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**Quality of Life in Adults with a Head Injury
living in the Community: A qualitative study**

**and
Clinical Research Portfolio**

**Volume 1
(Volume 2 bound separately)**

**Jemma Walker
August 2013**

*Submitted in part fulfilment of the requirements for the degree
of Doctorate in Clinical Psychology (D.Clin.Psy)*

Institute of Health and Wellbeing
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CHAPTER 1: Systematic Review

Family Caregiver Anxiety & Depression Following Severe Head Injury: A Systematic Review

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Abstract

Background & Aims: Family members are increasingly depended upon for the care of their relatives following severe head injury. They consequently not only have to adjust to changes witnessed in the head injured, but also adapt their lifestyle to incorporate their role as carer. This systematic review evaluates the current evidence-base to explore the prevalence of anxiety and depression symptoms for this carer group, and factors associated with the development of such symptoms.

Methods: Seven studies were selected for inclusion in the review, following a systematic search of electronic databases and study reference lists. The included studies were then rated using a modified version of the Downs and Black checklist (1998).

Results & Conclusions: Of the seven included studies, four were rated as high quality and three as moderate quality. All the identified studies utilised reliable and valid self-report measures of anxiety and depression with their sample. The quality of studies was however negatively impacted by limitations in participant recruitment and reporting of information about their sample. Whilst carer anxiety and depression symptoms were reported in all the studies, only one identified these as clinically significant symptoms. Several of the studies explored factors relating to the experience of anxiety and depression, with only two factors identified as having a significant association: social support, and neurobehavioral impairments. Further research is needed to clarify what distinguishes carers who experience symptoms of anxiety and depression, with those who do not. Studies in this area would also benefit from improvements in research methodology.

Introduction

A head injury may occur under many different circumstances, including an assault, fall, road traffic accident, or sports injury. Severe head injuries often have long term effects on physical, cognitive, and emotional functioning. Based on a Glasgow cohort, Thornhill, Teasdale, Murray, McEwen & Roy [1] found that ‘the incidence of newly disabled young people and adults after a head injury ... 100-150 per 100 000 population per year’ [1, p.1634]. The most common cause of head injury in Europe is road traffic accidents followed by falls [2] although in Scotland falls and assaults are the most common causes [1]. As a consequence of disabilities, arising from head injury, many require support at home to carry out daily tasks, or to engage in activities outwith their home. To provide this support they are reliant on paid or family caregivers, and most frequently this responsibility lies with parents or partners [3]. Cutbacks in health and social care make it likely that family members will increasingly be required to take on a greater role in the support and care of their head injured relative. Consequently family members will not only need to adjust to the physical, cognitive, and emotional changes that occur for their relative, but also adapt their lifestyle to accommodate the carer role. This is in addition to adjusting the goals they had envisioned for both themselves and the individual they care for [4], which may encompass ‘a sense of loss, both of the person they loved and their own former lives [5, p.416].

Kaplan [6] found that psychological well-being is greater following head injury where there are good social supports, including support from the family network. It is therefore important to understand factors which may impact upon the support family members can offer the head injured individual. A number of studies have explored the impact that caring for an individual with a head injury has on family members. These studies have explored the adjustment of family members in different areas including quality of life, stress, burden, and psychological distress. There is conflicting evidence as to whether it is characteristics of the individual who has sustained the head injury, or characteristics of the caregiver which best predict carer’s adjustment [7].

It has generally been agreed that personality and behavioural changes witnessed after head injury, have a greater impact on the adjustment of family carers than physical or communication difficulties [8-10]. Personality and behavioural changes may be particularly distressing as the carer not only has to face the challenges in managing changes, such as aggressive or unpredictable behaviour and the impact of cognitive deficits, but may also have to contend with the head injured individual's lack of insight into these changes and their consequences [5]. Personality and behavioural changes are likely to become more significant issues as the injury severity increases. For example, Peters, et al. [11] found that the wives of people with severe head injury had greater adjustment difficulties than wives whose partner had a moderate injury.

Panting and Merry [12] were among the first to explore the psychological distress in relatives of head injured individuals. They found that 61% of 31 patients in their study had relatives who required medication to cope with the stress of having a family member with a head injury. Depression and anxiety symptoms at 'clinically significant levels' are reported to be common in relatives, ranging from 16 - 51% for anxiety, and 8 - 47% for depression [9]. This could mean that a significant number of carers may require support relating to their role, to prevent burn out and reduced quality of care for the head injured individual.

In some families there are pre-morbid problems for the carer. Gillen, Tennen, Afflek & Steinpreis [13] reported that 41% of their sample of carers had experienced depressive symptoms prior to the injury. Sander, et al. [14] found that 37% of their caregiver participants had experienced significant emotional distress prior to the injury, and 27% had received treatment for psychological difficulties. It is possible that such pre-existing difficulties impact upon their perception of their ability to cope, and contribute to a belief that the demands being placed upon them are greater than the coping strategies they have available. As a result, it is not uncommon for carers who perceive that they are faced with significant stressors to experience depression and anxiety symptoms [10]. This subjective perception of burden reportedly becomes greater as the time since injury increases [4, 15].

Ennis, Rosenbloom, Canzian & Topolovec-Vranic [16] recently conducted a review of depression and anxiety symptoms in family carers following head injury. The focus of their review was on parent and spouse carers, as the evidence was unclear whether spouse carers, due to a greater change in their role within the relationship, experienced more psychological distress than parent carers [17]. Ennis, et al. [16] conclude that there is evidence that both parent and spouse carers experience clinically significant symptoms of depression and anxiety. In addition, the evidence does not suggest a difference in the experience of depression and anxiety symptoms between parents and spouse carers. There were however, some limitations to this review including the misreporting of study characteristics, and as a consequence of focusing their review on parent and spouse carers some recent key studies were not included.

Rationale & Current Review Aims

Since family carers are increasingly relied upon for the support and care of their head injured family member it is important to consider the impact that such care has upon them, to ensure that appropriate supports are in place to aid them in this role. In particular, for those caring for individuals who have sustained a severe head injury, as the carer demands may be increased.

This systematic review appraises the recent literature relating to symptoms of depression and anxiety in family carers of adults with a severe head injury, and the measures used to assess these symptoms. The primary aim is to explore the reported prevalence of anxiety and depression symptoms for this carer group, and factors identified as being associated with these symptoms. The secondary aim is to examine whether the conclusions of Ennis, et al. [16] remain valid when studies are included based on injury severity, and a broader carer group.

Method

Search Strategy

The following databases were used to conduct an electronic search for studies relevant to systematic review: EBSCOhost (MEDLINE, PsycINFO, Psychology and Behavioral Sciences Collection, and PsycARTICLES); and Web of Knowledge (Web

of Science). The search was run in May 2012, using the combined search terms outlined below:

- severe AND head injur* OR brain injur* NOT stroke NOT tumour
- family OR relative OR spouse OR partner
- burden OR depression OR anxiety

The electronic search identified 529 studies, 205 of which were duplicates. The title and abstract of the remaining 324 studies were reviewed for inclusion based on the following criteria:

Inclusion Criteria:

