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DOCTOR OF PHILOSOPHY

Awareness and the emotional experience of acquired brain injury

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Awareness and the Emotional Experience of Acquired Brain Injury

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**Bangor University
2015**

Alice Elizabeth Roblin

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Thesis Summary

Across three papers, this thesis explores emotional adjustment and its relation to self-awareness following an acquired brain injury (ABI). The first paper, a literature review, discusses the findings of studies that have investigated the relationship between self-awareness and emotional distress following an ABI. Some of the studies demonstrated an association between the two variables, whilst others did not. Three variables, namely; time since injury, injury severity and the influence of rehabilitation were found to exert some influence on findings. The second paper presents findings from an empirical study that explores the lived experience of emotional adjustment following an ABI, in individuals who participated in an Emotional Management therapeutic group. The study was undertaken according to the principles of interpretative phenomenological analysis (IPA), with semi structured interviews being conducted with six individuals aged between 58-69 years. Distinct aspects of experience emerged, forming three overarching super-ordinate themes: biographical disruption, adjustment and post-traumatic growth. Biographical disruption described the instant and devastating onset of an ABI which imposes significant change and loss. Pre-injury personality, self-awareness and societal perceptions were discussed in regards to their influence on self-appraisals. Adjustment outlined a process of adaptation to the ABI, which appeared to be facilitated by meeting others who had also sustained an ABI. Post-traumatic growth explored how participants acquired new insights and meaning to life, whereby they discussed enjoying richer relationships and worrying less. The third paper discusses implications for theory and clinical practice that emerged from the first two papers. It outlines a range of factors and patient characteristics that may contribute to the development of emotional adjustment disorders following ABI, thereby drawing attention to how clinical interventions should be designed to minimise their impact. In addition, it explores areas for development and further research. A personal reflection of the research process and outcomes is included.

Acknowledgements

I wish to acknowledge the invaluable support from my supervisors, Dr Karen Addy and Dr Val Morrison. Many thanks for all your contributions.

I also wish to thank the patients and staff at the North Wales Brain Injury Service, who have been a continued source of inspiration, and without whom the making of this thesis would not have been possible.

And finally, I wish to thank my friends and family for your continued support over the last three years. In particular, to Ben, who has put up with more than most; here's to a future with fewer deadlines and more adventures!

Declarations

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

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

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Word Count without references:	6425
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Paper 2: Empirical Study

What helps, what hinders? Emotional adjustment following an acquired brain injury: an interpretative phenomenological analysis.

Word Count without references:	6999
Word count with references:	8131
Tables, Figures and Appendices:	3177

Paper 3: Contributions to Theory and Practice

Word Count without references:	3131
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OBJECTIVE:

METHODS:

RESULTS:

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Anderson, A. K. (2005). Affective influences on the attentional dynamics supporting awareness. *Journal of*

Experimental Psychology: General, 154, 258–281.

Anderson, A. K., Christoff, K., Panitz, D., De Rosa, E., & Gabrieli, J. D. E. (2003). Neural correlates of the automatic processing of threat facial signals. *Journal of Neuroscience*, 23, 5627–5633.

Armony, J. L., & Dolan, R. J. (2002). Modulation of spatial attention by fear-conditioned stimuli: An event-related

fMRI study. *Neuropsychologia*, 40, 817–826.

Beck, A. T., Epstein, N., Brown, G., & Steer, R. A. (1988). An inventory for measuring clinical anxiety: Psychometric properties. *Journal of Consulting and Clinical Psychology*, 56, 893–897.

Calvo, M. G., & Lang, P. J. (2004). Gaze patterns when looking at emotional pictures: Motivationally biased attention. *Motivation and Emotion*, 28, 221–243.

Carrette, L., Hinojosa, J. A., Martin-Loeches, M., Mécado, F., & Tapia, M. (2004). Automatic attention to emotional stimuli: Neural correlates. *Human Brain Mapping*, 22, 290–299.

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Self-awareness and emotional distress following an acquired brain injury; a review of the literature.

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Abstract

BACKGROUND: Acquired brain injury (ABI) can result in a range of deficits including emotional distress, which can have implications on wellbeing and the extent of recovery. The magnitude of distress experienced may be influenced by the degree to which an individual demonstrates awareness of their deficits. This association is not clear cut, however.

OBJECTIVE: Studies within the literature that investigated the relationship between self-awareness and emotional distress following an ABI were identified. Inconsistencies were explored to identify potential mediating factors.

METHODS: A comprehensive search of the literature was conducted for studies published between 1990 and 2014. Studies which investigated the relationship between self-awareness and emotional distress following an ABI were incorporated into the review.

RESULTS: Fourteen studies were identified. Nine studies reported an association between self-awareness and emotional distress, whilst four did not. One other reported a near significant result. Three variables, namely; time since injury, injury severity and the influence of rehabilitation were found to exert some influence on findings.

CONCLUSIONS: Gains in self-awareness were commonly observed during the first year post-injury in less severe ABIs. These gains appear to be associated with a greater incidence of emotional distress; however rehabilitation efforts appear to reduce the occurrence to some extent.

Keywords: ‘acquired brain injury’, ‘self-awareness’, ‘insight’, ‘emotional distress’, ‘depression’.

1. Introduction

An acquired brain injury (ABI) is a significant life event with often an acute and unanticipated onset that results in a number of cognitive, behavioural, emotional, physical, sensory and functional deficits making recovery a complex and challenging time for survivors and their families (Fitzgerald et al, 2012). Awareness of one's resulting deficits can have a significant impact on physical and psychosocial outcomes. Self-awareness is the subjective acknowledgement, observation or recognition of one's own actions and the drawing of subjective inferences about their effects. It relies on knowledge about the past and present, along with information inferred about the future. (Abreu et al 2001; Fleming et al 1996). A lack of self-awareness or lack of insight following an ABI is characterised by an individual's inability to appreciate the severity of their deficits and/or the impact they may have on their ability to live or work independently (Evans et al, 2005). Impaired self-awareness can have a negative impact on motivation and participation in treatment, resulting in implications for independent living, vocational outcome and caregiver stress (Fleming et al 1996; Fitzgerald et al 2012). With regards to emotional functioning however, it has been suggested that deficits in self-awareness can act as a protective barrier to developing emotional distress, as the individual is shielded from the true reality of life post injury (McBrinn et al, 2008). Increases in awareness of deficit however may be accompanied by emotional distress (Fleming et al, 1996).

A better understanding of emotional distress following an ABI is critical. Emotional distress can become a problematic complaint amongst individuals who are attempting to reintegrate back into family, community and vocational settings (Ownsworth & Oei, 1998; Moldover et al, 2004), with prevalence rates for depression following an ABI ranging from 11-77% (Evans et al, 2005; Malec et al, 2007; McBrinn et al, 2008; Carroll & Coetzer, 2011).

Depression can also make an individual vulnerable to suicide, with 1% successfully committing it within 15 years following an ABI, more than twice the general population risk (Fleminger et al, 2003). Identifying factors which may exacerbate emotional distress following an ABI may assist clinicians to better identify those who may be at risk, allowing for more effective support and rehabilitation interventions.

Currently there are inconsistencies within the literature base exploring the relationship between self-awareness and emotional distress. Some studies report a direct association whereas others do not. Some implicate variables such as time since injury and severity as having an impact on any association, whereas others do not. The aim, therefore of this review is to help clarify the relationship between self-awareness and emotional distress following an ABI by investigating research studies that have directly investigated self-awareness and emotional distress by including measures of both constructs within their design. As such, factors which may account for the contrasting findings between studies will be identified and explored in more detail.

2. Method

2.i. Literature search

An electronic search of PsycINFO, Web of Science and Medline was performed for all English language peer-reviewed articles published between January 1990 and December 2014. A comprehensive set of words and phrases relating to acquired brain injury, self-awareness and emotional distress were used to search for relevant articles. Key words and phrases included: 'self-awareness', or 'impaired self-awareness', or 'awareness deficit', or 'lack of insight', and 'emotional distress', or 'depression', or 'low mood', and 'acquired brain

injury’, or ‘traumatic brain injury’, or ‘stroke’. An example of a search request was as follows: ‘impaired self-awareness and emotional distress following an acquired brain injury’. The reference lists of all articles deemed appropriate for the review were inspected for additional papers. Only studies that explicitly investigated the relationship between self-awareness and emotional distress following a brain injury were selected for the review. Those that investigated the relationship as part of a wider study were also included if the findings pertaining to self-awareness and emotional distress could be extracted.

2.ii. Data Evaluation

Two hundred and four papers were identified via the database searches. A further five were identified through reference list searches. One hundred and nine papers were excluded on the basis of being duplicates and a further seventy four were excluded on the basis of review criteria in terms of study aims, methodology or being a discursive paper. Twenty six papers therefore remained for title and abstract analysis by the first author. A further twelve were excluded on the basis of focusing more specifically on rehabilitation interventions for improving self-awareness or the effect on caregivers. This left fourteen papers which were selected as relevant for the review. Please see Figure 1a for a flow diagram of how relevant studies were selected.

*Insert Figure 1a here.

2.iii. Data analysis

Key data was extracted for each study included in the review and tabulated (please see Table 1a). This included study author(s), date and country of publication, study aim(s), design, time since injury, measures, key findings and limitations. Similar trends and commonalities within the data were identified.

3. Results

3.i. Description of studies included

Fourteen studies were selected for this review (Godfrey et al, 1993; Fleming et al, 1998; Wallace et al, 2000; Evans et al, 2005; Ownsworth & Fleming, 2005; Sawchyn et al, 2005; Fleming et al, 2006; Ownsworth et al, 2006; Ownsworth et al, 2007; Malec et al, 2007; McBrinn et al, 2008; Carroll & Coetzer 2011; Sasse et al, 2013 and Smeets et al, 2014), which were conducted across seven countries (1 x Germany, 1 x Netherlands, 1 x Canada, 1 x New Zealand, 2 x UK, 3 x USA and 5 x Australia). Sample sizes across the studies ranged from 29 to 166. Nine studies recruited traumatic brain injury (TBI) participants exclusively (Godfrey et al, 1993; Fleming et al, 1998; Wallace et al, 2000; Evans et al, 2005; Sawchyn et al, 2005; Fleming et al, 2006; Malec et al, 2007; Carroll & Coetzer 2011 and Sasse et al, 2013), whilst the others also included participants who had received other ABI's including cerebral vascular accidents (CVA), hypoxic injuries and brain tumours.

All studies employed either a cross sectional or longitudinal design. Relationships between variables and differences between participants groups were investigated using a

range of correlation coefficients, cluster analyses, non-parametric and parametric statistical tests.

3.ii. Measurement of self-awareness

A number of strategies have been developed to measure awareness; these include the discrepancy based approach and interview methods. The discrepancy approach is the most widely used method and typically involves the comparison of participant's self-ratings of their own functioning with another measure which is considered more objective. Comparisons can be made with those made by a significant other (family member or treating clinician), or via comparison of participant's estimates of their abilities with that of actual performance measures (Fleming et al, 1996; Flashman et al, 2002). A discrepancy in scores is considered an indication of impaired awareness (Roberts et al , 2006).

Two of the most commonly used instruments employed in the discrepancy approach include the Patient Competency Rating Scale (PCRS) (Prigantano 1986) and the Awareness Questionnaire (AQ) (Sherer et al 1998). Both use standardised questionnaires with items relating to functional abilities that are rated on a Likert scale. Level of awareness is indicated by the discrepancy between participants and significant others ratings; a positive discrepancy score is suggestive of the presence of poorer self-awareness, while a negative score reflects over reporting of impairments (Fleming at al, 1996; Ownsworth et al, 2007). Both instruments have established reliability and validity (Sherer et al, 2003).

An example of the interview method is the Self-Awareness of Deficit Interview (SADI) developed by Fleming et al (1996). The interview incorporates three areas of questioning: (1) self-awareness of deficits; (2) self-awareness of functional implications of

deficits and (3) ability to set realistic goals. Following consultation with a significant other, total SADI scores are calculated by summing the three subscales to give a range of possible scores between zero and nine, with higher scores reflecting a greater disorder of self-awareness.

Most studies within the review utilise at least one or more of the instruments discussed to evaluate self-awareness. In addition, Godfrey et al (1993) developed and employed The Head Injury Behaviour Scale (HIBS) along with the Neuropsychological Impairment Scale (NIS) (O'Donnell et al, 1984), while Malec et al (2007) utilised the Neurobehavioural Functioning Inventory (NIF) (Kreutzer et al, 1996).

3.iii. Study Findings

Of the fourteen included studies, nine concluded that a tendency for participants to overestimate their abilities, demonstrating reduced awareness of deficit (i.e. positive discrepancy scores) was associated with less depressive symptoms, whereas underestimation of abilities (i.e. negative discrepancy scores) was associated with more depressive symptoms (Godfrey et al, 1993; Fleming et al, 1998; Wallace et al, 2000; Sawchyn et al, 2005; Malec et al, 2007; McBrinn et al, 2008; Carroll & Coetzer 2011; Sasse et al, 2013 and Smeets et al, 2014). One longitudinal study indicated a trend in the same direction, however it did not meet significance (Fleming et al, 2006), whilst the remaining studies did not demonstrate the association (Evans et al, 2005; Ownsworth & Fleming, 2005; Ownsworth et al, 2006 and Ownsworth et al, 2007). The following sections will explore similarities and differences within the studies on the basis of time post injury, injury severity and the influence of rehabilitation.

3.iv. Time Since Injury

Five studies within the review reported on the influence of time since injury on self-awareness and emotional distress following brain injury. Three studies controlled directly for the variable (Godfrey et al, 1996; Fleming et al, 1998 & McBrinn et al, 2008), whilst the others comment on its contribution to findings (Wallace et al, 2000 & Kelley et al, 2014).

Godfrey et al, (1996) examined the course of insight and emotional dysfunction in patients who had received a Closed Head Injury (CHI). A CHI was defined as ‘a head-injury resulting from blunt trauma, associated with a period of Post Traumatic Amnesia’. Sixty-six patients who had been admitted to hospital between January 1985 and December 1988 were eligible to participate in the study and were subsequently divided into three groups on the basis of time post injury at follow up. The groups were: patients assessed at 6 months post injury (n=24); patients assessed at one year post injury (n=19) and patients assessed between two to three years post injury (n=23). No significant differences with respect to injury severity, age or employment status prior to the injury were identified between the three CHI patient groups. A significant other also participated in the study.

This study found that CHI patients assessed at 6 months post-injury underreported their behavioural and neuropsychological problems and overestimated their level of social skill, with the authors suggesting that they do not accurately appraise the extent of their impairments. This presentation was termed *Post-Traumatic Insight Disorder*. In contrast, CHI patients assessed at one, two and three years post injury reported significantly more behavioural impairments and their scores were more consistent with the reports of their significant others. The highest levels of emotional distress were reported at one (p=.0005),

two and three ($p=.001$) years post injury, compared to no increased emotional dysfunction at 6 months which is interpreted as an indication that increased insight and awareness of impairment is accompanied by increased emotional dysfunction. They argue that increases in awareness may represent a psychological mechanism in that the acknowledgement of the significance of their impairments requires acceptance of the fact that they can no longer engage in a variety of activities, both vocational and recreational.

The authors highlight the role of the availability of accurate and relevant feedback as a key factor. They note how during the initial months of recovery spent in hospital, individuals receive little information about the nature and significance of their deficits as the environment is highly structured and focus is often on physical recovery. Upon discharge and following attempts to reintegrate back into society, the individual may be confronted with difficulties at work or whilst engaging in activities they completed with ease pre-injury. In regards to time post-injury, the authors conclude that CHI patients who are less than one year post injury appear to underreport the presence of their impairments. They stress the importance of supporting the individual as their insight emerges in order to minimise the negative emotional response. This study's limitation is that despite analyses not identifying any statistically significant differences between the CHI patient groups on a range of demographic factors, there nevertheless could have been other variables that could account for the differences observed between groups. An improvement to the study could be employing a longitudinal within-subjects design whereby the same individuals could be reassessed at six months, one year and two to three years post injury.

Another study by Fleming et al (1998) carried out an assessment of self-awareness, emotional distress, motivation and outcome in adults with TBI at one year post injury

following discharge from an acute brain injury rehabilitation facility. Using cluster analysis, they identified three sub-groups that were statistically different from one another ($p=.005$); high self-awareness, low self-awareness and a good recovery group. Similarly to Godfrey et al, (1996), the high self-awareness group also demonstrated the greatest levels of emotional distress, along with high levels of motivation to change at one year post injury. Despite their enhanced motivation, this group had not achieved better functional outcomes, suggesting that their emotional state was hindering their ability to adopt positive coping behaviours in some way. The authors concluded that a range of factors are likely to contribute to outcome following TBI, and that one year post injury is too premature a timescale to observe significant differences in outcome. They suggest that given time, the high self-awareness group may be able to work through their distress and make better functional gains.

In contrast, another study examining the relationship between awareness and time since injury on emotional distress had a slightly opposing outcome. McBrinn et al (2008) investigated awareness of deficit and time since injury in fifty -nine participants who had had an ABI. Time since injury ranged from four months to 12 years, with a mean of 33.12 months ($SD=34.9$). The variable '*time since injury*' had two conditions: Short (less than 2 years post injury) and Long (more than 2 years) which the authors explain was chosen to represent the median split. The authors identified a direct relationship between the acknowledgement of difficulties post-injury and the development of symptoms of emotional distress, however no main effect of time since injury and no interaction effect between time since injury and awareness was observed. The findings suggest that those with better awareness evidenced higher levels of emotional distress regardless of how much time had elapsed since their injury.

This finding is in contrast to that of the previously reported studies in which the greatest magnitude of change in self-awareness and emotional distress was observed between 6 months and one year post injury. Setting broad categories of ‘less than 2 years’ and ‘more than 2 years’ may however have masked the effect of *time since injury* as most participants will have already experienced any effect of this variable before the onset of two years post injury. This study may have been improved by setting time since injury as a continuous variable.

In a differing approach, Wallace et al (2000) investigated the relationship between emotional distress and differing perceptions of the extent of deficits in 50 individuals with brain injury and their significant others. They concluded that the degree of psychological distress experienced by the individual is partially related to the extent to which they report the presence of sequelae following the brain injury. This study also found that with increased time, individuals perceived themselves as more competent, even if significant others did not report experiencing the same change in perception. Time since injury did however impact on significant others depression, with fewer symptoms of depression reported if more time had elapsed post-injury. These findings appear to suggest that with time, both patient and significant other appear to undergo a process of acceptance and ‘coming to terms’ with what has happened.

A more recent study by Kelley et al, (2014) examined self-awareness at five years or more following TBI and its relation to outcome. The study found that improvements in awareness are observed in individuals who have had a TBI for up to five years post injury, following which they plateau and may not change significantly after that time. As for those who continue to demonstrate impaired self-awareness, they may experience distress not as a

result of acknowledging their deficits but, as suggested in Prigatano, (2005), as a consequence of experiencing continued failure and social difficulties that they are unable to explain.

3.v. Injury severity

Three studies investigated the influence of brain injury severity on awareness of deficit and emotional distress in individuals who had sustained a TBI (Sawchyn et al, 2005; Malec et al, 2007 & Sasse et al, 2013).

