however provide an indication of how to focus future investigation more clearly on factors likely to have an influence. Furthermore, qualitative findings in comparison with previous literature suggests that there may be some benefit in gaining a better understanding of the ways in which different types of support may be of benefit to individuals.

There is no evidence from the current studies that response shift plays a major role in overall quality of life ratings after brain injury. This is reassuring for studies that use quality of life measures as outcomes after TBI. However, the current studies had a number of limitations, and the precise role that response shift may play in recovery after brain injury remains an issue for future research.

Various factors that influence QoL were explored in current studies, and also indicate a number of avenues for future investigation. The use of different measures over the course of the research gives an indication of the strengths and weaknesses of different scales. The Hadorn's scale in particular bears a strong relationship with emotional aspects of functioning (e.g. HADS and SF-36 MCS). While there is much to support the use of the Hadorn's scale in its relationship with other QoL measures it is likely that it is influenced by current emotional state. The SEIQoL-DW provides a method by which the way in which people conceptualise QoL can be understood. This makes it a particularly useful measure where response shift is being investigated. In Chapter 5, rating the importance of different QoL domains as measured by the QOLBRI-OS and the GOSE provides an indication of what is

important post injury. This lends support to the QOLIBRI-OS as a measure that addresses areas of life which are of particular importance after a brain injury.

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