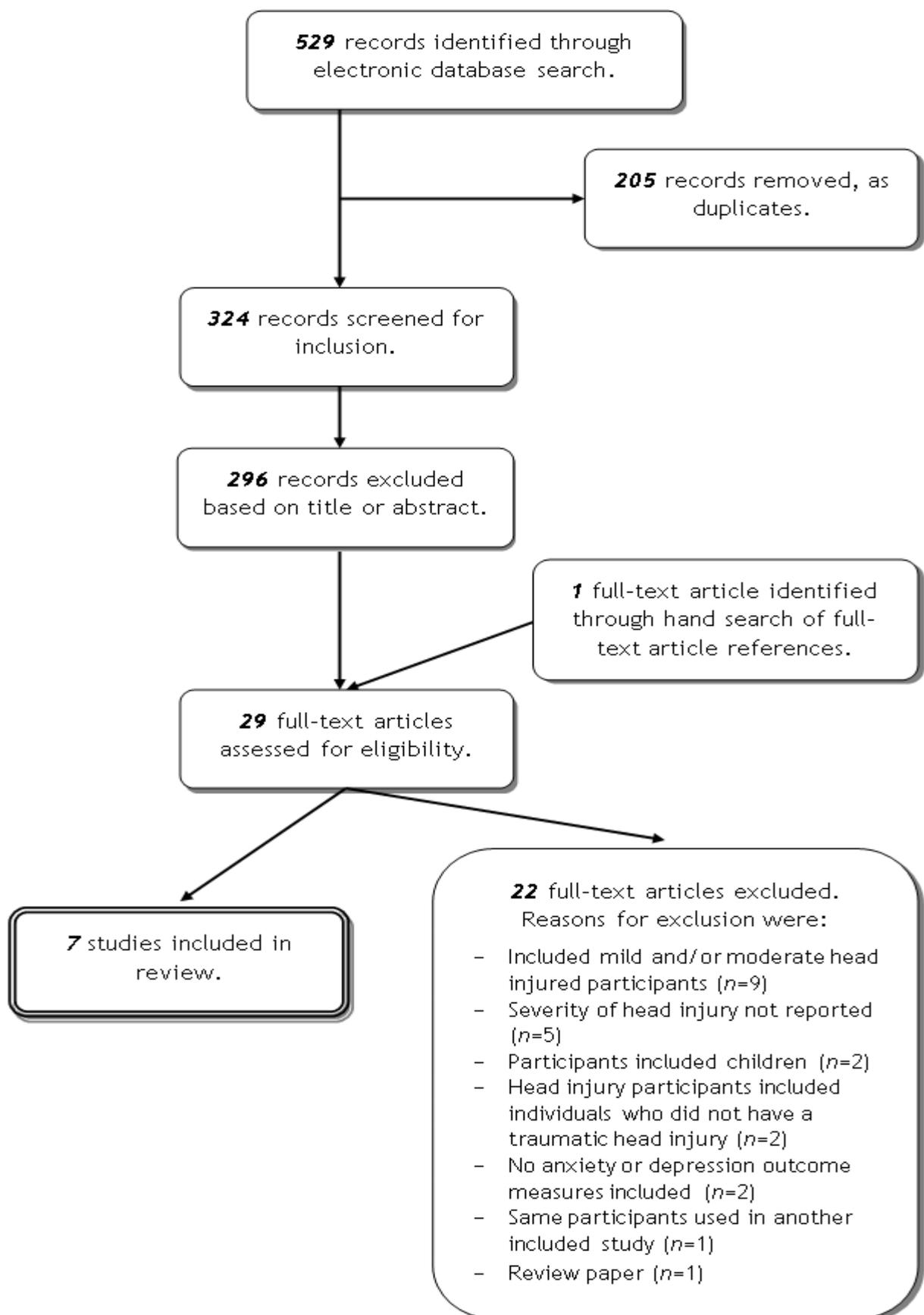
- published since the year 2000
- the head injured individual was an adult at the time of injury, between the ages of 16 years and 64 years
- the head injury is described as severe based on at least one of the following characteristics: Glasgow Coma Scale (GCS) <9; Post Traumatic Amnesia (PTA) >1 day; or Loss of Consciousness >30 minutes

Exclusion Criteria:

- published in a language other than English
- single Case Studies, Reviews, Dissertations, Conference Abstracts, and Book Chapters
- studies which do not include a clear measure of depression or anxiety
- studies involving paid carers

If it was not clear from the abstract whether the study met the aforementioned criteria, the full text article was obtained and reviewed. The reference lists of the included studies and the review conducted by Ennis, et al. [16] were also hand searched to identify any relevant studies which were not identified by the electronic search. The process of the search strategy and reasons for papers excluded following full text review are illustrated in figure 1.1.

Figure 1.1: Flow Diagram of Systematic Study Selection Process



Quality Rating Criteria

The quality of the included studies was assessed using a modified version of the Downs and Black checklist (1998) (Appendix 1.2). The National Collaborating Centre for Methods and Tools [18] identified it as a valid and reliable quality rating tool for non-randomised studies. It was also the tool used by Ennis, et al. [16], with which the findings of this review will be compared. Nine of the 27 questions from the checklist (Questions 4, 7, 8, 13, 14, 15, 19, 23, and 24) were not included in the quality rating for this review as they were specific to intervention studies, and consequently not relevant for this review. This left 18 items which were given a score of '1' if the study met the criteria and '0' if the study they did not, or if it was not possible to determine if the study met the criteria. Based on the potential overall score a quality percentage rating was calculated for each paper. These were subjectively categorised by the researcher, as 'High Quality' ($\geq 75\%$), 'Moderate Quality' (50% - 74%), and 'Low Quality' ($\leq 49\%$).

Each study was rated by two final year Doctorate in Clinical Psychology trainees, one of whom was independent of this review. Inter-rater reliability was 93% on the studies reviewed, and inconsistencies in the quality rating scores were discussed and resolved by the two reviewers.

Results

Study Selection

Of the 324 studies identified for potential inclusion from the electronic database search, 296 were excluded following examination of the article title and abstract. Of the remaining studies, 22/28 were excluded following a full text review. The reasons for exclusion are outlined in figure 1.1. One additional study was identified via the hand search of reference lists from studies identified for inclusion by the electronic database search. Hence, a total of seven studies were included in the final review.

Four of the included studies were rated as high quality [7, 19-21] with quality ratings of 83% and 77% on the Downs and Black checklist (1998). The remaining

three studies were rated as moderate quality [5, 10, 22], with quality ratings between 61% and 72%.

Study Characteristics

The key characteristics of the studies in this review are outlined in table 1.1. Five of the included studies were undertaken in Australia [5, 7, 19, 21, 22], and the remaining two in New Zealand [10, 20]. The participants included in the studies were recruited from a range of sources including brain injury rehabilitation programmes [7, 21, 22], hospitals [10, 19, 20], and head injury charities [5]. Whilst some studies compared carers of head injured individuals to a control group [5], others measured anxiety and depression symptoms along with other variables to identify correlations [19, 21, 22], or at different time points [7, 10, 20].

Carer Characteristics

Overall, there were 454 carers in the seven studies reviewed. Their age at the time of participation ranged from 15 years to 67 years. Six studies reported the carers' gender; the majority of carers were female (81%) [5, 7, 10, 19, 20, 22]. The carers' relationship with the head injured individual included parents, spouses/partners, siblings, grandparents, friends, and roommates. The majority of carers were parents or the spouse/partner of the head injured individual.

Two studies referred to the employment status of the carer, and indicated a varied skills and socio-economic mix [7, 21]. Again, only two studies stated information about the frequency of contact between the carer and individual with a head injury. Harris, et al. [10] reported that 70% of their carer sample lived with the head injured individual, and overall 95% saw them every day. Marsh, et al. [20] found that 71% of carers were living together six months post-injury, and 67% one year post-injury.

Table 1.1: Quality Rating and Sample Characteristics of Included Studies

Author (Year)	Quality Rating	Patient Characteristics	Caregiver Characteristics
Turner, et al. [7]	High Quality (83%)	<p><i>n</i> = 29 (23 males; 6 females)</p> <p><i>Age at Interview (years)</i>: M=35; SD=15; Range=17-63</p> <p><i>Injury Severity (PTA days)</i>: M=49.15; SD=35.62; Range=12-173</p> <p><i>Time since injury (months)</i>: NR¹</p>	<p><i>n</i> = 29 (6 males; 23 females)</p> <p><i>Age at Interview (years)</i>: M=48; SD= 9; Range=27-61</p> <p><i>Relationship</i>: 15 parents; 13 spouses /partners; 1 daughter</p>
Anderson, et al. [21]	High Quality (83%)	<p><i>n</i> = 93 (Gender NR)</p> <p><i>Age at Interview (years)</i>: Mean=34 ; SD= NR</p> <p><i>Injury Severity (PTA days)</i>: (<i>n</i>=83) M=57; SD=40; Range=2-224</p> <p><i>Injury Severity (Coma)</i>: (<i>n</i>=9) Range=4 days - 4 months²</p> <p><i>Time since injury (months)</i>: Mean = 41; SD = NR; Range = 4 - 183</p>	<p><i>n</i> = 122 (Gender NR)</p> <p><i>Age at Interview (years)</i>: Parents M=52; Spouses M=45</p> <p><i>Relationship</i>: 64 spouses; 58 parents (29 couples)</p>
Marsh, et al. [20]	High Quality (77%)	<p><i>n</i> = 52 (42 males; 10 females)</p> <p><i>Age at Interview (years)</i>: M=28; SD=11; Range=16-55</p> <p><i>Injury Severity</i>: GCS = <9</p> <p><i>Time since injury (months)</i>: NR</p>	<p><i>n</i> = 52 (6 males; 46 females)</p> <p><i>Age at Interview (years)</i>: M=43; SD=9; Range=18-65</p> <p><i>Relationship</i>: 36 parents (69%); 15 spouses /partners (29%); 1 sibling (2%)</p>

¹ NR = Not Reported

² Severe injury defined by PTA >24 hours, or coma ≥ 6 hours if PTA not known.