Sawchyn et al (2005) examined these relationships in 166 individuals with a history of TBI who had been referred for post-acute assessment and/or treatment. In regards to TBI severity, participants were categorised as follows; '*mild*' (n=83), '*moderate*' (n=25) and '*severe*' (n=58). On average, participants were approximately two years post injury. As expected, participants who had received moderate to severe injuries showed PCRS discrepancies in the expected direction, whereby they rated themselves as more competent than their significant others. The mildly injured TBI patient unexpectedly demonstrated an underestimation of their abilities as compared to ratings provided by significant others. The authors noted that individuals who had sustained mild injuries demonstrated a response style that was highly deficit focused and demonstrated a tendency for individuals to exaggerate their deficits, a pattern of symptom reporting which has been associated clinically with emotional distress and functional sequelae (Prigatano et al, 1990).

In regards to emotional adjustment, all three severity groups had clinically significant elevations on a variety of factors of emotional adjustment. The mildly injured patients

however were rated as being more dysfunctional in terms of helplessness and confusion than the more severely injured patients. The authors conclude that high levels of emotional adjustment difficulties are observed following TBI, and that mildly injured patients in particular are more likely to display emotional adjustment problems, along with reporting a variety of other neurobehavioral difficulties.

Similarly, a study by Sasse et al (2013) found that in their sample of 141 adults who had been hospitalised with a TBI, disturbances in self-awareness were more common in those with more severe degrees of trauma. These individuals also tended to report higher levels of health related quality of life. This too was the case in a study by Malec et al (2007) who sought to identify patient features associated with early and late depression following TBI. The study found an inverse association between depression and impaired self-awareness ($r = -0.47$, $p < .0001$), whilst impaired self-awareness was associated with more severe injuries. Those patients with impaired self-awareness tended to minimise impairments that were apparent to their significant other, a tendency that may have acted as a protective barrier to them developing depression. The authors conclude that subjective assessment of limitations rather than objective indicators of injury severity are more important factors, suggesting that the evolution of depression post-injury is more likely attributable to cognitive processes as opposed to neurological damage. Those therefore, who are most aware of their problems maybe more likely to dwell on them and worry about their perceived deficits. In addition, a pre-injury psychiatric history was found to significantly increase the odds of post-injury depression, suggesting that a negatively biased cognitive style could make an individual at greater risk of developing emotional distress following a brain injury.

As the studies discussed have only looked at TBI populations, it is difficult to confidently generalise their findings in regards to severity to other ABI patients (e.g. stroke, neurological illness) as injury profiles are likely to be different. The evidence reviewed here suggests that those with relatively mild ABI's may also present with greater self-awareness of their injury and therefore may be a greater risk of developing emotional distress post injury.

3.vi. The influence of rehabilitation

The following studies reported findings based on participants who were recruited from either an inpatient rehabilitation facility (Evans et al, 2005), were undergoing discharge from an inpatient facility (Fleming et al, 2006), or were actively receiving input from an outpatient rehabilitation service (Ownsworth et al, 2005; Ownsworth et al, 2006; Ownsworth et al, 2007 & Carroll & Coetzer, 2011).

Ninety-six inpatients were assessed in a study by Evans et al (2005) which sought to examine the incidence and intercorrelation of impaired self-awareness and depression following TBI. Inpatients who demonstrated more accurate awareness of their deficits reported poorer life satisfaction than patients with poorer self-awareness. Contrary to their hypotheses however, the degree of impaired self-awareness was not inversely related to depressive symptoms. One explanation they provide for this finding is that whilst in inpatient care, individuals are shielded from the full implications of the long-term residual effects of their injuries. These may only be recognised at a later date in their recovery, potentially resulting in more depressive symptoms at that time.

Another study allows for a unique insight into the process of transitioning from an inpatient rehabilitation environment back into the community. In the study by Fleming et al (2006), thirty four participants who had sustained a TBI were assessed in the week prior to and two months following discharge home. They found that after discharge, self-awareness increased and a trend towards increased depression was found, but did not reach significance ($p=0.09$). According to the SADI, almost all participants demonstrated evidence of some impairment in self-awareness prior to discharge, however at 2 months follow-up, there was a general shift in scores towards higher levels of self-awareness ($p<0.01$). The authors recognise how the transition from hospital to home can be a challenging time for individuals who have sustained a TBI as it involves exposure to activities of daily living that are away from the structure and support of the rehabilitation setting. This could understandably lead to low mood as the individual experiences struggles and set-backs whilst trying to re-engage back into society. Although a trend towards increased depression was observed, it did not reach significance. They conclude that 2 months is too premature a time frame to observe any great changes in mood as during this time, the person is still becoming accustomed to being at home. They suggest that further longitudinal research would capture patterns of self-awareness and emotional distress at later stages.

A study carried out by Ownsworth et al, (2005) investigated the interrelationships between metacognitive skills and measures of emotional status and executive function following ABI in sixty seven individuals who were receiving outpatient rehabilitation. Metacognition, as described by the authors encompasses self-awareness, along with self-knowledge, conscious reflection and self-regulatory skills. The study did not find an association between higher levels of awareness and emotional adjustment. The authors postulate that the absence of an association may be accounted for by the fact that most of the

participants were in the later stages of their recovery and as such, any emotional impact will have taken place earlier on, i.e. during one-two years post injury. In addition, they highlight the influence of coping style and cognitive beliefs on emotional processing following an ABI. It could be argued that an ability to think optimistically about ones capabilities following such a catastrophic injury is greatly fostered by participation in rehabilitation opportunities, whereby individuals are encouraged to engage in positive coping behaviours such as self-monitoring and the use of compensatory strategies.

A longitudinal study by Ownsworth et al (2006), focused on employment outcome following ABI. Participants were recruited from either an outpatient brain injury rehabilitation centre or a specialised service providing vocational rehabilitation and/or case management. Assessment took place on two separate occasions, 12 months apart. The study found that significantly more people were competitively employed at Time 2 (56%) as compared to Time 1 (26%) ($p < .001$). Participants also demonstrated an improvement in self-awareness and self-monitoring skills, however this was not directly correlated with time since injury, suggesting that other factors such as life experiences may be responsible for the observed increase. The study also found partial support for an association between improved employment outcome and emotional wellbeing at Time 2. This finding is in direct contrast to the findings discussed previously (Godfrey et al, 1993 & Fleming et al, 1998), suggesting that the rehabilitation the participants were engaged in may have prevented them from developing emotional distress post-injury. Indeed, the majority of individuals were receiving either a case-managed vocational work trial or were in training or study, during which they received feedback about their performance and engaged in structured opportunities to learn about their post-injury deficits. This study appears to provide evidence that rehabilitation along with engagement in purposeful activity such training or employment, reduces the impact of loss,

assists with gains in self-awareness and reduces the development of emotional distress post ABI.

A further study provides an alternative insight into self-awareness following brain injury. Ownsworth et al, (2007) recruited 86 participants with ABI who were attending community based outpatient rehabilitation. The authors identified four distinct awareness typologies and compared their long term emotional adjustment and psychosocial outcomes over the course of 12 months. The typologies included: (1) *the poor self-awareness group* who on assessment indicated neuropsychologically based awareness deficits ; (2) *the high defensive group*, who had a tendency to minimise their symptoms, therefore displaying a psychologically-based awareness deficit; (3) *the high symptom reporting group* who presented with a tendency to magnify symptoms and the (4) good self-awareness group who demonstrated moderate symptom reporting, normal defensiveness and good error regulation. On initial assessment, the study found that the greatest emotional distress was experienced by both the *poor self-awareness group* and the *high symptom reporting group* ($p < .05$), however at 12 month follow up there were no overall differences between the awareness typology groups in regards to emotional distress ($p = .12$). This finding may be due to the fact that all participants were receiving ongoing rehabilitation such that, regardless of awareness typology, the support they were receiving assisted in lessening their emotional distress. The authors recognise how the highly heterogeneous nature of the groups in regards to cause of ABI, severity and time since injury, makes it difficult to generalise findings to other brain injury samples.

And finally, another study that also recruited participants who were receiving input from a community brain injury rehabilitation service by Carroll & Coetzer (2011),

investigated awareness and emotional distress following TBI as part of a wider study looking at identity and grief. In contrast to the other studies that had recruited from outpatient facilities, the study found a modest negative correlation between depression and awareness. Poorer self-awareness, as indicated by larger discrepancy scores, was also associated with higher levels of self-esteem. During assessment, participants reported significant changes in self-concept, whereby present self was viewed negatively in comparison to pre-injury self. This perceived change in identity was positively associated with depression and grief. These findings mirror the general consensus of studies discussed earlier in this review, regardless of the fact that participants were engaged in active rehabilitation at the time. The study doesn't clarify however, the type of rehabilitation the participants were engaging in, suggesting that they may have been receiving rehabilitation aimed at improving physical functionality as opposed to addressing emotional and psychological needs. This comment could be expanded to the other studies reviewed under the title 'Influence of Rehabilitation' as not enough information on the nature and intensity of rehabilitation delivered is provided from which to make definitive conclusions about the influence of rehabilitation on self-awareness and emotional distress (with the exception of Ownsworth et al, 2006). One can only speculate that individuals may have been receiving some emotional support at the time of assessment.

4. Discussion

4.i. Summary of results

This review encompasses studies that have addressed the relationship between self-awareness and emotional distress following an ABI. The studies addressed indicate that impaired self-awareness is most commonly observed following a severe brain injury,

especially one that is traumatic in nature. The author is aware that following an ABI, neurocognitive disruption can affect cognitive processing of deficit awareness, however further explanation of the cerebral structure and neuroscientific correlates of brain injury localisation and impaired self-awareness is beyond the scope of this review. The interested reader may wish to consult Fitzgerald et al (2012) & Moldover et al, (2004), which further explores psychological processes. From a psychological perspective, failure to acknowledge one's deficits following an ABI has been described as 'adaptive' (Flashman & McAllister 2002) and 'protective' (Fleming et al, 1998) as it effectively shields an individual from the true realities of their injury, however it can have negative implications for engagement in rehabilitation and social re-integration (Roberts et al, 2006). In contrast those who sustain milder injuries are more likely to be acutely aware of their deficits, and studies have shown that this is often associated with elevated levels of emotional distress (Sawchyn et al, 2005; Malec et al, 2007 & Sasse et al, 2013).

In regards to time since injury, Godfrey et al (1993) demonstrated that an increase in awareness is observed approximately one year post injury, and is often accompanied with increased emotional distress for up to another two years. This finding suggests that increased awareness of deficit can be a distressing time for individuals as they begin to comprehend how their injury will impact on their ability to re-engage in activities and roles they performed with ease prior to their injury. This realisation may be most prominent following discharge from hospital or an acute rehabilitation facility. During this time, support is reduced and the individual may be confronted with new and unexpected challenges in the community, as demonstrated in Fleming et al (2006). Increases in self-awareness have been observed to continue for up to five years in individuals who have sustained a TBI (Kelley et

al, 2014). Whether this increase is accompanied with continued increases in emotional distress is unclear as this is yet to be studied directly.

Despite these findings, a number of studies failed to identify an association between an increase in self-awareness and emotional distress following an ABI (Evans et al, 2005; Ownsworth & Fleming, 2005; Ownsworth et al, 2006 and Ownsworth et al, 2007). One commonality between these studies was that participants recruited into the studies were in active receipt of rehabilitation services from either an acute inpatient or community outpatient facility. It appears therefore, that rehabilitation can assist individuals as their awareness increases by providing emotional support, education and explanation for their difficulties. Without it, an individual could be at risk of developing self-limiting beliefs which reduce a person's ability to develop adaptive coping strategies and a renewed sense of mastery (Ownsworth & Fleming, 2005).

4.ii. Practice Implications

These findings allow for better identification of individuals who may be at risk of developing potentially debilitating emotional distress post brain injury. Those who have sustained a relatively mild ABI and have recently been discharged from hospital or an acute rehabilitation facility may present as being most vulnerable as they are confronted with unexpected difficulties and limitations imposed by their resulting deficits. These findings may prompt longer term neurorehabilitation facilities to improve identification of potentially vulnerable individuals and ensure that appropriate support is delivered in a timely manner so to prevent chronic and disabling emotional distress from becoming entrenched.

This review also highlights the potentially negative implications of interventions aimed at increasing an individual's awareness following an ABI, due to the potential for it to be coupled with increases in emotional distress. Studies or interventions aimed at achieving greater self-awareness in their subjects must ensure that they also provide appropriate support and guidance for those individuals who do make gains in self-awareness. In addition, despite being beyond the scope of this review, the impact on carers of both impaired self-awareness and emotional distress as a result of intact awareness should be emphasised as great expectations are made of these individuals who are all too often left to suffer in silence.

4.iii. Limitations

a. *Study limitations:*

One of the major limitations identified across studies is the relatively small sample sizes. In addition, the heterogeneous characteristics of many of the samples limit the generalisability of findings. The majority of studies that investigated impaired self-awareness and emotional distress did so in individuals who had sustained a TBI. Those that also investigated other types of focal and diffuse ABI's such as ischemic or hypoxic injuries often grouped all participants together, making any comparisons or unique findings between groups difficult to identify. Studies that recruited from rehabilitation services did not detail the type or intensity of rehabilitation individuals were receiving at the time of their assessment.

A further limitation identified by many of the studies is in regards to the measures used. Firstly, the use of questionnaires and structured interviews relies solely on the patient's ability to understand written or verbal questions, understand their meaning, and then

communicate their opinions. This immediately excludes a number of individuals due to speech and language disorders, further reducing generalisability (Fleming et al, 1996). In regards to measuring impaired self-awareness itself, although a commonly observed phenomenon in cognitively impaired populations, it is difficult to quantify. Discrepancy measures, where a comparison score is calculated between self-assessment and the opinion of a significant other or clinician, is merely a measurement of inference (Trahan et al 2006). Judgements made by significant others or clinicians can be marred by biases, such as conflicts with their value systems, their emotional response to the individual and simply due to limited opportunities to observe the individual since their injury and therefore make a balanced judgement (Wallace & Bogner, 2000).

The question of causality is also an issue as despite the identification of significant associations, it is not possible to attribute change in emotional distress to changes in self-awareness, or vice versa. Knowing the direction of causality would have the benefit of further informing patients, families and treating clinicians.

b. Review Limitations

The author recognises how this review of self-awareness and emotional distress following an ABI is a rather crude ‘one size fits all’ summary as it is based on studies that have largely failed to acknowledge other factors, such as cognitive processing impairments, premorbid ability, personality style, illness beliefs, familial support and/or financial stressors etc., that may be implicated in the process of developing awareness of ones limitations and the presence of emotional distress following brain injury. The relatively scant number of studies addressing these specific phenomena has resulted in gathering findings from studies

that are contrasting in regards to participant selection, design, methodology and outcome criteria. This further compounds any conclusions drawn from the studies.

c. Research Recommendations

Further research in this field is required to better understand the association between self-awareness of deficit and emotional distress, both of which play a significant role in the success and extent of an individual's recovery and subsequent quality of life following an ABI. More rigorously controlled studies are required to allow for greater clarity when drawing conclusions about the impact of factors such as injury type, time since injury and the effect of rehabilitation. Longer term longitudinal within-subject studies may provide a unique insight to the process of recovering from an ABI.

As hypothesised by Crosson et al (1989), self-awareness is not to be viewed as a single entity, but one that develops over the course of three distinct stages. These include: *intellectual awareness*, whereby an individual first gains the ability to acknowledge that a deficit exists, through to *emergent awareness*, whereby an individual recognises problems related to deficits when they are actually occurring and finally, *anticipatory awareness*, whereby an individual is capable of anticipating a problem as a result of a deficit. As many of the currently available tools only measure intellectual awareness (Fleming et al, 1996), an enhanced means of assessing all aspects of self-awareness is required, along with an indication of when emotional functioning begins to play a role in a person's functioning as they begin to experience fluctuations in their awareness of deficit.

5. Conclusion

An ABI can result in a number of deficits, including emotional distress, which can have significant implications on a person's recovery if not addressed appropriately. This review has found evidence to suggest that those who demonstrate self-awareness of their deficits may be most at risk of developing emotional distress, as they come to recognise the extent of their resulting deficits. The greatest gains in self-awareness, and therefore emotional distress are often observed during the first year post injury, especially in those who sustained relatively mild injuries that did not involve damage to the frontal lobes of the brain. Rehabilitation efforts during this time however, appears to reduce the likelihood of emotional distress developing as the individual is in receipt of invaluable guidance and support. It is hoped that the findings of this review will prompt neurorehabilitation services to improve identification of 'at risk' individuals so that they may prioritise support to reduce the probability of individuals developing chronic and entrenched emotional difficulties later on in their recovery.

Declaration of Interest

The author has no conflict of interest to declare.

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*Studies included in the review are indicated with an **

Table 1a: Information pertaining to studies included in the literature review.

	Study; date & country	Participants: (type of injury, n)	Time since injury at point of assessment	Measures ¹	Design/ Analysis	Study Aims	Outcome	Association found between self-awareness and emotional distress?	Study Limitations
1	Godfrey et al, 1993, New Zealand	TBI 1. n=24 2. n=19 3. n=23	3 groups: 1. 6 mths, 2. 1 yr, 3. 2&3 yrs post injury.	HIBS NIS SDS STAI-Y RSE	Cross-sectional One way group ANOVA.	Examine the course of patients insight into their behavioural impairment and the course of emotional dysfunction following a CHI, and to examine the relationship between the two variables.	TBI patients assessed at 6 months post injury underreported the number of behavioural & neuropsychological problems. CHI patients 1 year post injury evidenced greater insight about their level of behavioural impairment and demonstrated higher levels of emotional dysfunction.	Yes	Group differences could be due to cohort effects. No attempt made to match for factors such as length of hospitalisation or time between injury and assessment.
2	Fleming et al, 1998, Aus	TBI n=55	Acute rehab. Assessed 1 yr post injury.	SADI PCRS HIBS CAQ BDI BAI DRS CIQ SIP	Longitudinal. Cluster analysis	Investigate the relationship between self-awareness, emotional distress, motivation and outcome in adults with severe TBI.	Three groups identified; high self-awareness, low self-awareness and good recovery. High self-awareness was associated with motivation and emotional distress. A range of factors contributes to outcome following TBI	Yes	Recruitment from a single facility small sample size limited external validity Only 1 yr post injury.

¹ **Measures:** - HIBS: The Head Injury Behaviour Scale; NIS: Neuropsychological Impairment Scale; SDS: Zung Self-Rating Depression Scale; STAI-Y: State-Trait Anxiety Inventory Form; RSE: Rosenberg Self Esteem Inventory; BDI: Beck Depression Inventory; BAI: Beck Anxiety Inventory; CIQ: Community Integration Questionnaire; CAQ: Change Assessment Questionnaire; SADI: Self-Awareness of Deficit Interview; PCRS: Patient Competency Rating Scale; SIP: Sickness Impact Profile; DRS: Disability Rating Scale; AQ: Awareness Questionnaire; DEX: Dysexecutive Questionnaire; HADS: Hospital Anxiety & Depression Scale; TBIFI: TBI Follow up Interview; SF-36: Short form 36 health survey; CQOLQ: Cognitive Quality of Life Questionnaire; POMS: Profile of Mood States; GOSE: Glasgow Outcome Scale Extended; NIF: Neurobehavioural Functioning Inventory; FAD: Family Assessment Device; MSPSS: Multidimensional Scale of Perceived Social Support; CES-D: Centre for Epidemiologic Studies-Depression Scale; SWLS: Satisfaction with Life Scale; SRSI: The Self-Regulation Skills Interview; BHS: The Beck Hopelessness Scale; ILS: The Health and Safety subtest of the Independent Living Scales; TTT: The Tinker Toy Test; SPRS: Sydney Psychosocial Reintegration Scale; HISDS-III: Head Injury Semantic Differential Scale-III; BIGI: The Brain Injury Grief Inventory.

3	McBrinn et al, 2008, Ire & UK	TBI & CVA n=54 Age: 18-65	Min of 3 months post injury.	AQ DEX HADS	Cross sectional. Four 2x3 btw groups factorial ANOVA	To explore the relationship between awareness and time since injury on reported emotional distress.	Main effect of awareness, such that participants with better awareness of their difficulties had higher emotional distress, regardless of time since injury.	Yes	Not possible to state causal relationship. No discrimination between psychological denial and neurologically based impaired self-awareness.
4	Wallace et al 2000, USA	ABI n=50 Age: 15.7-79.0	Years R=0.19-9.44 M=1.95	- PCRS - BDI - BAI	Cross sectional. Pearson correlation.	The relationship between emotional distress and differing perceptions of the extent of deficits was investigated in individuals with a brain injury and their significant others (SO).	Individuals who reported fewer deficits than their SO were less likely to report symptoms of depression. Significant others reported less depression if they perceived their loved one as more competent. With increased TSI individuals see themselves as more competent, but SO do not necessarily experience the same change in perception.	Yes	Restricted population Measures: potential for bias.
5	Kelly et al 2014, USA	TBI n=62 Age 23-70 M=35	Interviewed between 5-16 yrs post injury	TBIFI CIQ Quality of Life Scale. Satisfaction with Life Scale. Sig Others-Caregiver Burden Inventory	Cross sectional. Cronbach coefficient.	To examine self-awareness 5 years or more following TBI and its relation to outcomes.	Discrepancy in self-awareness functioning evident 5 years after TBI between individual and SO. Injury severity predicts self-awareness. Increases in self-awareness observed over time. Plateau after 5 yrs.	Yes	Only 61% follow up. Other potential factors influencing ratings e.g. premorbid personality, pursuit of compensation etc. Measures: no assessment of communication ability.
6	Sawchyn et al 2005, Canada	TBI Mild: n=83 Mod: n=25 Severe: n=58 Age M=38.56	Days Mild= 687 Mod= 665 Sev= 745	- PCRS - KAS-R - Injury severity data inc LOC, PTA and GCS score.	Cross sectional. Paired-sample t-tests and ANOVA	Explore the relationships among awareness of deficit, injury severity and emotional adjustment in patients with TBI.	Patients with more severe injuries rate themselves as more competent than SO's. Mild sample exaggerated deficits or highly deficit focused. Clinically associated with emotional distress. Mildly injured pts more likely to display emotional adjustment problems.	Yes	Select population. Measures: potential bias.

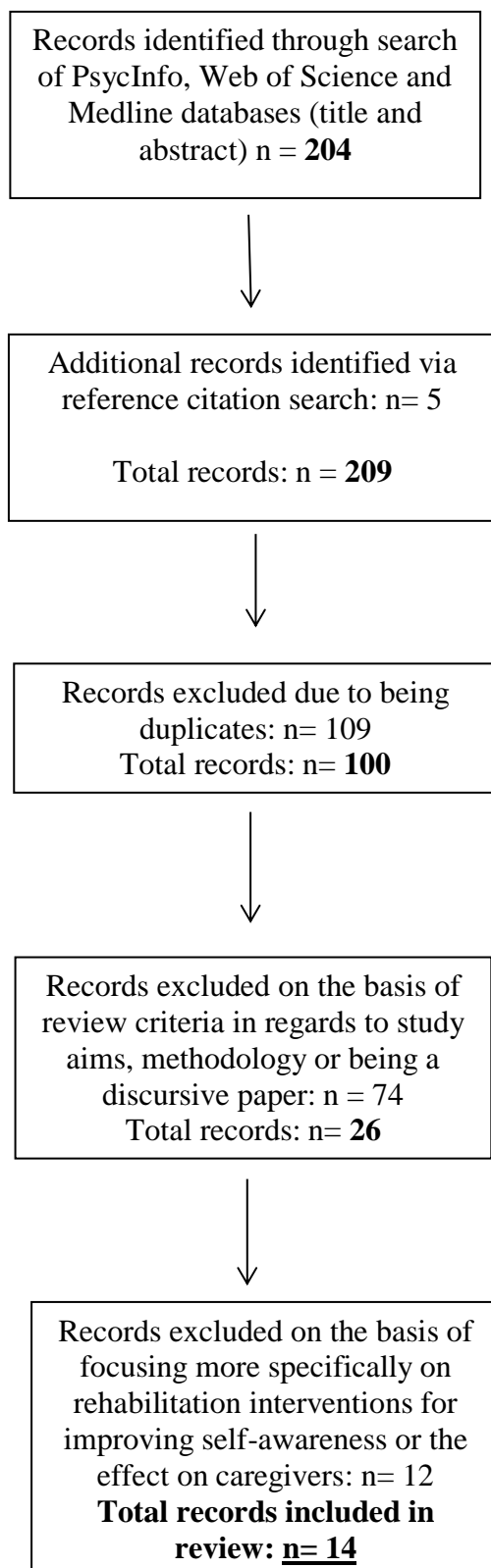
7	Sasse et al 2013, Germany	Trauma and neurosurgery centre n=141 Age: 17- 68.	3months-15 years. Testing took place ave 40.2 mths since injury.	PCRS SF-36 COQOL TBI specific HRQOL HADS POMS GOSE	Cross sectional. Spearman's correlation.	To investigate relations among self-awareness, impaired self-awareness and health related QoL after TBI.	Lower levels of self-awareness were accompanied by higher levels of HRQOL. Weak but significant correlation of self- awareness with anxiety and depression. No significant associations with time since injury and self-awareness. Self- awareness is more commonly observed following severe trauma.	Yes	Sample composition; size and sample bias. Range and average of time since injury. Potential bias in participant selection.
8	Malec et al, 2007, USA	TBI Mild: n=42 Age M=35.8y r Mod/Sev : N=51 Age M=35.7	Recruited following hospital admission.	Measures of pre- injury factors and injury severity: PTA etc & neuroimaging. NIF (NIF- Dif). FAD MSPSS	Cross sectional. Regression model and ANOVA	To identify patient features associated with early and late depression after TBI	Depression was present regardless of injury type or severity. Early and late depression was most strongly related to patient's perception of their level of impairment. Impaired self- awareness associated with more severe injuries. Self-ax of impairment correlated highly with depression. Suggests cognitive processes are more important in the evolution of depression than neurologic damage.	Yes	Measures: not designed to separate actual and perceived impairment.
9	Evans et al, 2005, US	TBI n=96 Age M: 32	Acute rehab service?	DRS AQ CES-D SWLS	Cross sectional. Spearman's rank correlation coefficients	Examine incidence and intercorrelation of impaired self-awareness and depression after TBI, as well as their contributions to prediction of patients subjective well-being at discharge.	Impaired self-awareness and depression nor correlated. Impaired self-awareness is an important factor in determining subjective well-being in patients with TBI at acute discharge.	No	Possibly not a fully representative sample of person with TBI who receive inpatient rehab. Self-ratings of depression as opposed to clinical diagnoses.
10	Fleming et al, 2006, Aus	TBI n=34 Age: M= 26.4	Length of acute rehab M=25.4 (0- 67) and rehab M=37.8 R= 5-105	SADI CES-D HADS CIQ	Longitudinal Wilcoxon Signed Ranks and Spearman's correlation.	To investigate relationship between self-awareness, emotional distress and community integration in adults with TBI.	Significant decrease in SADI scores (p<.001) was found between pre and post discharge assessments indicating gains in self-awareness. Approaching significance: higher levels of depression following discharge.	Evidence for emerging association.	Small sample size. Only one measure of self- awareness used. Short follow up period.

11	Owensworth & Fleming, 2005, Aus	ABI n= 67 Age: M=39	Ave= 4.05yrs since injury.	SADI SRSI HADS BHS ILS The Five Point Test The Key Search Test TTT SPRS	Cross sectional. Spearman correlations. Regression analysis.	Examine the interrelationships between metacognitive skills and measures of emotional status and executive functioning following ABI, and examine their importance to psychosocial outcomes.	Higher levels of metacognitive skills were associated with greater emotional adjustment & better performance on measures of executive functioning. No evidence of higher self-awareness being associated with poorer emotional adjustment.	No	Limited sample size & sample characteristics. Control data & design. Mixture of TBI and ABI, difficult to generalise findings.
12	Owensworth et al, 2006, Aus	ABI n=43 Age M=38.4	Time since injury yrs M=4.3 (R=0.5-12)	- SADI - SRSI - HADS Employment classification.	Longitudinal McNemars test, Wilcoxon, Kruskal- Wallis, Spearman's correlation or Mann Whitney	To investigate self-awareness and emotional well-being according to change in employment outcome in people with an ABI. Assessment at 2 time points, at rehab centre and 12 months following.	Improvement in employment at 12mths. Level of self-awareness improved at 12 mths, however not correlated with time since injury. Improved self-awareness was not associated with increased emotionality. Majority of sample attending rehabilitation services.	No	Direction of associations cannot be determined. Measures vulnerable to bias.
13	Owensworth et al, 2007, Aus.	TBI and ABI n=86 Age=M 38.4 R=18- 67.	M=3.9 years	- SADI - SEC - Marlowe- Crowne Social Desirability Scale - HADS - Sydney Psychosocial Reintegration.	Longitudinal Cluster analysis.	Aimed to identify typologies of individual according to neuropsychological and psychological factors related to awareness deficits and compare emotional adjustment and outcomes at initial assessment and 12 mth follow up.	Four awareness subgroups identified: 1.poor self-awareness, 2.high defensiveness, 3.high symptom reporting, 4.good self-awareness. Individuals with poor self-awareness can be distinguished according to neuropsychological and psychological factors. Emotional adjustment stable and did not differ according to awareness typology. Ind's with good self-awareness and high defensiveness had the most favourable emotional adjustment and psychosocial outcomes.	No	Heterogeneous nature of sample, difficult to generalise.

14	Carroll & Coetzer, 2011, UK	TBI n= 29 Age: 22-64	Years M= 11.17 (11.4) R= 2.25-40	HISDS-III) RSE BIGI HADS AQ	Cross sectional. Correlation Pearson	Investigate perceived identity change in adults with TBI.	Correlation between depression and awareness r=-.380) Poor self-awareness associated with higher levels of self-esteem.	Yes	Issues of causality have not been addressed. Small sample size Exclusion criteria resulting in relatively well sample
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Figure 1a: This figure outlines the process by which studies were selected for inclusion within the literature review.

Figure 1:



Paper 2: Empirical Study

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**What helps, what hinders? Emotional adjustment following an acquired brain injury:
an interpretative phenomenological analysis.**

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Abstract

This study explored the lived experience of emotional adjustment following an acquired brain injury (ABI). Attendees of a community outpatient neuro-rehabilitation service who had attended an eight week Emotional Management, Cognitive Behavioural Therapy (CBT) informed group were eligible for participation. Semi-structured interviews were conducted with four male and two female patients aged between 58-69 years. Data was collected and analysed according to the principals of interpretative phenomenological analysis (IPA). Three overarching super-ordinate themes were identified; biographical disruption, adjustment and post-traumatic growth. Biographical disruption describes the instant and devastating onset of an ABI which imposes significant change and loss. The contribution of pre-injury personality, self-awareness and societal perceptions of ABI are discussed in regards to their influence on self-appraisals. Adjustment outlines a process of adaptation to the ABI. Meeting others who had also sustained an ABI appeared to assist individuals to accept the changes imposed by their ABI and become reacquainted with their new selves. Post-traumatic growth explores how over time participants acquired new insights and meaning to life. Individuals discussed enjoying richer relationships and worrying less. This process appears to have been facilitated by engagement in purposeful activity. Clinical implications and future research perspectives are discussed.

Keywords: ‘Emotional adjustment’; ‘acquired brain injury’; ‘cognitive behavioural therapy’, ‘interpretative phenomenological analysis’.

Introduction

An acquired brain injury (ABI) is an unexpected, life changing event that can have profound effects on the individual and their family. Insult to the brain can occur as a result of ischemic abnormalities, haemorrhages, infections and traumatic injuries. Consequences of an ABI can be many and varied depending on the type, location and severity of the trauma with difficulties spanning physical, cognitive, social, vocational and emotional functioning (Carroll & Coetzer 2011). The speed and extent of recovery can vary, with some individuals regaining many lost skills whilst others must contend with lifelong disabilities, such as physical weaknesses, dysphasia or slowed processing speeds to name but a few. Recovery often entails a long and complex process of adaptation to changed circumstances (Roundhill et al 2007).

It is not uncommon for survivors of an ABI to experience difficulty adjusting emotionally to what has happened as they come to terms with an array of losses such as physical health, employment, finances and relationships, alongside a perceived loss of the self (Myles 2004). The way an individual appraises their injury can often determine the extent of emotional adjustment difficulties they experience. If an injury is perceived as threatening and coping resources are considered compromised, depression and anxiety can arise (Folkman & Lazarus, 1988; Snell et al 2011). Failure to address emotional distress following an ABI may result in increased social isolation, loneliness, poor lifestyle and reduced compliance with rehabilitation and treatment (Ostir et al 2002).

Psychological interventions have the potential to resolve emotional difficulties following an ABI as they promote independence and self-efficacy; an individual's belief in their ability to achieve desired goals (Hsieh et al 2012). As complicated emotional reactions

following an ABI are sometimes maintained and exacerbated by psychosocial factors that emerge during community reintegration, the potential for psychological approaches is indicated further. Cognitive Behavioural Therapy (CBT) (Beck et al, 1979) is an evidence-based therapy which operates on the premise that psychological distress can be effectively managed using adaptive thinking and behavioural strategies. If the appraisals and beliefs an individual develops are inaccurate or unrealistic, cognitive restructuring, behavioural experiments and graded exposure may prove useful in helping the brain injured survivor adopt more realistic assumptions about themselves, their situation and their abilities (Riley et al 2010). Research also suggests that an encounter with trauma, which incorporates great suffering and loss can for some people lead to highly positive changes which can include new perspectives and personal growth (Calhoun & Tedeschi, 2014).

A number of studies have provided evidence for the efficacy of CBT to address emotional distress and enhance emotional wellbeing in ABI populations (Khan-Bourne et al, 2003; Anson & Ponsford, 2006; Bradbury et al, 2008). There is a shortage however, of studies investigating the lived experience of life following an ABI, including subjective appraisals of emotional adjustment and experiences of planned interventions (Levack et al, 2010). Qualitative methodologies allow for greater understanding of the lived experience of ABI, by allowing the researcher to enter the world of their participants and gain an insight into their thoughts and feelings (Murray & Harrison, 2004). Qualitative research is designed to generate rich data that is intended to communicate the perspective of research participants (Gracey et al, 2008), which can allow for the development of effective care interventions (Jumisko et al, 2005).

Study Aims

The aim of this study is to explore the emotional experience of recovering from an ABI, in addition to the experience of attending a CBT informed group intervention aimed at addressing emotional distress. Factors which appear to assist or hinder the recovery process will be identified and discussed in regards to informing rehabilitation practice.

Method

Design

This cross-sectional qualitative design was informed by the principles of Interpretative Phenomenological Analysis (IPA). IPA aims to explore in detail how participants make sense of their personal lived experience. It is phenomenological in the sense that it is concerned with individual's perceptions of object or events, yet it also recognises the role of the analyst in making sense of that experience. IPA involves a double hermeneutic; the participant is trying to make sense of their personal and social world, while the researcher is trying to make sense of the participant trying to make sense of their personal and social world (Smith, 2008). IPA is particularly useful for exploring topics that are dynamic, contextual and subjective and where there are issues relating to identity, the self and sense-making. As the emphasis is on the detailed analysis of each case, sample sizes are usually small (Smith & Osborn, 2007).

Recruitment

All participants were attendees at a specialist NHS community based multidisciplinary ABI rehabilitation service. Those who had been referred to and participated in a CBT informed

Emotional Management therapeutic group were eligible for inclusion in the study. Referrals to the group were made by clinicians if they considered its contents to be of use to their client. An information sheet to notify clinicians of the group can be found at Appendix 2a. Information regarding inclusion and exclusion criteria for the group and therefore the study is contained within this document.

Emotional Management Group

The group was developed by psychologists at the service in response to a recognised need for individuals presenting with emotional adjustment difficulties. Over the course of eight weeks, participants were introduced to the core elements of CBT. In order to make the content more appealing, individuals were encouraged to present their own real life scenarios as opposed to utilising vignettes. With the assistance of group facilitators, participants were encouraged to assist one another to identify negative automatic thoughts and offer a more balanced, alternative perspective. Following completion of the course, participants are routinely invited to attend quarterly follow up sessions.

Participants

Individuals were notified of the study via an information pack delivered to them by the group's facilitators. Six out of eighteen adult group attendees indicated their interest in participating by returning an opt-in form, allowing the investigator to contact them directly to arrange a convenient time and place to meet to conduct the interview, prior to which a consent form was completed.

Four males and two females aged between 58-69 years participated. All had been in full time employment at the time of their injury, following which all were either retired or in part time voluntary positions. Four individuals lived with a partner, whilst two lived alone (see Table 2a for further participant demographics). All were assigned a pseudonym to ensure anonymity.

Data Collection

A single semi-structured interview was conducted with each participant by the lead investigator. An interview schedule was used to guide and prompt the interview (see Appendix 2b), however participants were invited to talk at length about their thoughts, feeling, attitudes and beliefs in regards to their experience of brain injury. Interviews were audio-recorded and transcribed verbatim. Notable features of speech, such as pauses, laughs, false starts etc were recorded along with observations of body language and non-verbal communication. The duration of interviews ranged from 63 to 95 minutes.

Data Analysis

Following guidelines provided in Smith et al, (2009), transcripts were read and re-read several times to establish familiarity with the data and allow for a holistic understanding to be established. Initial responses to the text were made in one margin, which were later translated into emergent themes via a process of abstraction. Connection between themes were identified and organised into super-ordinate and sub-ordinate theme allocation. A detailed description of this process is provided in Appendix 2c, and a sample of analysis is presented in Appendix 2d.

Ethical Considerations

Ethical approval was granted by North Wales NHS Research Ethics Committee (Ref: 14/WA/1033) and the study was subject to site-specific NHS R&D approval after full review.

Results

The following results are based on the six interviews conducted. Five participants expressed quite similar opinions; however one participant, Peter, held quite different views. During his interview, he appeared to struggle to remain focused on topic, resulting in a limited amount of information being captured. For this reason, the analysis contains a limited contribution from Peter.

From the views captured, three overarching super-ordinate themes were identified; Biographical Disruption, Adjustment and Post-Traumatic Growth. ‘Biographical Disruption’ describes the immediate and devastating impact of the injury. ‘Adjustment’ represents a challenging process of acceptance and hope, while ‘Post-Traumatic Growth’ allows an insight into how positivity can emerge from adversity. Themes are outlined – along with descriptive summaries – in Table 2b.