Douglas & Spellacy [19]	High Quality (77%)	<p><i>n</i> = 35 (21 males; 14 females)</p> <p><i>Age at Interview (years)</i>: M=36.71; SD=11.99; Range=22-71</p> <p><i>Injury Severity (PTA days)</i>: M=88.26; SD=87.91; Range=8-370</p> <p><i>Time since injury (months)</i>: M=84.29; SD=20.59; Range=42-124</p>	<p><i>n</i> = 35 (7 males; 28 females)</p> <p><i>Age at Interview (years)</i>: M=47.69; SD=11.74; Range=23- 67</p> <p><i>Relationship</i>: 20 spouses; 15 parents</p>
Harris, et al. [10]	Moderate Quality (72%)	<p><i>n</i> = 58 (Gender NR)</p> <p><i>Age at Interview (years)</i>: M=25.39; SD=9.25; Range=15-61</p> <p><i>Injury Severity (PTA days)</i>: M=14.98; SD=11.82; Range=24hrs - 10wks</p> <p><i>Injury Severity (GCS)</i>: Range=4 -14</p> <p><i>Time since injury (months)</i>: NR</p>	<p><i>n</i> = 58 (13 males; 43 females; 2 = unknown)</p> <p><i>Age at Interview (years)</i>: M=36.40; SD=14.09; Range=15-64</p> <p><i>Relationship</i>: 47% parents; 27% spouses/partners; 17% friends/roommates; 2% siblings; 4% others</p>
Winstanley, et al. [22]	Moderate Quality (67%)	<p><i>n</i> = 134 (103 males; 31 females)</p> <p><i>Age at Interview (years)</i>: M=31.9; SD=13.1</p> <p><i>Injury Severity (PTA days)</i>: Median=29; Range=7-182</p> <p><i>Time since injury (months)</i>: NR</p>	<p><i>n</i> = 134 (25 males; 109 females)</p> <p><i>Age at Interview (years)</i>: M=45.0; SD=10.6</p> <p><i>Relationship</i>: 67 parents (50%); 52 spouses (39%); and 15 others</p>
Boyle & Haines (2002)	Moderate Quality (61%)	<p><i>n</i> = 25 (18 males; 7 females)</p> <p><i>Age at Interview (years)</i>: NR</p> <p><i>Injury Severity</i>: Severe injury defined by inability to resume previous lifestyle and requiring care.</p> <p><i>Time since injury (months)</i>: NR</p>	<p><i>n</i> = 24 (6 males; 18 females)</p> <p><i>Age at Interview (years)</i>: M=54.5; SD=12.5</p> <p><i>Relationship</i>: 12 spouses; 12 parents</p>

Head Injury Characteristics

All of the studies reported characteristics of the individuals with a head injury. Their age at the time of participation in the study, ranged from 15 - 71 years. One study did not detail the age of the head injured individuals [5]. Five studies reported the head injured individual's gender, with 75% being male and only 25% female [5, 7, 19, 20, 22].

The studies reviewed used different methods of defining the severity of the head injury. Five of the seven included studies used PTA to indicate severity [7, 10, 19, 21, 22]. PTA scores from these studies ranged from 1 day to 370 days. One study used a GCS score of less than 9 to define severe head injury [20]. Whilst, Boyle & Haines [5] classified severity based upon an inability to resume previous lifestyle and the subsequent requirement of care. Four studies reported the cause of head injury. One study simply stated that the most frequent cause of injury was road traffic accidents [5]. The remaining three studies report that 48-71% of head injuries were caused by road traffic accidents, 9-17% by falls, 3-14% from assault; and 8-20% other causes, including sporting injuries [7, 20, 21]. Two studies outline the time since injury. In one this ranged from 4 to 183 months [21] and the other 42 to 124 months [19].

Measurement of Anxiety & Depression

The self-report questionnaires used to measure anxiety and depression are outlined in table 1.2. Five of the seven studies included measures of anxiety and depression. Harris et al. [10] and Douglas & Spellacy [19] only included a measure of depression, and were the only two studies to use the same self-report measure. In addition to measures of anxiety and depression, the studies also included a range of other outcome measures, as indicated in table 1.2.

Table 1.2: Measures of Anxiety and Depression

Author (Year)	Measures	Scores M (SD)	Other Included Measures
Turner, et al. [7]	Depression Anxiety Stress Scale (DASS)	<i>n</i> =29 Pre-D/C ³ Depr ⁴ : 7.4 (9.3) Pre-D/C Anx ⁵ : 3.8 (5.0) 1 month post-D/C Depr: 5.2 (7.6) 1 month post-D/C Anx: 2.5 (3.5) 3 months post-D/C Depr: 3.9 (8.0) 3 months post-D/C Anx: 1.9 (3.8)	The Caregiver Strain Index (CSI) Functional Independence Measure (FMI) Disability Rating Scale (DRS)
Anderson, et al. [21]	Brief Symptom Inventory (BSI)	<i>n</i> =122 Depr: 58.72 (10.80) Anx: 56.19 (11.70)	Neurobehavioral Problem Checklist (NPC) Family Assessment Device (FAD)
Marsh, et al. [20]	Beck Depression Inventory (BDI-SF) State-Trait Anxiety Inventory (STAI)	<i>n</i> =52 6 months post-IR ⁶ Depr: 5.08 (5.90) 6 months post-IR Anx: 39.31 (12.70) 1 year post-IR Depr: 4.24 (4.78) 1 year post-IR Anx: 38.61 (11.49)	Social Adjustment Scale (SAS-SR) Head Injury Behaviour Rating Scale Caregiver Questionnaire
Douglas & Spellacy [19]	Zung Self-rating Depression Scale (SDS)	<i>n</i> =30 <i>Depression</i> : 44.83 (11.16)	Disability Rating Scale (DRS) Instrumental-Expressive Social Support Scale (IESSS)
Harris, et al. [10]	Zung Self-rating Depression Scale (SDS)	<i>n</i> =58 <i>Depression</i> : 33.28 (7.42)	Social Behaviour Assessment Schedule (SBAS)
Winstanley, et al. [22]	General Health Questionnaire (GHQ28)	<i>n</i> =134 <i>Depression</i> : Median=1; Range=0-17 <i>Anxiety/insomnia</i> : Median=7; Range=0-21 <i>Total Score</i> : Median=23; Range=0-60	Sydney Psychosocial Reintegration Scale (SPRS) Family Assessment Device (FAD) BIOS Family Needs Questionnaire
Boyle & Haines [5]	Profile of Mood States (POMS)	<i>n</i> =23 <i>Depression-Dejection</i> : 10.9 (12.1) <i>Tension-Anxiety</i> : 9.6 (7.7)	Family Environment Scale (FES)

³ D/C = Discharge

⁴ Depr = Depression

⁵ Anx = Anxiety

⁶ IR = Injury

Study Findings

Turner, et al. [7] - High Quality (83%)

This prospective cohort study explored depression, anxiety, stress, and strain in head injury carers at pre-discharge, one month and three months post-discharge. Turner, et al. [7] reported that pre-discharge mean scores for depression and anxiety on the DASS [23] were above that of normative, general adult, sample means. At one and three months post-discharge the mean scores were below that of the normative sample.