Biographical Disruption

Shock: *‘I felt like I’d been hit by lightning’*

All but one participant describe how their injuries were a sudden, unexpected occurrence that stopped them in their tracks. George portrays a sense of imposed transition and disablement; ‘one minute you’re up and down ladders then the next minute you’re in a hospital bed’. Mark recalled the moment he was diagnosed with a brain tumour and was advised of his imminent surgery; ‘so that all came as a bit of a...well it was a hell of a shock!’. Similarly, when Rose learnt that she’d had a stroke, she struggled to believe what she was being told by the hospital staff; ‘I kept asking all the doctors “what have I had, what is the matter?” And the nurses said “you’ve had a stroke”, but I asked everybody, I still wasn’t convinced really’. George later recalls how he felt a few days following his stroke;

‘it was a considerable problem when I first came around and I slowly started to realise that something drastic has gone on here, so I was very concerned....what’s life going to be like now?’

Describing his stroke as ‘drastic’ implies the recognition that this wasn’t a trivial illness, but one that would impose change on all aspects of his future. Regardless of the fact that she was surrounded by her family and friends, Emma stated; ‘I found it quite distressing, it’s very isolating’. This suggests that despite the support she was receiving, she somehow felt alone and disconnected from others in her attempt to make sense of her injury.

Loss: *‘There’s this constant stripping away’*

Many of the participants describe a catalogue of losses following their injuries. The loss of practical skills and abilities represented lost work roles, a means by which many participants identified themselves. George states:

‘I suppose what I was thinking was that, “here I am, I’ve got a whole load of skills I can do, all sorts of things I’ve been trained to a very high standard [...], but that’s all gone out of the window, what am I going to do? I’ve still got a family I’ve still got a mortgage and I still want to do things in the world”...I don’t know. Sort of lots of questions with no answers, no solutions, and that I wasn’t used to. I was used to being able to look at a problem see what the solutions were and work on the solutions, but when you can’t logically get your brain in order, all the little dots just wouldn’t line up’.

George describes finding himself in a situation in which he struggles to understand and take control of; skills and solutions that once worked are no longer appropriate or available to him anymore. In addition, he is distinctly aware of his roles and responsibilities within the family. Similarly, Mark identifies expectations of himself that he feels incapable of fulfilling:

‘I couldn’t do things that I should do as a man. [...] I feel that I should still be working and earning some money, I should be able to protect my wife and the house’.

The use of the word ‘should’ implies a sense of failure to fulfil his identified roles as a man, breadwinner and protector. This is further referenced to by George, who as a father stated; ‘I felt a great deal of, a great sense of failure and desertion towards the kids, [...] as an active father it made me feel very diminished’. Leonard too expresses how before his injury, he and his sons considered him to be ‘super dad’, suggesting that his opinion of himself pre-injury is substantially more positive than his current self.

Both Emma and Rose identified strongly with their work roles. For example, in her account, Rose described feeling distraught when having to give up her job:

‘I got up every day and I never thought “oh I don’t want to go to work”. I loved it, you know I really did and when I realised I wouldn’t be able [to go back]....oh it broke my heart’.

Work is evidently not simply a means to an end for Rose, as demonstrated by the emotion expressed when she learns that she will no longer be able to fulfil her role.

Personality: *‘Just one of them types’*

As the participants discussed their experiences, a sense of uniformity emerged in regards to their personalities. Mark identified himself as ‘a workaholic’, whilst Leonard indicated how; ‘I used to go to work even if I felt a bit rough’. George demonstrated his persistence to get things done in the following quote:

‘I never used to quit, if I had a problem to solve I would stay at it, even if that meant staying on the job for 12, 24 hrs, I would always try to see it [through]....or I would try to see something through to a point where I knew I could pick it up later, if not to completion then to half completed’.

This tendency was mirrored by Leonard, as he described how; ‘I’ll be like a dog with a bone, I won’t let bloody go!’. Whilst describing herself at work, Rose commented how a colleague noted her perfectionistic qualities;

‘you were always like fussing with my work, you know it had to be just right!’

She further described how she perceives her responsibilities at home; ‘I feel like I’m the anchor in my family, always have been you know, and if I’m ill, ohhh everything sort of falls to pieces’.

These self-evaluations are indicative of a personality style characterised by high self-expectation, over-achievement and perfectionism; tendencies that appear to contribute to a person’s sense of vulnerability to criticism from both themselves and others when their physical and cognitive abilities are compromised. Indeed, when Emma reflected on the difficulty she continues to experience as a consequence of having to give up her position at work, she simply commented; ‘that’s ego’.

Misconceptions: *‘I don’t think people understand’*

Participants described how other people, namely family members, friends, members of the public and even health care professionals had responded to them in a way that was either dismissive or lacked an appreciation of the physical and cognitive difficulties they experienced as a consequence of their injuries. Leonard explained;

‘I don’t think people understand what happens to you [...] they don’t see it. It’s not like having a broken leg or something like that, [...] I think they should be more patient. [...] I mean, you don’t want to carry a placard around with you do you but, um I think um people get impatient’.

In the absence of any overt indicator of injury or disability, such as a limb in plaster or a wheelchair, judgements by others appear to be made based on what is culturally expected or deemed appropriate for someone who looks ‘normal’. Leonard went on to explain the reaction he experienced when he approached his local accident and emergency service when feeling particularly low in mood;

‘one particular time I went into hospital and there was a nurse there and I said to her ‘I need help, I can’t’...I just couldn’t function somehow, it’s horrible [...] and this nurse said, ‘you do know this is accident and emergency?’ And I said ‘this is an emergency right, I’m not well’ [...] ‘Look, I haven’t got a plaster or anything but, it’s an emergency and that’s it!’

The lack of any explicit indicator of injury or suffering resulted in Leonard having to demand recognition for his needs. This is suggestive of how mental health difficulties are potentially perceived as less problematic by the wider community and even within the health service itself.

Emma presents evidence of misconceptions held by even her closest of friends;

‘People try to compare and it’s not the same, my Ann, we’re very close friends and have been for years, but she keeps on saying to me “I’m just the same”, I say “you’re not!”. It’s not the same, there’s something subtly different’.

It appears Ann is attempting to reassure her friend by downplaying her difficulties and expressing common ground with her own. Emma however, appears to express a need to have her injuries and their unique effects recognised. Interestingly however, she goes on to say:

‘I’m very aware of this, um....falling into a new chapter and I fight, I fight to stay out, I’m not going to be relegated to being ill, retired or old [...] I’m still bloody here with an opinion!’

There appears to be a conflict within Emma whereby she expresses a desire for others to appreciate and recognise her difficulties as unique, whilst articulating a steadfast desire to retain her position in society, regardless of her injuries and increasing frailty.

Adjustment

Camaraderie: *‘someone to bounce off’*

Participants discussed their experiences of attending the Emotion Management Group. Mark states;

‘It has been amazing getting together with people with different brain injuries who’ve had similar problems I find’.

Rose too demonstrates a sense of affinity with others, and appears to benefit personally from making direct comparisons;

‘I think it’s good, cos you get to meet other people, [...] it gave you confidence to talk and you saw that there were other people much worse off than you and you felt “oh, you’ve got a lot to be thankful for”, you know, um, that has helped me really’.

In regards to the material discussed in the group, Emma noted;

‘I could clock when people said things... “oh yes yes yes!, I understand that, I understand that!”, [...] it was all the normalising stuff, the stuff that brought out the universality of brain injury, that’s what was useful’.

She appears to express relief in the fact that she is not alone, and that the difficulties she was previously experiencing in relative isolation are keenly described and acknowledged by other group members. Mark describes how the groups content specifically helped him with his emotional difficulties;

‘it did teach me about my emotions, I still get very emotional over daft things. I can watch the telly and start crying and then I don’t feel like a man anymore cos I shouldn’t be crying over something so stupid like that, but that course told me that it’s normal. I may be a bit more reactive than normal, but people do get emotional over certain things so just because my emotions are, I can go from there to there really quickly, rather than going from there to there, urr.. and they’ve taught me that that’s ok, and the circle, how you can break that circle, do something else, you know when you see that it’s causing you emotions, then how can we get past it or work a way to get around it’.

Mark indicates that he is more accepting of his emotionality and attributes it to his injury as opposed to failing to fulfil what he perceives to be the prerequisites of what ‘a man’ ought to be. His explanation of how he applies the skills introduced in the group demonstrates

the usefulness and generalisability of the information delivered. Rose too finds relief by recognising; ‘how you feel impacts on what you do, so then it makes sense, you think, “oh, it’s not me that’s thinking silly things!”’.

George describes how meeting other people allowed him the opportunity to reflect on his own experience;

‘I suppose it made me feel less isolated and buttoned me up to think, “come on there are other people who....they may not have suffered the same degree of stroke, [...] but it’s still been as much as a trauma to them as it has been to me, so come on there’s other people who are managing in the world so you can do the same”’.

George appears to gain comfort from relating to others who have endured similar experiences and is encouraged by their resilience.

Not all participants reported such positive experiences from attending the group. When asked what if anything he felt he had gained from attending, Peter replied, ‘nothing specific’. He denied finding any common ground with the other participants and reported;

‘It’s Emotional Adjustment group....I do not find my emotions adjusted’.

Despite this, Peter attended every session perhaps reflecting that on some level the experience was a positive one for him.

Adapting: *‘I’ve accepted a lot’*

Aside from the group, many of the participants described a process of coming to terms with their situation. George remarked;

‘I think when I finally accepted that this was life as it is now, and there’s no use going back into the past, about how I would like it to be, things are going to be different, there’s going to be vast changes and the changes are going to happen anyway, and I knew I was going to be scared about some of the changes, frightened, but then I said to myself, “let’s do this slowly, go along with it, and if things get better then brilliant, but if they don’t then you’re no worse off”.

This powerful statement implies how George has elected to relinquish his hold on his past and commit to an alternative future. His use of the word ‘finally’ implies that he remained steadfast and resistant for some time. His understandable sense of apprehension for what challenges may lay ahead is clear, yet he demonstrates having adopted a more compassionate tone towards himself. Mark too indicates how he has become more accepting of his difficulties; ‘I think I’m beginning to live with the fact that I can’t remember, you know [...] it’s taken six-seven years to do it’. Rose echos his sentiments as follows; ‘time is a good healer’, whilst Leonard simply states ‘I’m better, I’ll never be 100%...never’.

Renewed acquaintance: ‘In my end is my beginning’ (T.S Eliot)

Emma expressed via this famous quote by T.S Eliot how she felt she had arrived at a new beginning, a place that was in some sense familiar, yet ‘everything has changed and so have I’. She continued:

‘I started to get more familiar with myself, I remember first looking in the mirror [...] and not recognising this face, I knew it was me but I was fascinated “wow!, is that what I look like?”, and talking to myself, “you’re not the same”, I know I’m not the same and looking and looking and I carried on doing that and it’s only a few months ago that I suddenly realised that I had become familiar with myself. I’m still not the person I was, but something’s become more familiar. [...] I’m beginning to become....maybe make friends with it’.

Despite no physical changes to her appearance, Emma initially struggles to recognise one of the most salient features of her identity, her own reflection. It’s as though her injury had erased a part of her that she defined herself by. Her inability to recognise herself may represent an unconscious defence against accepting her losses. In time however, a familiarity begins to emerge which may reflect a gradual process of making peace with her new identity. Describing herself as ‘making friends with it’ denotes a willingness to accept, yet implies a degree of separation remains. Leonard also expresses how he has moved on to accept this new person while recalling a conversation;

‘I remember one person saying to me “you’ve got to let that person go now, they don’t exist, you’re not the same person anymore”. And I thought, “well I can remember that person you know, I can still remember him now” [...]...you’ve got to let it go, got to start again more or less kind of thing’.

Accepting that his past self no longer exists whilst he remains living and breathing is a perplexing mind-set. It’s as though a survivor of an ABI must carry around memories of the person they once were, in a similar way a bereaved person retains recollections of a past

loved one. Leonard suggests that he was only able to move on with his life once he had put his memories aside.

Post-Traumatic Growth

Optimism: *'There is a future'*

The majority of participants were able to identify ways in which their life post injury was to some extent richer. This renewed sense of meaning was often accompanied by engagement in a new activity. George describes how enrolling on a computer skills course opened up a whole array of options to him;

'I was going to go to the college and I wanted to do a couple of different courses [...] I thought "this is wonderful, I can perhaps do things I never thought I would do, go take a completely different road to where I thought I was going!"...[college] showed me that there was a future, I mean it was going to be chaotic and somewhat unpredictable, but there was a future of a kind, I just had to go and find it'.

George demonstrates how despite initially perceiving his stroke as a catastrophic event, he is now able to acknowledge and welcome alternative opportunities. Again, a sense of ambiguity is portrayed in regards to what the future may hold, however George appears better able to relinquish his stronghold and has become more accepting of what will be.

Leonard conveys his answer to a friend who asked; "is it [stroke] a blessing or a curse?";

‘Well I’m doing things I’ve always wanted to do now, which I couldn’t do before because I was in work all the time and doing this and that, and now I can do things, and I say, “I don’t know, I can’t answer that really”’.

The fact that Leonard struggles with the predicament put before him implies that he welcomes the opportunity to engage in an activity that is of his own choosing. There appears to remain an air of trepidation however, as he considers never having had the stroke, another welcome prospect for consideration. Life may have not turned out the way Leonard expected, however he demonstrates a determination to make the best of his situation.

Both Rose and Mark were introduced to woodwork following their injuries. Whilst acknowledging a piece she had handcrafted Rose voiced; ‘I feel ever so proud’. Mark too describes having gained so much from the experience;

‘I’ve got the woodwork to fall back on because I’ve hit on something I enjoy doing that I could do, it’s settled me down, a lot. I’m not useless. Cos that was a big thing [after the diagnosis], I was useless. I couldn’t drive, I couldn’t remember things, I was absolutely useless, I beat myself up because I was useless. Um, so that gave me something, I’m not useless, I have got a purpose’.

Mark implies that his tumour had, in his opinion, stripped him of his meaning and purpose in life. Being offered this opportunity to learn a new skill had had a profound impact on him as it allowed him to appreciate a renewed sense of worth.

Peter described a very different reality. He remarked;

‘Well I don’t have any friends which is one problem to start off with, but the main problem is that I’m not acquiring any friends either and old friends seem to have drifted away and my children have drifted away’.

Peter implies that for him, his experiences post injury have been quite different. He identifies his lack of friends as a problem, yet appears completely at odds with how to resolve it.

Contentment: *‘You can’t take things for granted’*

The majority of participants volunteered their personal outlook on life which appears to have been inspired by their experience of brain injury. Emma explained;

‘the stuff I used to spend a lot of time worrying about or stuff from childhood has gone, I can’t imagine what all that was about, um and also I don’t do much worrying about the future’

Emma presents a contentedness, a willingness to let go of her worries and concerns and live instead for the moment. Similarly, Rose offers her perspective; ‘there isn’t [any] point worrying about things you cannot change, if it’s happened it’s happened, try not to worry about silly things, just take a day at a time’. George too indicates his objective to ‘just enjoy every moment, while I can’.

In the extreme, Emma claims how she feels ‘privileged’ to have had her injuries which have been ‘a fascinating experience’, and allowed for ‘extraordinary learning’. She recognises how it has ‘changed my mind and how I perceived things’, whilst allowing for ‘much closer connections with people’. The ability to speak so positively about her experience is indicative of having come such a long way from her initial appraisals.

Discussion

This study offers an insight into the emotional experiences of people who have suffered an ABI and taken part in a CBT informed therapy group aimed at assisting them to manage their emotional difficulties. The majority of participants interviewed appeared to describe an emotional journey, from initial despair, through to hope and finally arriving at a sense of contentment with their situation. This was not observed for all participants however. Possible explanations will be discussed for these findings.

Biographical Disruption

An ABI can be considered a disruptive event, throwing a person’s life off course in an instant. For those who have an awareness of their injury and its implications, surprise, perplexity and anxiety may accompany these initial discoveries (O’Callaghan et al, 2006). Indeed, the majority of participants in this study portrayed the shock, anguish and despair they experienced during the initial stages of their injuries. Those with impairments in self-awareness however, may fail to recognise their deficits, a presentation more commonly observed following a traumatic type brain injury (TBI) that involves damage to the frontal

parts of the brain (Ownsworth et al, 2005; Ham et al, 2013). Indeed, the participant in this study who had sustained a TBI differed in that they did not experience a similar emotional reaction to their injury as the others.

Several participants went onto describe the losses their injuries had imposed. Emotional distress was evident when participants observed themselves as being unable to fulfil a role they felt defined them, such as a parent or spouse. Many also identified strongly with their work roles, evidencing how they had become an integral component of their self-concept, as opposed to simply a means of making a living. Internal psychic conflicts involving sense of self, self-esteem, an inability to fulfil expectations and negative perceptions of self may result in distress. Suffering may result from the violation or impending threat to the integrity of the person, not solely the body and its functions (Langer 1994; Watermeyer 2012).

Whilst discussing their experiences, it was noted how participants demonstrated similar personality traits; these included perfectionism, conscientiousness and high-expectations of self. Tendencies such as these may allow one to succeed and be viewed favourably within society when all personal capabilities are intact. Following an injury however, an individual may become vulnerable to developing emotional distress if they consider themselves to have failed to achieve these high standards, and feel at a loss to reclaim lost skills and abilities with which to do so. Indeed, studies conducted some time ago noted how certain personality types may make an individual more at risk to developing emotional disorders following an ABI (Kay, 1992; Ruff et al, 1996). There appears to have been little research on this topic done since.

Participants who had little or no physical indicators of their injuries expressed frustration at what they perceived to be a lack of understanding from others. They described how the invisibility of their injuries led others to minimise or dismiss their deficits completely. A study by Stone (2005) which investigated the experiences of stroke survivors detailed similar findings. The author commented on how societies tend to apply simplistic understandings of how to read the bodily presentations of others.

Furthermore, a study by Swift & Wilson (2001) demonstrated how the lay public and non-expert health professionals do not fully appreciate the long term nature of an ABI, resulting in unrealistic expectations being made of a brain injured person's abilities. A possible explanation may be provided by Leventhal's Common Sense Model of Illness (Leventhal et al, 2003). The model explains how an individual makes judgements about their own or another person's illness based on the illness representations or 'lay' beliefs they hold about that illness. The model supposes five components of illness representation, namely (i) identity: the label given to the condition; (ii) cause: an individuals perceived cause of the illness; (iii) time-line: the predictive belief about how long the condition will last; (iv) consequences: beliefs about the consequences of the condition and (v) curability/controllability: beliefs regarding whether the condition can be cured or controlled. If a lay person was to consider a broken leg for example, they may be relatively accurate in their conclusions. However, when applied to a person who has suffered an ABI with very little visible indicators of deficit, the resulting conclusions may prove to be highly inaccurate and result in potentially damaging misconceptions (McClure, 2011).

Adjustment

The majority of participants spoke favourably when discussing their experiences of meeting other people who had also sustained an ABI, and of their participation in the CBT informed Emotion Management therapeutic group. Individuals appeared to benefit from listening to one another through which they identified common ground and mutual understanding. Social comparison plays a role in adaptation to many chronic illnesses whereby, in the absence of an objective standard, comparisons are made with others who present with a similar affliction (Taylor et al, 1990; Festinger, 1954). Individuals are commonly observed to make either a positive (interpreting the self as same or better off than others) or negative interpretation (interpreting the self as different or worse off than others) of themselves based on others (Van der Zee et al 2000). Participants demonstrated positive interpretations as they noted common deficits, gained confidence and felt bolstered by the resilience of others.

Participants indicated how they utilised skills and techniques that they had learnt in the group by giving examples of how they applied them during social interactions and when making cognitive appraisals of themselves and others. It is possible that the group facilitated a shift from emotion-focused coping (denial and emotional avoidance) to a more adaptive style of coping; problem-focused coping (seeking support, planning and developing strategies to cope). Research has reported that greater use of problem-focused coping has been related to better psychosocial functioning (Malia et al, 1995; Wolters 2010). This finding provides further support for the effectiveness of CBT to enhance emotional wellbeing in ABI populations (Khan-Bourne et al, 2003; Anson & Ponsford, 2006; Bradbury et al, 2008). In addition, it has been suggested that a group setting may provide additional benefits as hearing the opinions of fellow patients may have the potential to be far more influencing than the opinion of a clinician (Hibbard 2002).

When discussing their experiences of adjustment, participants referred to having finally accepted the passing of a previous life or a past identity and making amends with a new. This process has been outlined quite eloquently in the ‘Y’ shaped model by Gracey et al (2009). The model links bodies of research relating to coping style, subjective self and social discrepancies, self-regulation, and awareness. It stipulates how the process of adaptation and reintegration into society initially involves the coming to awareness, understanding, and adaptive resolution of social and psychological discrepancies. These are represented by the separate strands of the ‘Y’ that eventually adjoin.

Adjustment was discussed as a continuously evolving process as discoveries were made about personal limitations via interactions with the world. There was evidence of participants learning to live with illness as opposed to solely living for it. This finding mirrors those discussed in studies and papers regarding the experience of appraisal, coping and adaptive psychosocial adjustment to illness (Charmaz, 1995; Shotton et al, 2007).

Post Traumatic Growth

The majority of participants discussed positive aspects of their injuries such as experiencing richer relationships with others, identifying new opportunities and worrying less. Post Traumatic Growth reflects a greater appreciation for life which can be characterised by a change in priorities and through gaining pleasure in aspects of life that were previously taken for granted. Indeed, studies have shown that survivors of an ABI can indeed achieve positive growth following their injuries (Hawley et al, 2008). To do so, a degree of unpleasant engagement with the reality of the long-term situation is necessary, and it has

been suggested that it may take many months or even years for it to develop (McGrath & Linley, 2006).

Many participants found consolation and a renewed sense of purpose through engagement in activity. This may illustrate an additional impact of their personality types, whereby they continue to strive for excellence and achievement. Indeed, the activities discussed provided a renewed sense of purpose and took up time their work roles would have done prior to their injuries. This demonstrates the importance of keeping active and engaged in activity during recovery.

Not all participants demonstrated Post-Traumatic Growth, however. This presentation may be explained by persisting impairments in self-awareness. Studies have shown how impairments in self-awareness can, during the initial years following an ABI, provide a barrier to developing emotional distress as the individual is shielded from the realities of their injury. In the longer term however, following repeated social and practical failures, the person may begin to develop emotional distress and frustration as a result (Ownsworth and Oei, 1998).

Clinical Implications

This study provides evidence for the importance of addressing emotional reactions to an ABI as opposed to focusing solely on assisting individuals to regain physical abilities. Those who present with a degree of insight into their injury and disabilities may be most at risk for developing emotional distress. This study has highlighted how it is critical for

treating clinicians to address emotional distress during the early stages of a person's recovery so that the likelihood chronic emotional disorders becoming entrenched is minimised.

This study has exposed the lack of knowledge and understanding of an ABI throughout the lay population, and even amongst health care professionals. With this in mind, clinicians must ensure that every effort is made to assist ABI patients and their families to make sense of their injuries and where possible, address any unrealistic assumptions or expectations. Pre-morbid personality styles characterised by over-achievement, high self-expectation and perfectionism may exacerbate the negativity of self-appraisals and must therefore be at the forefront of clinicians minds when conducting assessments.

This study has highlighted the benefits gained through facilitating opportunities for people with an ABI to meet one another and compare experiences. It has also emphasised the importance of assisting individuals to engage in activities which will enable them to rediscover a sense of meaning and purpose. Ideally, interventions aimed at addressing emotional distress following an ABI may achieve better outcomes if they are preventive rather than curative in nature.

Study Limitations and Future Research

All participants were relatively homogeneous in regards to age and pre-injury employment status, making it difficult to generalise findings. Further research with a broader population would be useful to identify similarities and disparities amongst opinions and experiences. The data contained in this study is captured from individuals who, following an

invitation, decided to participate in the study. Reasons for why other people declined participation are unknown, and as such, their opinions may be different to those reported.

The aim of this study was to identify contributing factors to a person's emotional experience of having had an ABI and their experiences of recovery. It was not intended as a means to evaluate or critique the group intervention that participants attended. It is not possible to say with confidence therefore, that the group was responsible for any observed changes in participant's mood or outlook on life. Further investigation of CBT informed group therapy and its effectiveness for relieving emotional distress in individuals who have suffered an ABI would therefore be warranted, so as to better inform practicing clinicians.

Conclusion

An ABI is an unwelcome occurrence; however this study has shown how individuals are capable to overcoming great adversity to achieve a renewed sense of hope and meaning in their lives. The journey through recovery is an intimately personal one, but one that can be supported and facilitated by rehabilitation professionals. The key is recognising when to intervene; observing increases in self-awareness maybe one such occasion.

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Table 2a: Participant Demographics

Pseudonym	Leonard	Rose	George	Emma	Peter	Mark
Gender	Male	Female	Male	Female	Male	Male
Age	62	58	67	69	67	59
Pre-injury Employment Classification²	4	4	3	2	5	7
Injury	Stroke	Stroke	Stroke	1 st : Subarachnoid haemorrhage 2 nd : Subdural Haemorrhage.	TBI	Brain tumour.
Time Since Injury	2 yrs 5 mths	3 yrs 8 mths	14 yrs 8 mths	4 yrs 6 mths	10 yrs 9mths	7 yrs.
Marital status	Married	Married	Married	Widowed	Separated	Married

² **Office for National Statistics: Major Groups of the Standard Occupational Classification 2010 (SOC2010). Group 1:** Managers, Directors and Senior Officials; **Group 2: Professional Occupations; Group 3:** Associate Professional and Technical Occupations; **Group 4:** Administrative and Secretarial Occupations; **Group 5:** Skilled Trades Occupations; **Group 6:** Caring, Leisure and Other Service Occupations; **Group 7:** Sales and Customer Service Occupations; **Group 8:** Process, Plant and Machine Operatives; **Group 9:** Elementary Occupations

Table 2b: Super-ordinate and sub-ordinate themes: labels and descriptive summaries.

Super-ordinate theme	Sub-ordinate theme	Descriptive summary
Biographical Disruption	Shock: <i>'I felt like I'd been hit by lightning'</i>	Captures the participant's sense of being struck down by their injuries which came out of the blue and imposed immediate and irreversible changes on their lives. Sense of disbelief and isolation.
	Loss: <i>'There's this constant stripping away'</i>	Describes the multiple losses the participants experienced following their injuries, from practical skills to roles within society. Participants appeared to identify strongly with these losses which appear to have defined their self-concept.
	Personality: <i>'Just one of them types'</i>	Whilst talking about their experiences, participants appeared to convey personality traits which include perfectionism, high self-expectation and high achiever which appear to have influenced self-appraisals and imposed internal conflict in light of their resulting disabilities.
	Misconceptions: <i>'I don't think people understand'</i>	Outlines reactions from friends, family, NHS and members of the wider society. Participants reflected on how they felt judged in a world where understanding of ABI is relatively poor.
Adjustment	Camaraderie: <i>'Someone to bounce off'</i>	Participants conveyed the benefits gained from meeting other people who also had an ABI. Individuals expressed a connectedness with others and an opportunity to have experienced validated and normalised.
	Adapting: <i>'I've accepted a lot'</i>	Explored the process of adjusting to an ABI; a process that demands adaptation and acceptance of ones circumstances. This was accompanied by an air of trepidation about what the future might look like.
	Renewed acquaintance: <i>'In my end is my beginning' (T.S Eliot)</i>	Describes how participants appeared to make friends with themselves again, reflecting a process of letting go of their previous selves and gaining a sense of familiarity with who they had become following their ABI.
Post-Traumatic Growth	Optimism: <i>'There is a future'</i>	Captures how participants were able to achieve new meaning and direction in their lives post injury. The engagement in purposeful activity appeared central to this process.
	Contentment: <i>You can't take things for granted content</i>	An expression of participants renewed outlook on life which focused on worrying less and living for the moment. Participants even conveyed feeling grateful for their injuries.

Paper 2: Empirical Study- Appendices

Appendix 2a: Emotion Management Information Sheet

Appendix 2b: Interview Schedule

Appendix 2c: Analysis Process

Appendix 2d: Sample of Transcript

Appendix 2a:
Referral to the Emotional Management Group: Information for Clinician

The Emotional Management Group addresses the emotional difficulties some patients experience following their brain injury. These can be a consequence of a number of factors including:

- The injury disrupting emotional circuits within the brain, making it difficult to recognise and process emotional information effectively.
- The individual experiencing difficulties due to the effects of their brain injury e.g. memory difficulties, which may impact on a person’s ability to live independently.
- The person developing negative core beliefs about themselves and their abilities.
- The person is struggling to adjust to life following their brain injury.

This emotional difficulty can often have a negative impact on a person’s overall enjoyment of life, engagement in rehabilitation and relationships with others.

Group Aims

The groups aims to:

- Provide patients with information regarding what emotions are and how a brain injury can impact on them.
- Discuss the adjustments people have been forced to make and the losses they have experienced following their brain injury.
- Introduce aspects of Cognitive Behavioural Therapy (CBT) through group discussions and situational examples.
- Empower the patient to use these skills along with alternative thinking and behavioural strategies to alleviate their emotional difficulty.

This group is most effective for those who are willing to engage in group discussions and are motivated to complete homework exercises.

The group will run over the course of 8 weeks, starting on

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> • The person has undergone an initial service assessment. • They have ideally completed the Understanding Brain Injury Group. • The person experiences emotional difficulties in their day-to-day life. • The person has a degree of insight into their brain injury. • The person is able to contribute to group discussions. • The person has capacity to decide whether or not to participate. 	<p>With regret we cannot include patients with the following:</p> <ul style="list-style-type: none"> • A severe learning difficulty or severely low intellectual ability. • High levels of disinhibited behaviour that is not amenable to feedback. • A current alcohol or drug problem • Current hallucinations or delusional beliefs which are not related to their brain injury.

If you wish to refer your patient, please complete the referral form on the reverse. Many thanks.

Appendix 2b

INTERVIEW SCHEDULE

Title of Study: *What helps, what hinders? Emotional adjustment following an acquired brain injury: an interpretative phenomenological analysis.*

Researchers: Alice Roblin, Dr Karen Addy & Dr Valerie Morrison

Introductory questions:

- Could you please confirm your age?
- How long have you been coming to the North Wales Brain Injury Service?
- Roughly, how long has it been since your injury?
- Can you tell me a bit about your injury?
 - o What happened?
 - o If you know, what part of your brain was injured?
- What did you do before your injury?
 - o What job did you do?
 - o What was your role in the family e.g. parent, grandparent, breadwinner etc

Brain Injury Specific Questions

- How has life changed since your brain injury?
 - o Have you experienced difficulties since your injury?
 - o Have there been positives since your injury?
- Have your relationships with others e.g. partner, family, friends, colleagues etc changed since your injury?
 - o In what way?

Group questions (if not already addressed earlier in the interview)

- What was your experience of the Emotional Management group?
 - o What was good about it?
 - o What did you dislike about it?
 - o What, if anything, would you change about it?

Concluding question

- What future plans do you have?

Thank you for participating. Is there anything you would like to ask me?

Appendix 2c: An outline of the process of data analysis using interpretative phenomenological analysis, adapted from Smith et al, (2009).

Stage in Analysis	Description of Process
1. Reading, re-reading	The initial step of IPA involves immersing oneself in the data. This is achieved by reading and re-reading the transcripts several times to become familiar with the data. Listening to the audio-recording is also recommended to further enhance active engagement with the data. This allows the researcher to gain an overall impression of what the participant was trying to convey and allow the participant to become the focus of analysis.
2. Initial note taking	The most time consuming section of analysis involves highlighting important and significant passages of text while making notes of initial and salient observations of the transcript. This process further enhances familiarity with the text and allows examination of the language and semantic content on an exploratory level. The overall aim is to achieve a comprehensive and detailed set of notes and comments on the data. The analyst is advised to look at the language used (linguistic comments), think about the context of their concerns (descriptive comments) and identify more abstract concepts (conceptual comments) which help to make sense of the pattern of meaning in participants accounts.
3. Developing emerging themes	Transcripts and notes are then reviewed to identify interrelationships, connections and patterns across exploratory comments with observations grouped together according to the context and meaning being conveyed. The aim is to reduce the volume of detail, whilst maintaining complexity. The task is to identify themes that express the psychological essence of the piece that reflect the participants own words, but are constructed around the interpretation of the researcher.
4. Searching for connections	The next stage involves mapping out how the themes fit together. Some themes may be discarded whilst others take greater precedence. The aim is to achieve a structure that draws together emergent themes that allow the most important and interesting aspects of a participants account to be exposed. A process of ‘abstraction’ involves formally grouping similar/related themes into ‘super-ordinate’ categories. A master theme is identified that summarises how each cluster of themes is interlinked; it involves putting like with like and developing a new name for the cluster.
5. Moving to other cases	The above process is then repeated for each transcript, which should be treated on its own terms to ensure justice is done to its own individuality. This requires one to ‘bracket’ off ideas that emerged from the previous analysis, however there is an acknowledgement that previous cases will inevitably influence each subsequent analysis. So long as the systematic approach outlined above is adhered to, bias should be minimised and new themes can emerge freely.
6. Looking for patterns across cases.	The next step involves looking for patterns across cases by asking the following questions; what connections are there across cases and how does one theme in one case help illuminate a different case? Reoccurring and conceptually similar themes are identified along with those that appeared most important or illuminated other cases. The end result is then expressed in the form of a table which summarises all super-ordinate/sub-ordinate themes along with representative quotes, a process of ‘modelling’.

Appendix 2d: Example of data analysis using transcript extract

This table provides an example of how raw data (central column) is analysed, with ideas and comments being noted down as an initial reaction to the data (right hand column), leading to ideas being encapsulated within the emerging themes (left hand column).

Emerging Themes	Interview Transcript	Exploratory Comments
Fear Confusion Experience of health service.	<p>Beginning at line 157:</p> <p>G: I think the only difficulty really, the foundation difficulty was just one of total confusion, I just didn't know where, if there was a future, let alone what the future would be, and I couldn't seem to get any information from anybody regarding that, it was just 'oh we'll just have to wait and see how you get on'. Which I suppose is fine really, you can't expect any more than that for anybody to say, because nobody can foresee what's going to happen</p> <p><i>I: Mmm, but how was that, to not have a definite answer?</i></p>	<p>Demonstrates awareness of injury and current situation. Expression of confusion, fear of unknown, uses emphasis to stress seriousness of situation. Desperation; searching for answers, not able to achieve any. Evidence of emotional needs not being addressed/ignored while in hospital? Ambiguity of situation.</p>
Isolation Identity Loss of previous skills/role Comparison	<p>G: Um...I think initially probably it was very very disturbing and frightening, because I was an engineer and I was used to looking at situations in situ and saying well if that is that, well we can make that into that, and step by step you start building again, um but there just didn't seem to be any foundation that I could start from, because nothing would work...nothing that worked prior was going to work post</p> <p><i>I: Right</i></p>	<p>Repetition of 'very'-stressing his distress at the time. Unable to apply pre-injury repertoire of skills, knowledge and understanding to this alien situation. Unfamiliar world, unsure what to do. Evidence of motivation of wanting to improve situation, but feeling at a loss, no obvious solution to current problem. Making distinction between pre and post injury self.</p>
Perception of recovery Experience of health service.	<p>G: Until it suddenly clicked in my head after I had been talking to the physiotherapist that the first step I need to take is literally the first step, until I can stand up then I can't take the step, so I spent a lot of time trying to stand up, but when I was doing that people were shouting at</p>	<p>Evidence of perceiving and judging extent of recovery by physical means. Personality: sheer determination. Relying on previous skill of identifying a solution and taking steps to accomplish it, however finds himself in an environment</p>

<p>Personality: determination</p>	<p>me because I shouldn't be standing up on my own, and inevitably I'd fall over and then that caused more problems...think of the paper work, think of the paper work!!'</p>	<p>where that isn't appreciated and actively discouraged.</p>
<p>Personality: stubbornness. Misconception? Emerging acceptance.</p>	<p><i>I: So what do you think it was that was driving you?</i></p> <p>G: Stubbornness I think, I think probably I thought, well look this is ridiculous, I can't just stay lying in a bed for the rest of my life. Ok, maybe I can't go back to the life I had before, so you've got to start moving forward in another direction, so that's when I thought to myself, 'well look until I'm standing I'm not going to be able move anywhere'. The first thing I wanted to do was get out of bed, and to just sit it a chair like this would have been wonderful, but unfortunately it was in the far corner of the room that I was in, so when I managed to swing my legs out, that's when I managed to disconnect the contraption that keeps the bed cot, so I managed to work how it worked so I flicked it down and promptly rolled out! 'What are you doing!!' 'Oh go away!'</p>	<p>Personality type coming through, not prepared to rest, relentless determination to get well. Evidence of misattribution of recovery expectations? Awareness that impact of injury is going to have permanent repercussions, evidence of accepting change however and looking for alternative options.</p>
<p>Personality Identity/self-concept Role Misconception</p>	<p><i>I: So there was a little bit of, um going against what the doctors and nurses were telling you?</i></p> <p>G: Well yes the um, the sort of opposition mentality locked in didn't it, obviously they wanted to acclimatise me to being in an institution, and I didn't want to be in an institution. And so it took a couple of weeks to realise that they were going to win, whatever I did! [both laugh].</p>	<p>Fighting spirit. Resistant to rehabilitation efforts, 'them and us' mentality. As though to accept assistance would jeopardise personal identity of being capable? Misinterpreting/misunderstanding purpose of rehabilitation. Why did the environment promote this style of thinking?</p>
<p>Social identity/ camaraderie</p>	<p><i>I: But you kept strong?</i></p> <p>G: Well, it wasn't long before Russell joined me And the first thing we did was organise an escape committee!</p>	<p>Finding common ground with another patient, 'brother in arms'.</p>