Pre-discharge, 27% of the 29 carers who completed the DASS, scored higher on the measure than individuals from the general adult population; including mild, moderate, severe, and extremely severe categorisations [7]. This reduced to 12% one month and three months post-discharge. There was a significant reduction in the depressive symptoms reported pre-discharge in comparison to three months post-discharge. The difference in scores was not significant between pre-discharge and one month post-discharge. Prior to discharge, 13% of carers reported experiencing anxiety symptoms above the normal cut-off score which indicates the presence of at least mild anxiety symptoms. This was slightly higher than the number of individuals who report experiencing similar anxiety symptoms within the general adult population (11%) [7]. Anxiety symptoms reduced to 3% one month post-discharge, and 6% three months post-discharge. The difference between self-reported anxiety scores at pre-discharge and three months post-discharge were significant. However, less specific symptoms of 'stress and strain' were more commonly reported than depression and anxiety symptoms. There was no significant relationship found between age, time in hospital/rehabilitation, GCS score or PTA and depression or anxiety scores. One month post-discharge, family carers reported significantly more anxiety symptoms than partners, and three months post-discharge carers of individuals who were less disabled reported less depressive symptoms.

Overall, this study was rated highly, however there were limitations. 26% of the sample did not complete the study and the reasons for this loss to follow-up were not made clear. Those lost to follow-up were younger than those who

completed the study, which may indicate that their sample was not representative of the entire population. In comparison to some of the other studies in this area their sample size was relatively small ($n=29$), and they gave no indication if analysis had been conducted to determine whether their study had adequate power.

Turner, et al. [7] chose the DASS as their measure of anxiety and depression which has been shown to be a reliable and valid measure of both constructs [24, 25]. However, they compared the mean scores on the DASS in their sample to the general adult normative data of a UK sample, rather than the appropriate Australian sample norms. This is significant as the UK sample had slightly higher scores and based on this the mean anxiety score was reported as higher than the norm, but was in fact lower than the norm for an Australian adult population. The reason for the selection of this normative data sample was not made clear.

Anderson, et al. [21] - High Quality (83%)

This study explored relationships between neurobehavioral impairments following head injury, and psychological distress in relatives and spouses and family functioning. The mean scores for anxiety and depression on the BSI [26] were greater than the mean scores for the non-patient normative sample. More spouses reported anxiety (36%) and depression (50%) symptoms, than parents (29% and 35% respectively), although these differences were not significant between groups. Anderson, et al. [21] described these participants as meeting 'caseness' which indicates they were reporting clinical levels of anxiety and depression. Overall, they concluded that neurobehavioral impairments significantly increase relatives' distress. In particular the impact that cognitive and behavioural changes have on family functioning.

Anderson, et al. [21] identified that a limitation of their study was the lack of exploration of confounding variables such as, coping style, re-integration, and social support, which they identified as potentially having a bearing on the link between psychological distress and neurobehavioral impairments. However, their measure of psychological distress (BSI) [26] is a reliable and valid measure.

Although they did not justify their sample size with a power calculation they did have a relatively large sample size in comparison to similar studies (n=122).

Marsh, et al. [20] - High Quality (77%)

Family head injury carers were asked to complete self-report measures six months, and one year post-injury. Six months post-injury 16/52 (31%) carers reported anxiety symptoms, and 17/52 (33%) reported symptoms of depression. There were no significant differences in the reporting of anxiety and depression symptoms at six months and one year post-injury. They indicated that the majority of those reporting anxiety symptoms were within the mild range, and the majority of those experiencing depression symptoms within the severe range, based on the standard cut-off scores of the measures.

Marsh, et al. [20] used reliable and valid measures of both anxiety and depression, normed on the general population; there was, however, some variability in the length of time to follow-up. Administration of questionnaires was at six months and one year post-injury. Yet their follow-up time periods ranged from 4 - 12 months, for six month follow-ups, and 11 - 16 months, for one year follow-ups. They also did not conduct an analysis to determine adequate power for their study (n=52).

Douglas & Spellacy [19] - High Quality (77%)

The aim of the study was to explore if there is a relationship between social support, disability, and depressive symptoms. They found that 18 of 30 carers reported elevated depressive symptoms based on the normative data for the SDS; this included 77% of parents and 47% of spouses [27]. Douglas & Spellacy [19] did not report descriptive data for these findings but stated the reported depressive symptoms were, “likely to be clinically significant” [19, p.82]. They found a significant relationship between carer symptoms of depression and higher levels of disability after head injury. Correlations between carer depression scores and self-report of social support were also significant, with better support having a positive impact in relation to lower depression scores.

Douglas & Spellacy [19] chose a well-established, reliable, and valid measure of depression for their study [28, 29]. They had, however, a relatively small number of participants whose questionnaires were included in the final analysis ($n=30$) and did not indicate if this was adequate power for such analysis.

Harris, et al. [10] - Moderate Quality (72%)

This study aimed to identify factors associated with emotional adjustment in head injury carers. In 84% of the 58 carers in the study, scores on the SDS [27] were higher than in the general population, with 23% of carers reported to be experiencing clinically significant depressive symptoms. This was determined as a raw score of more than 40 on the SDS [10]. There was a significant relationship between carer depression and the negative impact of the head injury on other family members. Carer appraisal of behavioural changes was identified as a mediator variable i.e. 'to the extent that it accounts for the relation between the predictor and the criterion [30, p.1176] for carer depression; while social support was identified as a moderator variable i.e. 'a qualitative ... or quantitative variable ... that affects the direction and/or strength of the relation between an independent or predictor variable and a dependent or criterion variable' [30, p.1174]. It was theorised that it was not the changes in the head injured individual's presentation that was significant but the reaction of other family members. There was no significant relationship between the carer's depressive symptoms and age, gender, socioeconomic status, time since injury, simultaneous significant life events, or if the carer and head injured individual lived together.

This study also used the SDS a reliable and valid measure of depression [28, 29]. They explored several potential confounding variables within their study but acknowledged that coping style was a key variable missing from their study. They recruited their participants from hospital admissions over a four year period and had a good response rate of 88% however, participants were recruited from only one hospital and there was no indication of a power calculation to justify sample size ($n=58$).

Winstanley, et al. [22] - Moderate Quality (67%)

This study aimed to look at variables associated with relatives' distress following head injury. They hypothesised high levels of relatives' distress would be related to higher levels of impairment following injury, lower reintegration following injury, and effect family functioning. They found that 50% of 134 relatives demonstrated psychological distress, based on a score of four or more on the individual sub-scales [22]. The composite scores for the 'anxiety/insomnia' and 'somatic symptoms' sub-scales on the GHQ28 [31] were higher, than that for 'depression'. They concluded that their participants met 'caseness' on the 'anxiety/insomnia' and 'somatic symptoms', but not the 'depression' sub-scale [22]. Winstanley, et al. theorised that distress was not directly related to neurobehavioral impairment following head injury but was indirectly related, via limited community reintegration [22]. There was no significant relationship between distress and family functioning.

This study included a sample which was not fully representative of the head injury population, as participants were only recruited from a rehabilitation unit. However, they did achieve a good response rate of 81%. They lost 26 participants to follow-up and, did not outline the characteristics of these participants, or the reasons for loss to follow-up. In comparison to the other studies included in this review Winstanley, et al. [22] had the largest sample size (n=134). The quality rating for this study was also negatively affected by the study's follow-up period. The authors analysed all follow-up responses as 18 months post-injury despite there being a six month difference in the follow-up timescale for the sample (Follow-up Range = 14 -19 months). The GHQ28 was applied as the measure of anxiety and depression for this study, and has been found to be a reliable and valid measure of these constructs. However, Winstanley, et al. [22] only administered this as a measure of psychological distress at follow-up, and included no measure in their questionnaire pack following admission. They did not state a reason for this, and it meant there was no opportunity for comparison of psychological distress between the two time points.

Boyle & Haines [5] - Moderate Quality (61%)

The researchers hypothesised that family carers of head injured individuals would score higher on self-report measures of depression, tension, anxiety, and anger than a comparison group matched by socio-economic status. They reported a difference in the mean depression-dejection scores, with the head injury carers having a significantly higher mean score than the comparison group. They did not however compare these findings to the normative data for the POMS to determine the severity of these symptoms. Boyle & Haines [5] also found that head injury carers reported significantly less involvement in social and leisure activities. There was no significant difference between groups for anxiety scores.

There were some limitations to this study, mainly in relation to their sample and recruitment. Points were lost on the quality rating scale as the sample may not have been representative of the entire population being studied. They recruited from head injury charities with which families were involved in because they felt they needed additional support which meant that families who were coping without support were excluded from the study. The two centres included in the study also used different recruitment methods. One centre directly contacted potential participants whilst the other took more of an indirect approach and advertised the study in their newsletter. Boyle & Haines [5] also defined the severity of the injury by level of disability rather than GCS or PTA which are more valid measures of initial head injury severity.

The number of participants in the study was the smallest of all the groups of participants included within this review (n=24). The researchers did not conduct a power analysis to determine if this sample size was adequate for their study. Boyle & Haines [5] chose the POMS [32] as their measure of anxiety and depression, and found it to have reasonable scores when tested for reliability and validity on their population.

Discussion

The aim of this systematic review was to explore anxiety and depression experienced by family carers of adults who have sustained a severe head injury. Seven papers that were published since the year 2000 were included in this review. These studies were published by different authors however, all used an Australian or New Zealand sample. It is of note therefore that there is a gap in the literature for other population samples, such as American and European.

The carers in the studies had a wide age range, with the majority being female. A weighting towards female caregivers within the head injury population has been previously identified [33]. The majority of those who had sustained the head injury were male, which again is representative of the general head injury population. There was variability between the studies on how they defined the severity of the head injury however most used GCS or PTA.

Anxiety and Depression in Carers

All the studies utilised measures which are reliable and valid. Whilst all the studies indicated a proportion of their participants reported anxiety and depressive symptoms only one indicated whether this was clinically significant [10]. However, four studies indicated that scores on the self-report measures were greater than the norms for the general adult population [10, 7, 19, 21], and one study found greater symptoms of depression for the head injury carers than their comparator group, matched by socioeconomic status [5]. The number of participants reporting anxiety symptoms ranged from 3-50%, and 12-84% for depressive symptoms. This indicates the frequency of anxiety and depression symptoms are very variable within this population.

Two of the studies compared reported anxiety and depression symptoms at two or more time points. Turner, et al. [7] highlighted a reduction in carer anxiety and depression symptoms pre-discharge to three months post-discharge. Marsh, et al. [20] reported no significant difference in the anxiety and depression score reported six months and one year post-injury. Given that there were only two

studies that measured anxiety and depression scores over different time periods it is difficult to draw any firm conclusions. However, these studies would indicate that carers' anxiety and depression symptoms are relatively stable, in the first year after injury.

There were some variations reported between different carer types. Turner, et al. [7] reported that family carers reported higher levels of anxiety one month post-discharge than partner, and Douglas & Spellacy [19] found that their parent sample reported more depressive symptoms than their spouse group. Conversely Anderson, et al. [21] found that spouses reported greater anxiety and depression symptoms than parents however this difference was not significant. It is therefore not entirely clear whether carer relationship has an influence on the anxiety or depression symptoms experienced.

Factors Associated with Anxiety and Depression

Six of the seven studies reported on factors for which they investigated the relationship with anxiety and depression symptoms, in carers. Turner, et al. [7], and Douglas & Spellacy [19] reported that carers' depressive symptoms were affected by the greater levels of disability experienced by the head injured relative. For relatives of head injured who were less disabled post-discharge, carer's depressive symptoms were lower [7]. Neurobehavioral impairments in the head injured individual were also found to be associated with anxiety and depression symptoms in carers [21, 22]. However, both studies acknowledged that this was not necessarily a direct relationship, and Winstanley, et al. [22] concluded that there was an indirect relationship resulting from limited community reintegration of the head injured individual.

Social support for carers was identified as an important factor in their experience of anxiety and depression symptoms [19]. Boyle & Haines [5] observed that their head injury carer group engaged in less social and leisure activities in comparison to their comparator group, matched by socioeconomic status. Harris, et al. [10] found a significant relationship between carer depression and the impact the head injury had on the wider family network.

They hypothesised that the reaction of other family members to the injury was a significant factor relating to the carers experience of depressive symptoms. Interestingly good social support has also been identified as a factor important for well-being for head injured individuals [6].

However, there were also factors identified as not being associated with depression or anxiety scores of carers. These included: age [7, 10]; duration of hospital/rehabilitation stay; GCS score; PTA [7]; gender; socioeconomic status; living arrangements of head injured individual and carer [7, 10]; and family functioning [22]. Time since injury was also identified as not being associated with depression or anxiety scores [10] which is in contrast to previous findings [15, 4]. None of the studies include in the review identified pre-morbid anxiety and depression symptoms in carers despite this being a potential contributory factor [13, 14].

Limitations of Included Studies

The majority of limitations were related to the recruitment and reporting of information about the sample, which impacted on the quality rating score they achieved. All the measures of anxiety and depression were identified as being reliable and valid self-report measures of these constructs. However, all were developed for a general adult population and were not specific to head injured individuals or their carers. Many of the studies also did not report enough information to determine whether the reported symptoms were of clinical significance. Turner, et al. [7] also compared their Australian sample results to the UK sample norms of their chosen measure. This meant that some of their results were interpreted as being above average when in fact this would not have been the case had they used the Australian sample norms. In addition, none of the studies indicated the use of a power calculation to ensure that their study was adequately powered for their chosen analysis, which may have resulted in Type II errors being made.

Four studies recruited a sample which may not have been representative of the complete head injury population, the reasons for this varied, and included:

recruitment only from a rehabilitation unit or charity in which participants were already seeking support [5, 22]; not reporting the reasons or characteristics of participants lost to follow-up [7, 22]; and variability in the length of time different participants were followed-up [20, 22].

Comparison with Previous Review

Ennis, et al. [16] found that 15/16 studies in their review reported clinically significant anxiety and depression in carers compared to the general adult population. Although the current review also identified evidence of anxiety and depression symptoms in carers, only 4/7 studies reported symptoms greater than the general population norms, and 1/7 identified a proportion of their sample as having clinically significant symptoms. This suggests a difference in the findings of studies whose head injury sample sustained a severe head injury, compared to studies with a broader head injury severity range.

Both the current review and that conducted by Ennis, et al. [16] identified that the quality of studies was adversely affected by methodological discrepancies. This included lack of: clarity as to whether the studies samples were representative of the general head injury population; reported loss to follow-up information; and calculations of power to determine sample sizes. Also similar to this review they identified that there was lack of consistency in the self-report measures used to assess anxiety and depressive symptoms.

Limitations of Current Review

One limitation was that only studies available in English were included which may have resulted in some relevant studies being excluded. Due to the time limitations of this review it was also only possible to include studies which were published in peer-reviewed journals and therefore there may have been a subsection of unpublished material which was not included.

Further research in this area is required to understand the wide variation in the number of carers reporting anxiety and depression symptoms. To gain a better understanding of the different experiences of carers and their anxiety and

depression symptoms, further qualitative research studies would be beneficial. This research methodology would also allow for exploration of the relationship between pre-morbid, and post head injury symptoms of anxiety and depression. Research in this area would also benefit from more rigorous consideration for the research methodology, studies utilising comparable self-report measures, and participant samples from outwith Australia and New Zealand. In addition, ensuring studies are adequately powered and differentiating based on the severity of the injury would be useful in exploring further confounding variables for this population.