<p>Shock Loss Identity Uncertainty Experience of health service.</p>	<p><i>I: Oh gosh! Can I ask, there was something you said that was really interesting, you said you had a realisation that life wasn't going to be like it was before your stroke...</i></p> <p>G: Yes</p> <p><i>I: How was that for you?</i></p> <p>G: Um, terrifying, because I was the wrong side of 60, so I suppose what I was thinking was that here I am I've got a whole load of skills I can do all sorts of things I've been trained to a very high standard as an engineer, but that's all gone out of the window, what am I going to do? I've still got a family I've still got a mortgage and I still want to do things in the world....I don't know. Sort of lots of questions with no answers, no solutions, and that I wasn't used to. I was used to being able to look at a problem see what the solutions were and work on the solutions, but when you can't logically get your brain in order, all the little dots just wouldn't line up, so I suppose I just went ohh, so for a while I think I just switched off really, and that annoyed Sister and there was um, a physician, the stroke physician who was attached to the ward who was forever coming around and poking and prodding me and who gave very little information, I now realise, I think it was 3 or 4 months afterwards that I realised that she couldn't give me information because they didn't have any information to give.</p> <p><i>I: As you say, as an engineer you're used to system that might malfunction, but you can put them back together can't you,</i></p>	<p>Shock. Not how he had planned or envisioned life to be. Plans or aspirations for the future to be set aside. Defining himself by his skills, part of his identity/purpose for existence. Aware of responsibilities, towards himself, towards others, an awareness of how personal capabilities will be impacted on, used to having the answers. Unpleasant uncertainty. Brain is injured so is incapable of processing information in the same way. A sense of helplessness, avoidance, depressive mood. Reaction from staff suggests frustration at his presentation. Patient not person.</p>
<p>Loss Control- lack of Unfamiliarity</p>	<p>G: I lived in an environment where there was always a solution to a problem, you've just got to find it, and once you've found it you've got a target, haven't you. I mean you may miss the target that you're along, that's part of the course but at least you have a direction to go in, every</p>	<p>A new unfamiliar world, leaving behind an idealised past universe of structure and predictability. A perceived lack of control as a result of strategies not working. Falling</p>

<p>Loss of role Failure as a Dad- identity. Self-critical (personality?)</p> <p>Guilt Anger Confusion</p>	<p>direction I was going in was, I was just falling over....literally!</p> <p><i>I: Ok, there was another thing that you hinted at, if it's ok I'd like to go back to that, you mentioned about the relationship with your sister and I suppose other members of your family, would you mind talking a little bit more about those, maybe how they changed?</i></p> <p>G: Um, I felt great deal of, a great sense of failure and desertion towards the kids, because they were in their mid to late teens and they were having to face big changes in their lives, and major decisions and I was incapable of offering them any support or help. So as an active father it made me feel very diminished..</p> <p><i>I: That you weren't able to carry out that role?</i></p> <p>G: Well Sue [wife] has had to take the burden of that, which wasn't fair. And that's, I think that's when I sort of became angry, but the only person I could direct the anger to was myself, but I couldn't see what I had done wrong to be angry about.</p>	<p>over in the literal and metaphorical sense.</p> <p>Perceived injury to impact on ability to perform duty as a parent to assist children during a transitional stage of their lives. Self-blaming, interprets self as having failed in role as a father. Reality/other people's perceptions may have been quite different?</p> <p>Experiencing very strong emotions but at a loss for where to direct them. Sense of guilt for what he interprets as handing over a burden of responsibility to his wife.</p>
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Paper 3: Contributions to Theory and Practice

This final paper incorporates findings from both the literature review and empirical study to consider their collective influence. It is presented in three sections; 1. contributions to theory and recommendations for further research; 2. clinical implications and finally 3. personal reflections on the research process.

1. Theoretical Implications and Further Research

Theoretical Implications

As far as the author is aware, the literature review is the first of its kind to offer an insight into the disparities that currently exist within the literature in regards to the association between self-awareness and emotional distress following an acquired brain injury (ABI). It identifies three variables; time since injury, injury severity and the influence of rehabilitation that may act as mediators and assist in providing a possible explanation for the variance observed across the studies. The findings of the literature review appear to be reflected in the accounts given by participants in the empirical study.

The literature review identified studies that reported how an awareness of one's injury and resulting deficits is often accompanied by emotional distress. Indeed, the empirical paper identified how participants who reported shock, sadness and a sense of isolation following their injuries also appeared to indicate an acute awareness of their situation, as evident through reports of multiple losses, changes in self-concept and a stark realisation of how their life had changed indefinitely. Although participants were reporting their emotional experiences retrospectively, they appear to have come to these realisations relatively early on in their recoveries. Once again this finding is in accordance with studies that have found that the greatest degree of depression is often observed between seven to twelve months post-injury (Lezak, 1987; Lezak & O'Brien, 1988, as cited in Fleming et al, 2006). This is often a time when support is reduced following discharge from hospital or an acute rehabilitation facility, and individuals are faced with the full reality of how their injury will impact on their future. Employment positions may be terminated or suspended, and other roles in society compromised due to mental and physical disabilities.

Not all participants relayed such experiences, however. One participant, who had sustained a serious traumatic brain injury (TBI), did not recall experiencing heightened emotional distress following his injury, nor did he appear to indicate awareness of his deficits, other than his visible orthopaedic injuries. In regards to low mood, the gentleman reported his greatest frustration as a consequence of not having any friends. As the gentleman was more than ten year post-injury, this presentation is in line with the literature which supposes that individuals who present with persisting impairments in self-awareness experience low mood as a result of being unable to account for continued social and practical failures (Prigatano, 2005). It also supports findings that attribute impairments in self-awareness to be more commonly observed following severe TBI's, especially those that involve damage to the frontal lobes of the brain (Ownsworth et al, 2005; Ham et al, 2013)

Despite the relatively relaxed inclusion criteria for the Emotion Management Group and therefore the study, the resulting cohort of participants were relatively homogenous in regards to age and pre-injury educational/employment status. Studies have suggested that older individuals may initially present with greater levels of distress as they are already engaged in work and have established family responsibilities, making the magnitude of their loss greater. Younger individuals may be less distressed initially, however as they go on in life and experience failure when attempting to achieve life goals, they may then experience heightened distress (Senathi-Raja et al, 2010). Likewise, people with a greater educational attainment may be more aware of the subtle problems, repercussions and implications of their ABI, which when combined with high expectations of self may result in more intrusive and distressing symptoms as a result (Snell et al, 2011). This further implies the contribution of personality type in the presentation of emotional distress following an ABI. The empirical study identified a number of individuals who, as a consequence of their high expectations of self and perfectionistic tendencies, evaluated their post-injury selves in a poor light. Within the literature, there is considerable interest in personality change as a result of an ABI, however research exploring the impact of pre-injury personality type on post-injury appraisal and coping ability is relatively scarce. Further research regarding this phenomenon is therefore indicated.

Studies that did not report an association between self-awareness and emotional distress following an ABI were similar in that participants recruited into the study were in receipt of rehabilitation. In general, relatively little detail was provided on the nature of the rehabilitation being delivered, however on all but one occasion, it appeared to act in defence of the development of emotional distress. The studies reported how rehabilitation can provide individuals with an explanation of their difficulties, offer emotional support and provide individuals with a means of engaging in a constructive activity. The empirical study differed somewhat in that individuals were referred for a rehabilitation intervention, as a result of them already experiencing emotional distress. It did however appear to show that for the majority of participants, the experience of attending a therapeutic group intervention was a positive one, with some individuals attributing a changed outlook on life to it.

Although the primary purpose of the empirical study was not an evaluation of the effectiveness of the group per se, it does however lend further support to the use of CBT interventions for addressing emotional distress following ABI (Bradbury et al, 2008). In addition, participants spoke in detail about their experience of acceptance, and how in time they came to recognise and embrace renewed meaning in their lives. This finding would suggest the usefulness of Acceptance and Commitment Therapy (ACT). The goal of ACT is to promote psychological acceptance and discourage deliberate attempts to suppress (experiential avoidance), or change the content of private thoughts. ACT aims to assist individuals to clarify life values and identify barriers to realising related goals, commit to actions necessary to attain such goals and learn to experience private events without engaging in counterproductive avoidance behaviour, thereby fostering psychological acceptance (Hayes et al, 1999).

At present, there are no studies that have investigated ACT in ABI populations; however a paper by Kangas & McDonald (2010) outlines its potential appropriateness. ACT guides individuals to recognise their thoughts, however unlike CBT, it does not require them to challenge or amend them. Indeed, the thoughts that many ABI survivors engage in may be quite rational and reflect their new reality. Instead, ACT facilitates acceptance of limitations and encourages individuals to reclaim their lives via the identification of personal values and goals. In addition, it does not require individuals to think flexibly or manipulate thoughts, something that

for many ABI survivors may be quite a complex undertaking. Studies which investigate the usefulness of ACT in ABI populations would be a useful contribution to the literature.

Further research to address study limitation.

Many of the studies on which the conclusions of the literature review are based recognised a number of limitations. Notably sample sizes across studies were relatively small, resulting in reduced power and therefore limited confidence in the findings. Further studies, possibly involving a multi-centre approach are therefore warranted. Generalisability of findings would be improved if factors such as gender, age, educational status and injury type were more rigorously controlled for. Furthermore, longitudinal studies conducted over a considerable period may help to shed light on whether or not a causal relationship exists between self-awareness and emotional distress. This style of study would have the added benefit of examining non-injury related factors that may further impact on mood.

Studies highlight how self-awareness is difficult to quantify as it can only be measured indirectly through inference. Measures which incorporate the technique of comparing ratings between patients and a significant other are subjective in nature and therefore susceptible to bias (Sawchyn, 2005; Trahan, 2006). Measures are also highly reliant on the assumption that patients are able to understand written and spoken questions and respond in a way that truly reflects their subjective opinions (Flashman, 2002; Kelley, 2014). The development therefore, of tools that facilitate measurement of self-awareness, reduce potential bias and incorporate an assessment of communication skills is warranted.

2. Clinical Implications

The empirical study illustrated a journey of recovery which, for the majority of participants, consisted of initial upset and despair, followed by adjustment to circumstances and finally a process of coming to terms with the injury. This process is mirrored by Klonoff's (2010), who recognises how patients pass through a process of awareness, through to acceptance and finally realism. She indicates how patient's

awareness of their deficits and their ability to accept and cope realistically with those deficits are central to the overall recovery process. It is the job of the rehabilitation professional to assist the patient to navigate the complex journey as adaptively as possible.

As the literature review and empirical study have illustrated, an awareness of deficit is often associated with increases in emotional distress. Gains in awareness are necessary, however for a person to embark on the journey of recovery. Although impairments in self-awareness can initially act as a protective barrier to developing emotional distress, the literature and the findings of the empirical study provide evidence for how in the long term, this can eventually prove detrimental (Prigitano, 2005). Those with impairments in self-awareness are often difficult to engage in rehabilitation and as such successful reintegration back into society can be compromised. A number of studies have therefore focused on various methods aimed at increasing awareness (Fleming, 2007). Methods include; structured experiences, direct feedback, videotaped feedback and various forms of cognitive or group therapy to name but a few. As increased insight can result in heightened emotional distress, clinicians must first consider the ethical implications of raising awareness in their patients. Indeed, treatments that highlight deficits in a confrontational way without appropriate support can trigger deeper depression (Fleming 1998).

In line with the literature, the empirical study has suggested that intact self-awareness is more commonly observed in those who have sustained a milder injury that does not involve damage to the frontal lobes of the brain. As such, clinician's should be mindful that they may observe greater levels of emotional distress in these patients. In addition, further vulnerability factors have been identified, namely; age (older individuals), educational level (higher educational attainment) and personality type (overachiever, perfectionist tendencies). These factors may exacerbate any emotional reaction post injury so should therefore inform formulation.

The empirical study indicated that the degree of emotional distress experienced by individuals is to an extent determined by the way in which they appraise their situation. As outlined in the Transactional Model of Stress and Coping by Lazarus and Folkman (1984), when faced with a stressor, an individual makes an

initial appraisal of it in regards to how significant and threatening it is. They then make a secondary appraisal which involves an assessment of their coping resources and options at hand to deal with the stressor. If an individual's mental and physical abilities have been compromised by their injury, they may perceive themselves as lacking the necessary skills to overcome the impact. For those who, prior to their injury, were accustomed to being in control or were used to holding positions of responsibility with ease, this may be a particularly disagreeable position. Left to their own thoughts and devices, they may be inclined to perceive themselves in a negative light. In addition, as research and the empirical study have revealed, public knowledge and understanding of ABI is generally poor. Patients and their families are therefore ill equipped to understand the implications of an ABI, and may be just as likely to make misattributions and unrealistic expectations of recovery and outcome.

With this in mind, rehabilitation services may be able to prevent significant emotional distress from developing in both patient and family members by intervening in a timely manner. For some, this may even necessitate input at the bedside. Indeed, participants of the empirical study discussed how they experienced very distressing thoughts whilst in hospital and on reflection commented how they would have appreciated greater focus on their emotional needs, in addition to the attention their physical impairments were receiving. Although this mode of practice may appear intensive and responsive in nature, it may deliver dividends by preventing the likelihood of complex chronic cases of depression or anxiety developing at a later stage, thereby reducing impact on resources further down the line.

Based on the findings of the empirical study, neurorehabilitation services may be enhanced by the inclusion of certain elements to help address and reduce the impact of emotional suffering in individuals who are recovering from an ABI. These include;

- Ensuring that the partnership between patient and therapist is collaborative in nature and guided by the goals and aspirations of the patient.
- Psychoeducation: promotes understanding and can provide vital explanations for both patient and family members to address any misconceptions. Delivery should ideally be pitched at the appropriate level and tailored to the individual's needs to prevent confusion and overloading.

- Problems should be externalised to allow the patient to perceive them as something separate that can be addressed and solved, as opposed to something they are defined by.
- Losses should be acknowledged and issues surrounding identity and self-concept addressed, possibly via biographical and narrative approaches.
- Patients may benefit from opportunities to discover new meaning and purpose through activity, with the focus on capabilities as opposed to disabilities.
- Facilitate opportunities for patients to meet and support one another. This could be achieved via patient groups aimed at equipping individuals with strategies to prevent or manage emotional suffering.

Throughout rehabilitation, patients should be empowered to recognise that they are operatives of their own recovery as opposed to passive recipients of treatment. This may foster greater resilience and independence, reducing longer term dependence on services. Just as each patient is an individual, so interventions should be personalised to the individuals needs and speed at which they progress through their recovery. Rehabilitation services should be viewed as a means of monitoring, scaffolding and guiding the process. As the participants of the empirical study demonstrated, achieving acceptance and finding new meaning and direction in life following an ABI is a greatly personal process; it would therefore be improper of any service to substitute this with an overly structured and predefined treatment protocol.

In addition, efforts should be made to improve awareness and understanding of ABI within the health service and across the wider general public. Changing perceptions of disability, especially those that cannot be seen is a considerable challenge, however within the health service; ignorance could result in serious ramifications.

3. Personal Reflections

With my research background being firmly quantitative in nature, venturing into the world of qualitative research has provided many insights and challenges along the way. I had to learn to sit with the discomfort of not being able to make prior

hypotheses and instead let the participants take control of what was and what wasn't revealed by the process. Surrendering myself to the data as opposed to commanding it took some getting used to, but I have valued the opportunity to experience the benefit of capturing a person's first-hand account, from which incredible insights have been brought to light. It has re-affirmed to me who is indeed the expert in any clinical domain, and how clinicians and researchers alike have so much to gain by simply listening to the experiences of our patients and participants in order to achieve a greater understanding of the world in which they live.

I quickly became aware of my novice status as a qualitative researcher whilst listening to the interview recordings. I noted a number of missed opportunities to delve deeper into the participants account for richer meaning, whilst struggling to maintain an open and non-directive questioning style. During the interviews themselves, I became distinctly aware of an internal struggle to maintain my position as researcher and not slip into the more familiar dialogue one might expect of a therapeutic interaction. This was particularly difficult when individuals spoke emotively of their experiences, or appeared to present current problems that necessitated a solution. In addition, conducting qualitative interviews with an ABI population presents its own set of unique challenges. These include the tendency for some participants to perseverate on a particular topic or respond in a tangential manner, resulting in reduced opportunities to obtain richer data.

Despite this, I was able to accumulate a wealth of information. During the analysis process it became evident however, that I wouldn't be able to represent every point that was captured. This was an ongoing frustration as I couldn't help but feel like an ambassador to the valued opinions I had obtained, and it was my duty to ensure that they were disseminated. This process demanded greater scrutiny of what my research aim was however, and ensured that the final product represented what I had set out to achieve. It is the most time-consuming and engaging analytical process I have ever experienced and if it wasn't for the looming deadline, I could have quite happily continued for some considerable time!

With personal experience of working with brain injury populations, I felt relatively prepared for the topics of conversation that would come up during the

course of the interview. What struck me however, was the similarities that emerged between participants accounts of their experience of an ABI and the experiences of others who have endured other injuries or illnesses such as spinal cord injuries (Dickson 2008), cancer (Gillies 2004) and dementia (Clare 2003). The reported themes of identity, loss and altered self-concept are just as prevalent within these populations, suggesting that the process of adjustment to illness is not remarkably dissimilar across them.

Whilst listening to the participant's accounts, I found myself reflecting on the fragility of life and how circumstances can change in an instant. I was to an extent saddened by how, for a number of participants, it took a life changing event for them to really appreciate what they had in life and recognise what was really important to them and take time to indulge in something they enjoyed. Indeed, it has made me reconsider my own priorities in life and ensure that I make every effort to get as much enjoyment out of the things I do.

The narrative of the recovery journey was to me a great insight and made me appreciate how neuropsychological services, although highly specialised, should not neglect the human experience of recovery. Whilst listening to some of the participant's accounts, I couldn't help but feel that they could have been shielded from some of the negative consequences if input had been delivered in a timelier manner, and addressed what an ABI feels like as opposed to what it looks like.

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Appendices

Appendix I: Empirical study research forms;

- i. Study Information Sheet
- ii. Opt-in form
- iii. Consent Form

Appendix II: NHS Ethics Proposal IRAS form

Appendix III: Ethics Approval Letters

1. RES Approval Form
2. R&D Approval Form

**RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME**



STUDY INFORMATION SHEET

Hello, my name is Alice Roblin. I am a Trainee Clinical Psychologist currently training at Bangor University. As part of my qualification, I am conducting some research with the North Wales Brain Injury Service.

This pack contains information about the study that you have the opportunity to take part in. The study involves conducting an interview in which you will be asked questions about your brain injury. In order for you to decide whether or not you would like to be included in the study, please take some time to read this information.



What is the purpose of this study?

This study is interested in capturing the experiences of people who have had a brain injury. It is particularly interested in exploring the process of emotional adjustment to a brain injury, in-particular anything that has been difficult or helpful to you during your recovery.

Who is being asked to participate in this study?

I am approaching those who have participated in the Managing Emotional Adjustment group at the North Wales Brain Injury Service.

What would be expected of me if I took part?

You will be invited to participate in an interview during which you will be asked questions about your experiences of having had a brain injury. This interview will last around 30-90 minutes and be conducted privately and held in your preferred location,

Title of Study: *What helps, what hinders? Emotional adjustment following an acquired brain injury: an interpretative phenomenological analysis.*

Researchers: *Alice Roblin, Dr Karen Addy & Dr Valerie Morrison*

either at the North Wales Brain Injury Service or at your home. We will audio record the interview to make sure we capture everything that you say.

What do I need to do if I want to participate?

Please complete the enclosed opt-in form and return it in the stamped addressed envelope. Alice will be in touch with you shortly to arrange a convenient time to meet.

Will my details and the recordings be kept confidential?

Yes. All personal details and interview recordings will be kept secure and confidential. Only the research team will be able to access this information. All information relating to you will be assigned a pseudonym, which means that no one will be able to identify you from the information you provide. Once the interview has been transcribed, the recording will be deleted.

I hope to use some direct quotes from the interviews in my final write-up, however it will not be possible for anyone to identify you from this quote.

The only time I may have to share information outside of the research team is if something is said that worries me. This may relate to information regarding your or somebody else's safety, or the improper action of a member of staff.

Are there any risks to me taking part?

It is unlikely that you will suffer any negative effects as a result of your involvement with the study however, you may find it difficult at times to discuss your experiences. You may choose not to answer certain questions, or withdraw completely from the study at any time, without giving a reason why. This will not affect the service you receive from the North Wales Brain Injury Service in anyway.

Are there any benefits to me or other people as a result of taking part in the study?

People who participate in similar interview studies find the opportunity to speak about their experiences to be a really positive and fulfilling undertaking. There are no direct benefits as such to you taking part in this study, however the information you provide may help to advance the way brain injury services help others in a similar situation to you, as our understanding of what it is like to experience and recover from a brain injury is improved.

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YSGOL SEICOLEG
SCHOOL OF PSYCHOLOGY

Will I get to know the outcome of the study?

Yes, if you wish to. You may receive feedback of the study on an individual basis, or during a follow-up group meeting, which are held regularly at the North Wales Brain Injury Service. We can discuss your preference further at the time of the interview.

Who do I contact if I want more information?

Please contact me for further information regarding the study at the following address;

Alice Roblin
Trainee Clinical Psychologist
North Wales Clinical Psychology Programme
School of Psychology
College Road
Bangor
Gwynedd
LL57 2DG

E-mail: psp0d5@bangor.ac.uk

Who do I contact if I want to complain about the way this study has been conducted?

Please address any concerns or complains to:

Mr. Hefin Francis
School Manager
School of Psychology
Bangor University
Gwynedd
LL57 2AS

Thank you for taking the time to read this information sheet.

Alice Roblin.

STUDY OPT-IN FORM

Please tick the statement that applies to you:



I have read the information sheet and would like to be a participant in the above study. I therefore consent to Alice Roblin contacting me to arrange a time to meet.



I have read the information sheet and I am **not** interested in participating in this study.

Name (PRINT):.....

Signed:..... Date:.....

Preferred Contact detail:

Phone:.....Best time to call:.....

E-mail:

Please return this consent form in the FREEPOST envelope provided in your pack.
If you have decided to participate, Alice will be in touch with you shortly.



Many thanks

Title of Study: *What helps, what hinders? Emotional adjustment following an acquired brain injury: an interpretative phenomenological analysis.*

Researchers: *Alice Roblin, Dr Karen Addy & Dr Valerie Morrison*

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NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME**



CONSENT FORM

Thank you for agreeing to take part in today's interview. Before we get started, I just need to check that you are aware of the following:

Please
initial

I confirm that I have read and understood the participant information sheet	
I have had the opportunity to ask any questions and have received satisfactory answers	
I agree to participate in an interview, however I understand that I have the right to omit any question if I would prefer not to answer it.	
I agree to the interview being tape recorded and later transcribed.	
I agree that quotations from the interview can be used and I understand that nothing which identifies me personally will be used in the final write-up.	
I understand that my participation is voluntary and I am free to withdraw at any time from the study without reason.	
I consent to my GP being made aware of my participation in this study	

Name (PRINT):

Signed: Date:.....

Title of Study: *What helps, what hinders? Emotional adjustment following an acquired brain injury: an interpretative phenomenological analysis.*

Researchers: *Alice Roblin, Dr Karen Addy & Dr Valerie Morrison*

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please enter a short title for this project (maximum 70 characters)

IPA study examining emotional adjustment following brain injury.

1. Is your project research?

Yes No

2. Select one category from the list below:

- Clinical trial of an investigational medicinal product
- Clinical investigation or other study of a medical device
- Combined trial of an investigational medicinal product and an investigational medical device
- Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
- Basic science study involving procedures with human participants
- Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
- Study involving qualitative methods only
- Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
- Study limited to working with data (specific project only)
- Research tissue bank
- Research database

If your work does not fit any of these categories, select the option below:

Other study

2a. Please answer the following question(s):

- a) Does the study involve the use of any ionising radiation? Yes No
- b) Will you be taking new human tissue samples (or other human biological samples)? Yes No
- c) Will you be using existing human tissue samples (or other human biological samples)? Yes No

3. In which countries of the UK will the research sites be located? *(Tick all that apply)*

- England
- Scotland
- Wales
- Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

- England
 Scotland
 Wales
 Northern Ireland
 This study does not involve the NHS

4. Which review bodies are you applying to?

- NHS/HSC Research and Development offices
 Social Care Research Ethics Committee
 Research Ethics Committee
 National Information Governance Board for Health and Social Care (NIGB)
 National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

- Yes No

6. Do you plan to include any participants who are children?

- Yes No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

- Yes No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

- Yes No

9. Is the study or any part of it being undertaken as an educational project?

- Yes No

Please describe briefly the involvement of the student(s):
The student will be the Chief Investigator.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

- Yes No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

Yes No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

Yes No

DRAFT

Integrated Research Application System
Application Form for Research involving qualitative methods only

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting [Help](#).

Please define any terms or acronyms that might not be familiar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
 IPA study examining emotional adjustment following brain injury.

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

An interpretative phenomenological analysis of emotional adjustment following brain injury.

A2-1. Educational projects

Name and contact details of student(s):

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title	Forename/Initials	Surname
	Dr	Karen	Addy
Address	The North Wales Brain Injury Service		
	Hesketh Road		
	Colwyn Bay		
Post Code	LL29 8AY		
E-mail	karren.addy@wales.nhs.uk		
Telephone	01492807770		
Fax	01492807777		

Academic supervisor 2

	Title	Forename/Initials	Surname
	Dr	Valerie	Morrison
Address	School of Psychology, Bangor University		
	Adeilad Brigantia		
	Gwynedd		
Post Code	LL57 2AS		
E-mail	v.morrison@bangor.ac.uk		
Telephone	+44 (0) 1248 382485		
Fax	+44 (0) 1248 38 2599		

Please state which academic supervisor(s) has responsibility for which student(s):
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)

Academic supervisor(s)

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

- Student
 Academic supervisor
 Other

A3-1. Chief Investigator:

	Title Forename/Initials Surname
	Miss Alice Roblin
Post	Trainee Clinical Psychologist
Qualifications	BSc (Hons) Psychology and Cognitive Neuroscience MSc Foundations of Clinical Neuropsychology
Employer	NHS
Work Address	Flat 4, Stafford House 23 Penrhos Road Colwyn Bay
Post Code	LL28 4DB
Work E-mail	psp0d5@bangor.ac.uk
* Personal E-mail	psp0d5@bangor.ac.uk
Work Telephone	
* Personal Telephone/Mobile	07801968833
Fax	

* This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.

A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?

This contact will receive copies of all correspondence from REC and R&D reviewers that is sent to the CI.

	Title Forename/Initials Surname
	Mr Hefin Francis
Address	School of Psychology, Adeilad Brigantia Bangor
Post Code	LL57 2AS
E-mail	h.francis@bangor.ac.uk
Telephone	+44 (0) 1248 388339
Fax	+44 (0) 1248 38 2599

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):

Sponsor's/protocol number:

Protocol Version:

Protocol Date:

Funder's reference number:

Project website:

Additional reference number(s):

Ref.Number	Description	Reference Number
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Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

Yes No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, this summary will be published on the website of the National Research Ethics Service following the ethical review.*

Every year, people are afflicted by an acquired brain injury (ABI); an unexpected, life changing event that can have profound effects on the individual and their families. Insult to the brain can occur as a result of ischemic abnormalities, haemorrhages, infections and traumatic injuries. Consequences of a brain injury can be many and varied depending on the type, location and severity of the trauma with difficulties spanning physical, cognitive, social, vocational and emotional functioning. Recovery often entails a long and complex process of adaptation to changed circumstances. It is common for survivors of an ABI to suffer difficulty adjusting emotionally to what has happened as they face a whole array of novel, unique and extensive demands, often with diminished personal resources. A number of factors can play a role in how well a person can navigate through this process of adjustment and recovery.

Cognitive Behavioural Therapy (CBT) is an evidence based therapy which operates on the premise that psychological distress can be effectively managed using adaptive thinking and behavioural strategies. Group therapy allows individuals to understand that they are not alone in their suffering, and it is suggested that hearing the opinions of fellow survivors may have the potential to be far more influencing than the opinion of a clinician. This study aims to capture the experiences of brain injury survivors who have participated in a CBT based emotion management group through conducting semi-structured interviews. The recorded material will be analysed using interpretative phenomenological analysis (IPA), a qualitative research approach that examines how people make sense of their major life experiences, through exploration of their understandings, perceptions and views.

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other

review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

A number of potential problematic situations could arise from the proposed study. Study participants may become distressed when discussing the topic of emotional adjustment difficulties, they may disclose a desire to self-harm or they may disclose professional malpractice.

There is the potential for participants to become upset when discussing the emotive topic of their brain injury, however this is unlikely to represent significant psychological distress or discomfort as the participant will have had prior experience of discussing and working through similar difficulties with their clinician at the NWBIS and through participation in the group. Despite this, the participant will be offered the opportunity for the information to be passed onto the group facilitator so that the issue(s) can be addressed at a follow-up group meeting, or in private with a clinician at the NWBIS. External supervision will be sought if the difficulty is deemed significant or in need of imminent attention.

A disclose of a desire to self harm will be managed by the investigator's clinical skills and judgement. Risk will be assessed and if deemed necessary, discussed further in supervision. Only in exceptional circumstances will confidentiality be broken in order to inform members of the clinical team so that the issue may be addressed further.

A disclosure of malpractice will result in the information being fed back to supervisors for further discussion and necessary actions.

All participants will be made aware of the above in the information sheets provided.

A6-3. Proportionate review of REC application *The initial project filter has identified that your study may be suitable for proportionate review by a REC sub-committee. Please consult the current guidance notes from NRES and indicate whether you wish to apply through the proportionate review service or, taking into account your answer to A6-2, you consider there are ethical issues that require consideration at a full REC meeting.*

Yes - proportionate review No - review by full REC meeting

Further comments (optional):

Note: This question only applies to the REC application.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. Please tick all that apply:

- Case series/ case note review
- Case control
- Cohort observation
- Controlled trial without randomisation
- Cross-sectional study
- Database analysis
- Epidemiology
- Feasibility/ pilot study
- Laboratory study
- Metanalysis
- Qualitative research
- Questionnaire, interview or observation study
- Randomised controlled trial
- Other (please specify)

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

To explore the experience of adjusting to life following a brain injury; what factors facilitate or impede this process?

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

What were people's experience of participating in a therapeutic emotion management group?

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

The study may further our understanding of the process of adaptation and recovery to an ABI. The outcome may help inform clinicians of the importance of addressing the emotional impact of a brain injury to ensure rehabilitation interventions are optimally beneficial to the client. It may also provide some insight as to how emotional disorders may be minimised for individuals recovering from an ABI.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

This will be a descriptive, cross-sectional qualitative study, utilising Interpretative Phenomenological Analysis (IPA) to explore the experiences of people who have had a brain injury and participated in a CBT based emotion management therapeutic group at the North Wales Brain Injury Service (NWBIS). Those individuals will receive an information pack sent out to them by the group's co-ordinator (a senior clinician at the NWBIS, so no breach of confidentiality will occur) informing them of the study and asking them to opt-in to the research and consent to having their details passed onto the researcher.

If patients consent to participate, a mutually convenient time will then be arranged to conduct a semi-structured tape-recorded interview in the participants preferred location; either at their home or at the NWBIS.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- Design of the research
- Management of the research
- Undertaking the research
- Analysis of results
- Dissemination of findings
- None of the above

Give details of involvement, or if none please justify the absence of involvement.

Patients will be involved in the data collection aspect of the study by participating in semi-structured interviews. If when asked participants request to be informed of the outcome of the study, the findings will be disseminated to them at a time and location that is convenient to them once the study is complete.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A15. What is the sample group or cohort to be studied in this research?

Select all that apply:

- Blood
- Cancer
- Cardiovascular

- Congenital Disorders
- Dementias and Neurodegenerative Diseases
- Diabetes
- Ear
- Eye
- Generic Health Relevance
- Infection
- Inflammatory and Immune System
- Injuries and Accidents
- Mental Health
- Metabolic and Endocrine
- Musculoskeletal
- Neurological
- Oral and Gastrointestinal
- Paediatrics
- Renal and Urogenital
- Reproductive Health and Childbirth
- Respiratory
- Skin
- Stroke

Gender: Male and female participants

Lower age limit: 18 Years

Upper age limit: 90 Years

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

The inclusion criteria, as specified by the groups criteria is as follows:

- The person has undergone an initial service assessment.
- They have ideally completed the Understanding Brain Injury Group.
- The person experiences emotional difficulties in their day-to-day life.
- The person has a degree of insight into their brain injury.
- The person is able to contribute to group discussions.

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

The exclusion criteria, as specified by the groups criteria is as follows:

- A severe learning difficulty or severely low intellectual ability.
- High levels of disinhibited behaviour that is not amenable to feedback.
- A current alcohol or drug problem
- Current hallucinations or delusional beliefs which are not related to their brain injury.
- The person lacks capacity to provide informed consent.

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. These include seeking consent, interviews, non-clinical observations and use of questionnaires.

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research,

how many of the total would be routine?

3. Average time taken per intervention/procedure (minutes, hours or days)

4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Semi-structured interview	1	0	45-90	Conducted by chief investigator, in location of participants choice, either private home address or NWBIS.

A21. How long do you expect each participant to be in the study in total?

The interview with the participant shall be their only active participation in the study. The participant will be approached again at the end of the study to accept or decline an opportunity to receive the outcome of the study. The entire period from initial contact to study results dissemination will be no longer than 10 months.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

The client may experience a degree of upset as a direct result discussing their experiences. Further information of how this will be dealt with is explained in further detail in question A23.

The investigators do not envisage any further risks or burdens to the participants.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

Yes No

If Yes, please give details of procedures in place to deal with these issues:

There is the potential for participants to become upset when discussing the emotive topic of their brain injury, however this is unlikely to represent significant psychological distress or discomfort as the participant will have had prior experience of discussing and working through similar difficulties with their clinician at the NWBIS and through participation in the group. If levels of distress are significant, participants will be offered the opportunity for the information to be passed onto the group facilitator so that the issue(s) can be addressed at a follow-up group meeting, or in private with a clinician at the NWBIS. External supervision will be sought if the difficulty is deemed significant or in need of imminent attention.

A disclosure of a desire to self harm will be managed by the investigator's clinical skills and judgement. Risk will be assessed and if deemed necessary, discussed further in supervision. Only in exceptional circumstances will confidentiality be broken in order to inform members of the clinical team so that the issue may be addressed further.

A disclosure of malpractice will result in the information being fed back to supervisors for further discussion and necessary actions.

All participants will be made aware of the above in the information sheets provided and reminded of their right to withdraw from the study at any point, without reason.

A24. What is the potential for benefit to research participants?

Although the interviews are not therapeutic, they will give the participants the opportunity to voice their personal experiences of their brain injuries and their experience of the Emotional Management group. Any findings of this study are likely to inform input with future service users; therefore direct benefit to the participants is limited.

A26. What are the potential risks for the researchers themselves? (if any)

The 1:1 nature of the study may present an element of risk to the interviewer as they will be alone in the presence of an

individual with a brain injury who may become emotionally aroused at the content of the discussion, leading to potential outbursts of verbal or physical abuse. The likelihood of such an occurrence is minimal however, as each study participant will be known to the service and they will have been assessed by a member of the NWBIS as appropriate for the group, having conformed to the strict inclusion criteria set out. The NHS lone workers policy will be implemented in any case to protect the interviewer and study participant.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? *For example, identification may involve a disease register, computerised search of social care or GP records, or review of medical records. Indicate whether this will be done by the direct care team or by researchers acting under arrangements with the responsible care organisation(s).*

All participants will be patients of the North Wales Brain Injury Service, a community based neuro- rehabilitation service situated in Colwyn Bay, serving the entire Betsi Cadwalдар University Health Board. Individuals approached for inclusion within the study will have been referred to the emotion management group by a member of the multi-disciplinary clinical team, in accordance with the inclusion and exclusion criteria stipulated by the group's facilitators. Initial contact will be made via Dr Karen Addy, Clinician at the NWBIS and academic supervisor to this project. The chief investigator will only make contact once consent to do so has been acquired.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

Yes No

Please give details below:

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

Yes No

A29. How and by whom will potential participants first be approached?

Individuals who have participated in the Emotional Management therapeutic group at the NWBIS will be initially approached via an information pack sent to them on behalf of the groups co-ordinator, a clinician at the NWBIS, so no breach of confidentiality will be made.

A30-1. Will you obtain informed consent from or on behalf of research participants?

Yes No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

Consent will be sought from patients once they have expressed an interest in participating in the study, having read the information sheet provided by Dr Karen Addy; group co-ordinator at the NWBIS and academic supervisor for this study. During the initial meeting, before consent is obtained, there will be the opportunity to discuss any uncertainties or address any queries. Consent will be established fully by the signing of a consent form.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

Yes No

A31. How long will you allow potential participants to decide whether or not to take part?

Potential participants will receive information about the study that they may read in their own time. Contact will only be made once participants themselves agree to be contacted by the investigator. They may therefore take as much time as they need and discuss their participation with partners/family members/clinicians if they choose to do so. Even if potential participants initially agree to be contacted, they may withdraw their interest at any time.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs?(e.g. translation, use of interpreters)

The ability to converse freely in English is a requirement of the group and therefore the study, as semi-structured interviews will be the main form of data collection. It will not be possible, therefore to translate information or use the services of translators.

A33-2. What arrangements will you make to comply with the principles of the Welsh Language Act in the provision of information to participants in Wales?

As stated above, it will not be possible to conduct any part of the study in Welsh. It is therefore a requirement that the participant is able to read and converse freely in English.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? Tick one option only.

- The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- The participant would continue to be included in the study.
- Not applicable – informed consent will not be sought from any participants in this research.
- Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study**A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)?(Tick as appropriate)**

- Access to medical records by those outside the direct healthcare team
- Access to social care records by those outside the direct social care team
- Electronic transfer by magnetic or optical media, email or computer networks

- Sharing of personal data with other organisations
- Export of personal data outside the EEA
- Use of personal addresses, postcodes, faxes, emails or telephone numbers
- Publication of direct quotations from respondents
- Publication of data that might allow identification of individuals
- Use of audio/visual recording devices
- Storage of personal data on any of the following:
 - Manual files (includes paper or film)
 - NHS computers
 - Social Care Service computers
 - Home or other personal computers
 - University computers
 - Private company computers
 - Laptop computers

Further details:

In order to contact participants to arrange a suitable time to conduct the interviews, it may be necessary to acquire contact details. This information will not be conveyed to the investigator without the participants knowledge or consent. The use of IPA in the analysis and write up of this study may utilise direct quotations to emphasise points within the write up. Quotes will only be selected on the ground that they do not lead to the identification of any individuals. The semi-structured interviews will need to be recorded on an audio device so that they may be transcribed at a later date. As soon as this has been completed, the recordings will be erased. Information will be stored on a password protected safe stick (USB drive). When under analysis, a private computer (laptop) will be used, however any data produced will be stored on the safe stick, and not on the private computers hard drive. It may be necessary to store some written information on University computers when the time comes to complete the write up, however by this time all participant identifiable information will have been removed.