Conclusions

There was a large variation in the frequency of reported anxiety and depression symptoms within the included studies. Two key factors found to be associated with these symptoms were social support and neurobehavioral impairments. None of the demographic or injury characteristics explored were found to have a significant relationship with anxiety or depression symptoms. Similar study limitations were identified by this review and that conducted by Ennis, et al. [16]. Whilst they found the majority of their included studies to report significant levels of anxiety and depression symptoms in the carer populations, the current review found this to be the case in just over half the included studies. The reasons for this are unclear however, may reflect the current review only including studies where individuals had experienced a severe head injury, or the inclusion of a wider range of carer relationships. Future research may therefore focus on further clarifying differences between carers who experience anxiety and depression symptoms and those who do not, in addition to improving the research methodology in this area.

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CHAPTER 2: Major Research Project

Quality of Life in Adults with a Head Injury living in the Community:
A qualitative study

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Plain English Summary

Background: Head injury is a common cause of disability in young adults. It can affect the individual's development of independence and ability to make autonomous decisions about relationships and career choices. These important life decisions are effected by both personality and cognitive changes frequently observed following a head injury; such as, a reduction in attention span, memory and learning difficulties, and low motivation. These areas of difficulty combined with a lack of insight to deficits and adjustment difficulties often result in a significant change in lifestyle for the individual. It is therefore not surprising that those who have experienced a head injury face a poorer quality of life in comparison to the general population. Quality of life is a subjective perception of the individual based on the positive and negative experiences of their life. Poorer quality of life following head injury has been associated with a reduction in the quantity and quality of social relationships, reduced leisure activities, depressive and anxiety symptoms, and negative beliefs about what they can achieve. Although the number of published studies on quality of life after head injury has been growing, along with the development of clinical measures; research exploring quality of life from the perspective of the individual and their relatives is limited.

Aims of the Study: This study aims to explore the individuals experience and perception of their quality of life following a head injury. It also will explore the similarities and differences between individual and carer reports of quality of life.

Methods: Adults aged between 18 and 65 years who have had a severe head injury and live in the community were invited to participate in the study. In addition, a carer whom the participant knows well was also invited to participate. Potential participants were provided with an information sheet about the study and those who consented to participate in the study were interviewed about their experience of quality of life and their narratives

analysed for key themes. Four pairs of individuals (a head injured individual and their relative) agreed to participate in the study.

Main Findings & Conclusions: Overall, both the head injured individuals and their relatives reported experiencing a good quality of life. This was found to be related to their day to day functioning, their relationships with family and friends, and the process of moving on from their injury and adapting to changes in their daily functioning. Both head injured individuals and their relatives discussed similar themes relating to quality of life, and also illustrated the points they were making with similar examples and stories from their lives. People who have experienced a severe head injury are able to self-report and reflect on a range of factors relating to their quality of life. It is hoped that future research in this area will more frequently use research methods using participants' narrative accounts.

Abstract

Background & Aims: Research suggests that severe head injury can result in a poorer quality of life compared to the general population. This is attributed to a reduction in the quantity and quality of social relationships, reduced leisure activities, symptoms of depression and anxiety, and low self-efficacy. In recent years this literature has been growing and there has been a development of head injury specific, health-related quality of life outcome measures; however, qualitative research which explores the views of people with head injury and their relatives or carers is limited. This study explores the subjective experience of quality of life following head injury, and similarities and differences between self and proxy reports.

Methods: Participants included four adults with a severe head injury living in the community and a relative or carer who knows them well. Participants and their carers took part in semi-structured interviews relating to their perceptions of quality of life, and analysis was conducted using an Interpretative Phenomenological Analysis (IPA) approach.

Results & Conclusions: Overall, the head injured participants and their relatives reported having a good quality of life. The emergent themes related to this were 'daily functioning', 'relationships', and 'moving on'. Convergence was identified between self and proxy reports of quality of life. Factors found to be important in the experience of good quality of life after head injury were: a 'sense of purpose'; supportive 'relationships'; and a focus on 'moving on' from the injury. The identification of factors associated with good quality of life sets the current study apart from existing literature which has focused on factors associated with poor quality of life. The study also demonstrates that it is possible for those who have experienced a severe head injury to self-report and reflect on a range of factors relating to their quality of life.

Introduction

The Scottish Intercollegiate Guidelines Network (SIGN 110) [1] utilises a broad definition of head injury as, ‘a history of a blow to the head or with altered consciousness after a relevant injury, or with a scalp or forehead laceration’ [2]. The prevalence of head injuries is difficult to estimate as mild head injuries may not be reported to healthcare providers. Prevalence estimates of head injuries are therefore often based on attendance rates at emergency departments. In Scotland, this is estimated at around 100,000 yearly attendances [3 cited in 1]. Experiencing a head injury can have a long lasting effect on several different areas of an individual’s life and is a common cause of death and disability in young adults [4].

Quality of Life

Quality of life is a difficult concept to define as it can be viewed by individuals in diverse ways. The World Health Organization Quality of Life (WHOQOL) Group [5] defined quality of life as:

‘an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns’.
[5, p.1405]

This defines quality of life as a subjective concept, which stems from their perceptions of lived experiences. Given that following a severe head injury, the individual is likely to have experienced both physical and psychological changes in functioning it is also possible that they will experience a change in their perception of their position in life and their views on the quality of their life. Although there is vast literature on outcomes following head injury only a small proportion of this literature is focused on quality of life. Within this literature there is a general consensus that health related quality of life is significantly lower for those who have experienced a head injury [6-8].

Head Injury in Young Adults

For young adults (aged between 18 and 65 years) living with a disability following a head injury can present many challenges, as it can be a time of life when important decisions are made about relationships and career choices, in developing independence [9, 10]. ‘Physical, cognitive, emotional, and behavioural impairments’ [11, p.1167] may limit the life choices a young adult with a head injury has, and potentially may affect their perception of quality of life. Cognitive deficits following head injury have been identified as being more challenging for head injured individuals and their carers than physical deficits and emotional difficulties [12]. Such changes often include a reduction in attention span, memory and learning difficulties, and low motivation. Cognitive deficits combined with a lack of insight and difficulties adjusting to their experience of a head injury often result in a significant change in lifestyle for the individual. It has therefore been suggested that one of the goals of post injury rehabilitation should be to assess and maximise the individual’s quality of life as far as possible [10, 13, 14]. Community based rehabilitation programmes have been identified as key in the facilitation of this [15] since living within the community is likely to maximise potential opportunities for social inclusion and leisure activities.

Quality of Life after Head Injury

Severe head injury is associated with poorer family, social, work, and leisure outcomes all of which are influential factors on quality of life [10]. Both demographic and injury characteristics show weak relationships with quality of life outcomes [16, 17], whilst changes in social and sexual relationships, and leisure activities have stronger correlations [10, 13]. ‘Perceived self-efficacy for the management of cognitive symptoms’ [14, p.264] has also been recognised as influential on the individual’s experience of quality of life. This may link to findings on the importance of relationships and leisure activities, since adjusting to cognitive limitations following head injury may affect willingness to actively make changes and maintain these areas of their life. Cognitive limitations pose challenges for therapeutic work in addressing areas which may impact on the individual’s quality of life; however, with adaptations they can be effective [18].

Several studies indicate that young adults with a head injury experience symptoms of anxiety and depression several years post injury; this is hypothesised to be related to feelings of isolation [19, 20]. A recent study exploring the self-reported quality of life of individuals living within the community and nursing homes, also found a significant relationship between high depressive symptoms and lower quality of life [21]. They also found a significant relationship between low self-esteem and lower self-reported quality of life within the community sample. These studies indicate that the individual's emotional state can have a significant impact on their experience of quality of life and it has been recommended that qualitative research to further explore related psychosocial factors would be beneficial [21].

Measurement of Quality of Life after Head Injury

Although there are now several clinical outcome measures specific to the head injury population, there are few measures specific to health-related quality of life [10]. The Quality of Life after Brain Injury Questionnaire (QOLIBRI) [11] has been identified as a useful tool in measuring aspects of health-related quality of life specific to the head injury population [21, 22]. It was developed using pooled items from existing measures of quality of life in head injury and the views of members of the task force, who were all health professionals. Views of people with a head injury on what constitutes their 'quality of life' were not sought. Despite the growing literature on quality of life and head injury this has largely focused on quantitative studies with participants who receive community care packages and qualitative research with this population is very limited.

Overall, the current literature indicates that quality of life is poorer for adults with a head injury who live in the community, compared with the general population. There has however, been variability in the reported effects. This may reflect of the use proxy reports, despite the subjective nature of quality of life and uncertainty as to how well proxy and self-reported quality of life relate. One of the main reasons for the use of proxy reports, with the head injury population, is the suggestion that cognitive and communication problems may cause individuals to struggle to self-report their cognitive, behavioural, and

emotional difficulties [23]. Sbordone, Seyranian & Ruff [23] therefore suggested that proxy reporting by a significant other may be valuable when exploring these areas with individuals who have sustained a head injury. As a reflection of this, it is not uncommon for proxy reports to be obtained from carers in relation to the head injured individual's quality of life. Judd & Wilson [18] conducted a qualitative study with clinicians regarding challenges faced in the development of therapeutic relationships with head injury clients. The identified challenges included aforementioned cognitive, behavioural, and emotional difficulties. It is possible therefore, that uncertainty over the distinction between self and proxy-reports, and challenges faced in the development of a therapeutic relationship have limited the qualitative research with the head injury population. In a review of the quality of life research of approaches and findings in the head injury population, Dijkers [24] concluded that there is a need for further qualitative research in this area.

Aims

The primary aim of this study is to explore how young adults with a head injury self-report their quality of life by use of qualitative research methods. Secondly, the study will examine similarities and differences between self and proxy reported quality of life within the young adult head injury population and their relatives.

Method

Ethical Approval

Prior to the commencement of the study ethical approval was sought and obtained from the West of Scotland Research Ethics Committee 3, and Board Approval from the NHS Greater Glasgow & Clyde Health Board (Appendix 2.1).

Design

The study employed a qualitative research design, inviting adults who had a severe head injury and their relatives to participate in a semi-structured

interview. The focus of these interviews was to explore the experience of quality of life for individuals with a head injury. Interpretative Phenomenological Analysis (IPA) has been used to analyse the narratives obtained; this approach allows for the exploration of 'lived experience' without constraint from 'predefined categories' [25, p.32].

Justification of Sample Size

Within qualitative research, small sample sizes are recommended to facilitate engagement with participants and to ensure in-depth analysis of individual experiences. It has been recommended within the IPA literature that a sample size of between four and ten interviews is appropriate for this type of qualitative research [25, p.52]. It was planned that between four and six primary participants (head injured participants) would be recruited with a related secondary participant (relative/carer participants) for each. Consequently, it was planned that between eight and twelve interviews in total would be conducted.

Participants

Participants were recruited from head injury rehabilitation services and a head injury charity within the NHS Greater Glasgow & Clyde area. Staff from these services were asked to identify adults who met the study inclusion criteria, and did not conform with any of the exclusion criteria (table 2.1). Severe head injury was defined as a score of 8 or less on the Glasgow Coma Scale (GCS) following their head injury. The GCS is a widely used measure of head injury severity based on three areas of functioning: eye opening, motor response, and verbal response [26]. The primary participants were also asked to identify a relative or carer whom they believed would have some understanding of their quality of life (secondary participants). The study criterion for secondary participants is outlined in table 2.2.

Table 2.1: Primary Participant Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> – Have sustained a severe head injury. – Live within the community. – Aged between 18 and 65 years. – English as first language (to ensure interpretations of the discourse between participant and researcher are not compromised). – Able to provide informed consent. 	<ul style="list-style-type: none"> – Significant comprehension or communication difficulties that may impact on the ability to participate in the interviews. – History of severe challenging behaviour (to ensure the safety of the participant and researcher). – Current alcohol and/or drug related dependency (due to the impact this may have on their quality of life). – Unable to provide informed consent. – A related secondary participant cannot be identified.

Table 2.2: Secondary Participant Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> – A relative or carer of the primary participant believed to have a good perception of the primary participant’s quality of life. – English as first language (to ensure interpretations of the discourse between participant and researcher are not compromised). 	<ul style="list-style-type: none"> – Unable to provide informed consent.

Materials

To facilitate the flow of the interviews, a semi-structured interview schedule (Appendix 2.2) was devised based on areas of relevance from the literature relating to head injury and quality of life. In addition, two demographic information sheets were developed to gather relevant background information from the primary and secondary participants (Appendix 2.3).

Procedure

Potential primary participants who fulfilled the study criteria were approached by staff in the service they attended and provided with an information sheet for themselves and another for a relative/carer (Appendix 2.4). After having an opportunity to read the information sheet, potential primary participants were asked by the relevant care team if they would like to be contacted by the researcher to discuss the study further. Those who wished more information about the study provided the team with a contact telephone number that they were happy for the researcher to contact them on. The researcher then contacted potential primary participants via telephone to: clarify their understanding of what the study involved; answer any questions they had about the study; and further check that the primary participant met the study criteria for inclusion. For those who then wished to participate in the study a meeting was arranged at the service which they attended, with the researcher.

During this initial meeting the researcher gave the primary participants the opportunity to re-read the relevant participant information sheet, obtained written consent (Appendix 2.5), and then conducted a semi-structured interview which also included the collection of demographic information. The interviews lasted between 45 minutes and 1 hour, with no participants choosing to use the breaks that were offered to them prior to the interview. During this meeting the primary participant was provided with contact details of the researcher to give to their relative or carer, in order to arrange their interview with the researcher. The secondary participants' interview followed the same format as the primary participants. Each semi-structured interview was digitally recorded by the researcher. Interview recordings were then transferred to an encrypted laptop, transcribed, and anonymised for analysis.

Data Analysis

Interview transcripts were analysed using IPA. Through exploring the reflections of individuals who have experienced a significant life event the researcher attempts to understand and make sense of the experience for the individual [25]. The interview transcripts were systematically analysed case by case with

emergent themes being identified and connections between these explored. To ensure reliability of the themes identified by the researcher, a supervisor and colleague conducted a blind second analysis of a random selection of four of the head injured and relatives' transcripts. The supervisor is experienced in using IPA and has worked with individuals with severe head injuries. The colleague was a final year Doctorate in Clinical Psychology trainee who had experience in using IPA but had not worked with individuals with severe head injuries. They both concurred with the themes identified by the researcher. A sample of analysed transcript is presented in Appendix 2.6.

Reflexivity

An important element of IPA analysis is reflexivity which relates to 'preconceptions' brought to the analysis by the researcher from personal experiences and beliefs [27]. The researcher of the current study is a Doctorate in Clinical Psychology trainee in her final year, who has limited experience of working with adults with a severe head injury. She has experience of working with carers and family members in other contexts. She had also in the past couple of years spent some time in hospital for the treatment of a medical condition. During analysis she reflected upon the influence this may have had on the interpretation of the participants' hospital experiences.

Results

A total of four pairs of individuals (a head injured individual and their relative) agreed to participate in the study, and were interviewed. In addition to this, two primary participants who were informed about the study chose not to be contacted by the researcher, and one further primary participant was contacted by the researcher but did not meet the study criteria. Primary and secondary participant characteristics are summarised in tables 2.3 and 2.4, respectively. This information was based on information self-reported by participants.

Table 2.3: Characteristics of Primary Participants

	A1	B1	C1	D1
Gender	Male	Male	Male	Female
Age at Interview	60	47	43	29
Cause of Injury	Fall	Fall	Assault	Road Traffic Accident
Time Since Injury	7 months	6 years	11 years	12 years
Current Living Arrangements	With wife	With Partner	Alone	Alone
Current Employment Status	Self-employed	Recently employed	Unemployed	Employed
Attended Rehabilitation Following Injury	No	Yes	Yes	Yes

Table 2.4: Characteristics of Secondary Participants

	A2	B2	C2	D2
Gender	Female	Female	Male	Female
Age at Interview	59	52	68	42
Relationship to Primary Participant	Wife	Partner	Father	Cousin
Length of Time Know	5 years	15 years	Whole Life	Whole Life
Frequency of Contact	Daily	Daily	Most Days	Couple of times per week

All the participants reflected on their life's journey, or the journey of their relative, since the head injury. This narrative journey presented both current circumstances and the impact on their life immediately after the head injury. From participant narratives three super-ordinate themes were identified, with a range of sub-ordinate themes within these (table 2.5). Quotes from the participants' transcripts are used to illustrate these themes, and have been anonymised to protect participant identity.