A37. Please describe the physical security arrangements for storage of personal data during the study?

Any personal data, which will be kept to a minimum at all times during the course of the study, will be stored on a password protected safe stick (USB drive). Any identifiable paper measures will be stored in a locked cabinet at the NWBIS.

A38. How will you ensure the confidentiality of personal data? Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.

Participants will be made aware of what personal information is needed for the study and will be asked to provide consent accordingly. The safe stick will be used to store any personal information, which at the earliest convenience will be pseudonymised, as direct quotes may be used, with the participants consent, in the final write up.

A40. Who will have access to participants' personal data during the study? Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.

Personal data will be required by the chief investigator for the purpose of contacting the participants to arrange a convenient time to conduct the completion of the semi-structured interview. Participants will be asked to consent to this transfer of data through the information packs provided by a NWBIS clinician. It will not be necessary to pass any personal information to individuals or agencies outside of the immediate research or care team.

Storage and use of data after the end of the study

A41. Where will the data generated by the study be analysed and by whom?

The data will be analysed either at the chief investigators private address or within the School of Psychology at Bangor University. The data will be analysed by the chief investigator with supervision from the named supervisors.

A42. Who will have control of and act as the custodian for the data generated by the study?

	Title	Forename/Initials	Surname
	Miss	Alice	Roblin
Post	Trainee Clinical Psychologist		
Qualifications	BSc (Hons) Psychology and Cognitive Neuroscience MSc Foundations of Clinical Neuropsychology		
Work Address	Flat 4, Stafford House 23 Penrhos Road Colwyn Bay		
Post Code	LL28 4DB		
Work Email	psp0d5@bangor.ac.uk		
Work Telephone	07801968833		
Fax			

A43. How long will personal data be stored or accessed after the study has ended?

- Less than 3 months
 3 – 6 months
 6 – 12 months
 12 months – 3 years
 Over 3 years

A44. For how long will you store research data generated by the study?

Years: 5

Months:

A45. Please give details of the long term arrangements for storage of research data after the study has ended. Say where data will be stored, who will have access and the arrangements to ensure security.

Anonymised transcripts will be stored in a secure, locked cabinet in the NWBIS for up to five years post qualification, as per NWCPP policy, should access be required for scrutiny by external parties during that time.

INCENTIVES AND PAYMENTS**A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?**

- Yes No

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

- Yes No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

Yes No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

Yes No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

A49-2. Will you seek permission from the research participants to inform their GP or other health/ care professional?

Yes No

It should be made clear in the participant's information sheet if the GP/health professional will be informed.

PUBLICATION AND DISSEMINATION

A50-1. Will the research be registered on a public database?

Yes No

Please give details, or justify if not registering the research.

The project is being undertaken as part of the award of Doctorate in Clinical Psychology.

Registration of research studies is encouraged wherever possible.

You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? Tick as appropriate:

- Peer reviewed scientific journals
- Internal report
- Conference presentation
- Publication on website
- Other publication
- Submission to regulatory authorities
- Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
- No plans to report or disseminate the results
- Other (please specify)

A52. If you will be using identifiable personal data, how will you ensure that anonymity will be maintained when publishing the results?

Caution will be used when deciding which direct quotes to include in the results to ensure that the individual's identification is not revealed by them.

A53. Will you inform participants of the results?

Yes No

Please give details of how you will inform participants or justify if not doing so.

Participants will be given the choice of whether or not they wish to receive feedback regarding the outcome of the study. An appropriate opportunity to do this will be arranged, either at a follow up group session or on a 1:1 basis.

5. Scientific and Statistical Review**A54-1. How has the scientific quality of the research been assessed? Tick as appropriate:**

- Independent external review
- Review within a company
- Review within a multi-centre research group
- Review within the Chief Investigator's institution or host organisation
- Review within the research team
- Review by educational supervisor
- Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:

The study will be approved by the Senior Research Tutor at the North Wales Clinical Psychology Programme and subsequently by the School of Psychology ethics committee, Bangor University.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A59. What is the sample size for the research? How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.

Total UK sample size: 7

Total international sample size (including UK):

Total in European Economic Area:

Further details:

The sample size will range from 7-10. This is dependent on the level of interest and success of recruitment.

A60. How was the sample size decided upon? If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.

7-10 participants is deemed appropriate by Smith (2009) for purposes of completing a PhD standard IPA research study.

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

The recorded interview data will be transcribed and analysed using interpretative phenomenological analysis (IPA), a qualitative research approach that examines how people make sense of their major life experiences, through exploration of their understandings, perceptions and views (Reid et al 2005). This approach provides richer data on the lived experience of the individual, allowing the researcher to extract common themes and meaning in people's experience of illness or disability that is unlikely to be captured through quantitative data alone (Moskowitz 2005).

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.

	Title Forename/Initials Surname
	Dr Karen Addy
Post	Clinical Neuropsychologist
Qualifications	BSc D.Clin Psychology QiCN
Employer	Betsi Cadwaladr University Health Board
Work Address	The North Wales Brain Injury Service Hesketh Road Colwyn Bay
Post Code	LL29 8AY
Telephone	01492807770
Fax	01492807777
Mobile	07917690143
Work Email	karren.addy@wales.nhs.uk

	Title Forename/Initials Surname
	Dr Valerie Morrison
Post	Reader
Qualifications	MA (Hons) Psychology, University of St Andrews, Edinburgh PhD University of St Andrews, Edinburgh CPsychol
Employer	Bangor University
Work Address	School of Psychology, Bangor University Adeilad Brigantia Gwynedd
Post Code	LL57 2AS
Telephone	+44 (0) 1248 382485
Fax	+44 (0) 1248 38 2599
Mobile	
Work Email	v.morrison@bangor.ac.uk

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor

Status: NHS or HSC care organisation
 Academic
 Pharmaceutical industry
 Medical device industry
 Other

Commercial status: Non-Commercial
 Commercial

If Other, please specify: School of Psychology, Bangor University

Contact person

Name of organisation School of Psychology, Bangor University
 Given name Hefin
 Family name Francis
 Address School of Psychology, Adeilad Brigantia
 Town/city Bangor
 Post code LL57 2AS
 Country UNITED KINGDOM
 Telephone +44 (0) 1248 388339
 Fax +44 (0) 1248 38 2599
 E-mail h.francis@bangor.ac.uk

Is the sponsor based outside the UK?

Yes No

Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.

A65. Has external funding for the research been secured?

- Funding secured from one or more funders
 External funding application to one or more funders in progress
 No application for external funding will be made

What type of research project is this?

- Standalone project
 Project that is part of a programme grant
 Project that is part of a Centre grant
 Project that is part of a fellowship/ personal award/ research training award
 Other

Other – please state:

A66. Has responsibility for any specific research activities or procedures been delegated to a subcontractor (other than a co-sponsor listed in A64-1) ? Please give details of subcontractors if applicable.

Yes No

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

Yes No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

	Title Forename/Initials Surname
	Dr Rossela Roberts
Organisation	Clinical Governance Officer (Research and Development/Ethics - West)
Address	Research and Development Office
	Clinical School
	Ysbyty Gwynedd
Post Code	LL57 2PW
Work Email	rossela.roberts@wales.nhs.uk
Telephone	+44 (01248) 384877
Fax	
Mobile	

Details can be obtained from the NHS R&D Forum website: <http://www.rdforum.nhs.uk>

A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/06/2014

Planned end date: 01/06/2015

Total duration:

Years: 1 Months: 0 Days: 1

A71-1. Is this study?

- Single centre
 Multicentre

A71-2. Where will the research take place? (Tick as appropriate)

- England
 Scotland
 Wales
 Northern Ireland
 Other countries in European Economic Area

Total UK sites in study

Does this trial involve countries outside the EU?

- Yes No

A72. Which organisations in the UK will host the research? Please indicate the type of organisation by ticking the box and give approximate numbers if known:

- NHS organisations in England
 NHS organisations in Wales
 NHS organisations in Scotland

1

- HSC organisations in Northern Ireland
- GP practices in England
- GP practices in Wales
- GP practices in Scotland
- GP practices in Northern Ireland
- Joint health and social care agencies (eg community mental health teams)
- Local authorities
- Phase 1 trial units
- Prison establishments
- Probation areas
- Independent (private or voluntary sector) organisations
- Educational establishments
- Independent research units
- Other (give details)

Total UK sites in study:

1

A73-1. Will potential participants be identified through any organisations other than the research sites listed above?

Yes No

A74. What arrangements are in place for monitoring and auditing the conduct of the research?

The NWCPP requires progress reports to be completed throughout the study period to ensure that the study remains on track. Further monitoring will be provided through frequent meetings with study supervisors.

A76. Insurance/ indemnity to meet potential legal liabilities

Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? Please tick box(es) as applicable.

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

- NHS indemnity scheme will apply (NHS sponsors only)
- Other insurance or indemnity arrangements will apply (give details below)

The study will be insured by Bangor University- see indemnity certificate enclosed.

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? Please tick box(es) as applicable.

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

- NHS indemnity scheme will apply (protocol authors with NHS contracts only)
- Other insurance or indemnity arrangements will apply (give details below)

As above, Bangor University will provide indemnity.

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

- NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)
- Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

As above, Bangor University will provide indemnity

Please enclose a copy of relevant documents.

A78. Could the research lead to the development of a new product/process or the generation of intellectual property?

- Yes
- No
- Not sure

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.

Research site		Investigator/ Collaborator/ Contact	
Institution name	Betsi Cadwaladr University Health Board	Title	Dr
Department name	North Wales Brain Injury Service	First name/ Initials	Karen
Street address	Hesketh Road	Surname	Addy
Town/city	Colwyn Bay		
Post Code	LL29 8AY		

PART D: Declarations

D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.
2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.
3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.
4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.
5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.
6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.
7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.
8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.
9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:
 - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
 - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
 - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
 - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
 - May be sent by email to REC members.
10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.
11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication *(Not applicable for R&D Forms)*

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

- Chief Investigator
- Sponsor

- Study co-ordinator
- Student
- Other – please give details
- None

Access to application for training purposes *(Not applicable for R&D Forms)*

Optional – please tick as appropriate:

I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

Signature:

Print Name: Alice Roblin

Date: (dd/mm/yyyy)

DRAFT

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.
7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Signature:

Print Name:

Post:

Organisation:

Date: (dd/mm/yyyy)

D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.
2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.
3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.
4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1

Signature:

Print Name:

Post:

Organisation:

Date: (dd/mm/yyyy)

Academic supervisor 2

Signature:

Print Name:

Post:

Organisation:

Date: (dd/mm/yyyy)



Pwyllgor Moeseg Ymchwil Cymru 5
Wales Research Ethics Committee 5
Bangor

Clinical Academic Office
Ysbyty Gwynedd Hospital
Betsi Cadwaladr University Health Board
Bangor, Gwynedd
LL57 2PW

Telephone/ Facsimile: 01248 - 384.877
Email: Rossela.Roberts@wales.nhs.uk
Website : www.nres.nhs.uk

Miss Alice Roblin
Trainee Clinical Psychologist
Flat 4, Stafford House
23 Penrhos Road
Colwyn Bay
LL28 4DB

psp0d5@bangor.ac.uk

23 June 2014

Dear Miss Roblin,

Study title: **An interpretative phenomenological analysis of emotional adjustment following brain injury.**
REC reference: **14/WA/1033**
IRAS project ID: **154909**

The Research Ethics Committee reviewed the above application at the meeting held on 19 June 2014. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Dr Rossela Roberts, rossela.roberts@wales.nhs.uk

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on question 2 of the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Summary of discussion at the meeting

Care and protection of research participants; respect for participants' welfare and dignity; data protection and confidentiality

The Committee discussed the arrangements made to protect privacy through confidentiality as well as the information governance aspects of the study, where and for how long will data be stored, and clarified who will have access to the data.

The Committee noted that the answer to question A36 of the application form states that information will be kept on a home computer and requested a clarification.

You clarified that recordings will be transferred from the recording device to be transcribed; no data is stored on the laptop - all data will be stored on encrypted USB stick.

Informed Consent process and the adequacy and completeness of participant information

The Committee noted that written informed consent is taken as part of a process - with participants having adequate time to consider the information, and opportunity to ask questions. The information is clear as to what the participant consents and there is no inducement or coercion. The Committee agreed that the procedures described in the protocol have been adequately addressed in the Information Sheet, but felt that minor amendments could be made to ensure consistency (first person/third person); this is a recommendation not a condition of ethical approval.

Other ethical issues were raised and resolved in preliminary discussion before your attendance at the meeting.

Social or scientific value; scientific design and conduct of the study

The Committee considered whether the objectives, design, methodology, and the conduct of the study are appropriately described in the protocol and concluded that the research design and the proposed analysis are adequate to answer the research question.

Recruitment arrangements and access to health information; fair participant selection

The Committee was satisfied that the selection of eligible data has taken into account the patients' clinical care and sufficient details are provided in the protocol regarding the inclusion and exclusion criteria. The Committee raised no further issues in relation to the recruitment arrangements.

Favourable risk benefit ratio; anticipated benefit/risks for research participants

The Committee discussed the anticipated benefits and potential risks to participants and was satisfied that the applicant has suitably identified the risks and benefits and highlighted them in the information given to potential participants.

Suitability of the applicant and supporting staff

The Committee discussed the suitability of the applicant and concluded that you are adequately qualified and well supported by the Academic Supervisor to carry out this research.

Independent review

The Committee discussed whether the study has been independently peer reviewed and whether the review is in scale of the research and risks involved. The Committee concluded that the review by the Research Ethics and Governance Committee, School of Psychology, Bangor University is sufficient evidence of peer-review for this project.

Suitability of supporting information

The Committee discussed the suitability of the supporting information (interview schedule) and raised no issues.

Other general comments missing information/ typographical errors/ application errors/

No issues were raised.

Suitability of the study summary

The summary of the study as it appears in section A6-1 of the REC application form was deemed to be an accurate description of the study and suitable for publication on the NRES website.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
REC Application Form		08 June 2014
Research protocol or project proposal [Research Proposal]	1	01 February 2014
Participant information sheet	1	03 June 2014
Other [Group Information Sheet - Referral to the Managing Emotional Adjustment Group: Information for Clinician]	1	03 June 2014
Participant consent form	1	03 June 2014
Other [Participant Opt-in form]	1	03 June 2014
GP/consultant information sheets or letters [Letter to GP]	1	03 June 2014
Interview schedule	1	03 June 2014
Other [NWBIS lone worker policy]	1	2004
Summary CV for Chief Investigator/Student [Miss Alice Roblin]		03 June 2014
Summary CV for Supervisor [Dr Valerie Morrison]	1	01 June 2014
Evidence of Sponsor insurance or indemnity [Bangor University]		11 July 2013

(end of list)

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Dr Karen Addy declared a conflict of interest in this application; the Committee decided that Dr Addy should leave the room for the duration of the review of this application.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

14/WA/1033

Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely



Mr Derek James Crawford, MBChB, FRCS
Chair

E-mail: rossela.roberts@wales.nhs.uk

Enclosure: *List of names and professions of members who were present at the meeting and those who submitted written comments*

Approval conditions - “After ethical review – guidance for researchers”

Copy: Sponsor: Mr Hefin Francis
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**Wales Research Ethics Committee 5
Attendance at Committee meeting on 19 June**

Committee Members

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>	<i>Present</i>
Dr. Karen Addy	Clinical Psychologist	Expert	Yes
Dr. Swapna Alexander	Consultant Physician	Expert	Yes
Mrs. Kathryn Chester	Research Nurse	Expert	No
Dr. Christine Clark	Consultant Obstetrician & Gynaecologist	Expert	Yes
Dr. Michael Cronin	Consultant Paediatrician (deputy to Dr. Clark)	Expert	No
Mr. Derek James Crawford	Retired Consultant Surgeon (Chairman)	Expert	Yes
Mrs. Gwen Dale-Jones	Retired Personal Assistant	Lay +	No
Mr. Eliezer Lichtenstein	Student	Lay +	No
Dr. Mark Lord	Consultant Pathologist	Expert	No
Dr. Paul Mullins	Senior Lecturer, MRI Physicist	Lay +	Yes
Mr. Vishwanath Puranik	Associate Specialist ENT Surgeon	Expert	Yes
Mrs. Lynn Roberts	Matron, Emergency Department	Expert	Yes
Mr. David Alwyn Rowlands	Retired Development & Monitoring Officer	Lay +	Yes
Dr. Jason Walker	Consultant Anaesthetist	Expert	Yes
Dr. Philip Wayman White	General Practitioner (Vice-Chairman)	Expert	No
Ms. Sydna Ann Williams	Lecturer	Lay +	Yes

In attendance

<i>Name</i>	<i>Position (or reason for attending)</i>
Dr. Rossela Roberts	Clinical Governance Officer / RES Manager



Miss Alice Roblin
Trainee Clinical Psychologist
Betsi Cadwaladr University Health Board
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Chairman/Cadeirydd – Dr Nefyn Williams PhD, FRCGP
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Tel/Fax: 01248 384 877

14 August 2014

Dear Miss Roblin,

Re: Confirmation that R&D governance checks are complete / R&D approval granted

Study Title An interpretative phenomenological analysis of emotional adjustment following brain injury
IRAS reference 154909
REC reference 14/WA/1033

The above research project was reviewed at the meeting of the BCUHB R&D Internal Review Panel

The Committee is satisfied with the scientific validity of the project, the risk assessment, the review of the NHS cost and resource implications and all other research management issues pertaining to the revised application.

The R&D office considered the response on behalf of the Committee and is satisfied with the scientific validity of the project, the risk assessment, the review of the NHS cost and resource implications and all other research management issues pertaining to the revised application.

The Internal Review Panel is pleased to confirm that all governance checks are now complete and to grant approval to proceed at Betsi Cadwaladr University Health Board sites as described in the application.

The documents reviewed and approved are listed below:

Documents Reviewed:	Version	Date
R&D Form – 154909/621554/14/805	-	09/06/2014
SSI Form – 154909/621036/6/701/245155/301531	-	06/06/2014
R&D Checklist	-	-
SSI Checklists x 2	-	-
Protocol	1	01/02/2014
Interview schedule	1	03/06/2014
Participant Information Sheet	1	03/06/2014
Opt-in form	1	03/06/2014
Group information sheet	1	03/06/2014
Consent Form	1	03/06/2014
Letter to GP	1	03/06/2014
Risk assessment form completed by CI		04/06/2014
UMAL Insurance EL Bangor University 2013-2014	-	11/07/2013
CV - CI - Alice Roblin		
CV – Dr K Addy	-	30/11/2013
CV – Dr V Morrison	-	07/04/2014