Table 2.5: Emergent Themes

Super-ordinate Themes	Sub-ordinate Themes
1. Daily Functioning	<ul style="list-style-type: none"> – Sense of Purpose – Hobbies and Interests – Impact of Injury – Alcohol
2. Relationships	<ul style="list-style-type: none"> – Support – Challenges for family
3. Moving On	<ul style="list-style-type: none"> – Memory of the Event – Sense of Normality – Attitude to Life – Quality of Life

Theme 1 - Daily Functioning

This super-ordinate theme reflects changes after the injury and elements of day to day functioning which were discussed by participants and identified as pertinent to their quality of life. Within this theme the sub-ordinate theme of ‘sense of purpose’ was most frequently raised by the primary participants as being important to their quality of life. Other sub-ordinate themes included: hobbies and interests, impact of injury, and alcohol.

1.1. Sense of Purpose

Primary Participants: Achieving a sense of purpose again for their lives came across strongly in the narratives of all the participants. Each participant made reference to work as being a key part of this sense of purpose. For three of the primary participants their head injury had significantly altered this aspect of their life, and they found these changes challenging:

‘But [pause] quality of life was poor at that stage because I was trying to [pause]. I had, I had an attitude to try and bring myself back to what I was doing in business before that ...’

Participant A1 (P5:L43)

For the youngest participant however, this was not the case:

'And you know I'm doing teaching which is what I wanted to do [pause] so really I feel I'm very fortunate because I've led the life really that I wanted to lead, pre the accident, if you like ...'

Participant D1 (P8:L29)

One participant was unable to obtain employment at the time, of the interview, but had regained this sense of purpose through involvement with a local head injury group. He had a key role in the running of the group which restored a sense of purpose and kept him occupied. In relation to it he stated:

'... and helping the group through you, it's fantastic. It's, for me it's everything. Not to be restrictive for this group, me or any of the members of the group, so they have a decent life. That's all I want, is the whole group to have a decent life.'

Participant C1 (P23:L34)

Losing their sense of purpose, through lack of work in particular, had a negative impact on some participants' mood and developed feelings of hopelessness:

'Just getting up every morning and nothing to do, know what I mean, it was [pause] it did get a bit depressing and it sounds it and all, doesn't it [laughs].'

Participant B1 (P19:L9)

For one participant, his mood and attitude to work completely changed when he was back in employment after several years. The positive impact he feels this had upon not only his life, but also his partner's is clearly evident:

'But I think the job has been the best thing that has happened to since I banged my head basically, it really is, know what I mean. It has just changed my whole perspective on life I think basically, you know what I mean. [Pause] yea the best thing that has happened to me, probably the best thing that has happened to <partner> as well, because [pause] she can get rid of me every now and again basically, a wee bit of time to herself as well basically, you know what I mean.'

Participant B1 (P21:L3)

Linked to the theme of work, for some, was the challenge of adapting from being financially independent, to becoming more financially reliant on others. This resulted in an increased amount of worry about this aspect of their life. For the two participants who had experienced unemployment there was also a real concern about boredom, and feeling trapped within their home.

'Aye, keep [pause] consider myself like a shark, got to keep moving, a shark's got to keep moving. So will I, I've got to keep myself going forward. Because if I don't I'll get [pause] bored, stale.'

Participant C1 (P5:L8)

Sense of Purpose

Secondary Participants: The narratives of the relatives were largely in agreement with those of the head injured participants for this theme. They recognised that having a sense of purpose through work or activity was significant for their quality of life.

'Well I, I think work. Work wise, I think he has got to be happy in his work because I know he wasn't, when the accident happened he wasn't happy in his, his work. He was, he was depressed, he didn't like it at all so. But [pause] he has got this wee job so, so he is over the moon. He is quite happy, as long as he is out working and making money.'

Participant B2 (P2:L21)

And there was also the recognition by one relative of the negative impact the loss of a sense of purpose may have on him:

'... he's doing something, and that's keeping him going. And as long as he's got something to do that, I think he'll be ok but if that stops, I dread to think what would happen to <C> because it would just be like something's, well cutting off an arm, what would you do without that, he hasn't got it in anymore.'

Participant C2 (P7:L32)

Another participant recognised that it was not only the injury that had influenced her husband's reduction in workload:

'I mean he has diminished [pause] it's not just the accident, he is getting older, you know and [pause] the level of work that he was doing before the accident, I don't think he could cope with that now.'

Participant A2 (P6:L36)

1.2. Hobbies & Interests

Primary Participants: All four participants identified that they were currently involved in most of the hobbies and interests that they enjoyed pre-injury. This was one area of life that seemed largely unaffected by their head injury. One participant made reference to lifestyle changes made as a result of his injury; now spending less time focused on work and having more time to pursue hobbies and interests:

'So [pause] its, its [pause] suited us in a funny sort of way, probably things we wouldn't have done if [pause] I hadn't had the problem, we might just have worked on.'

Participant A1 (P11:L40)

There was one participant who as a result of the physical consequences of his injury was no longer able to actively participate in one of his hobbies. He managed to resolve this by returning as a teacher, which he found very rewarding. Another participant also had a strengthening in his faith and was spending a great deal more time attending church, which he felt had an extremely positive influence on his life:

'I just always feel, I feel ... I feel happier coming out basically, know what I mean, that's, that's it. Just to make me happy, I go, say a prayer, know what I mean [I: Yea]. Dead easy [laughs] wish I had done that years ago, I wouldn't be here the now [laughs].'

Participant B1 (P10:L19)

There was a general sense from participants that they appreciated time spent with family and friends more now than pre-injury, and that they pursued this more frequently.

Hobbies & Interests

Secondary Participants: Again there were similarities between the narratives of both groups of participants in relation to hobbies and interests.

The wife of the head injured participant who had made reference to a change in lifestyle and spending more time on pre-injury hobbies and interests, also made reference to this. However she also observed that there would be some hobbies that they would not be maintaining, such as skiing:

'... I would be anxious [I: Yea] him skiing because skiing [pause]. Something could happen that you have got no control over, at all, and you are down. There's quite a lot of bad accidents skiing, you know. [Pause] I would rather not. Let's just go to the sun in the winter [I: Yea, that's it], forget about the skiing.'

Participant A2 (P16:L35)

The partner of the participant who had a strengthening in his faith also recognised this and indicated that this was a significant change in comparison to before his injury.

1.3. Impact of Injury

Primary Participants: The majority of participants made reference to the impact that their injury had on both their physical and cognitive abilities; with a clear distinction being made between the accounts of their abilities in the months following their injury, and their current functioning. One participant referred to his physical recovery in hospital, in a way that really reflected the restoration of abilities as a process:

'... and they eventually got me resurrected ...'

Participant A1 (P1:L19)

It was clear that initially they were more concerned with their physical and communication abilities however, as time progressed and their physical recovery improved the focus shifted to their cognitive abilities. Only one participant talked about current physical limitations, compared to three expressing continued concern about their cognitive abilities. For the participant who had physical difficulties, there was some evidence of difficulty accepting this change in ability and striving to not let it hold him back; however it also had an impact on general health as he was restricted in the exercise that he could participate in.

'... I find walking [pause] very hard and very tiring for me to do now. But, [pause] it's just got to get done.'

Participant C1 (P8:L2)

Two participants also made reference to a significant change in their levels of fatigue and emphasised this several times during their narratives. This impacted on different aspects of their lives including work, hobbies, and activities around the home.

'All I really done was sleep most of the time, same as I am now. So I'll go home from here and I'll have to go to my bed, I'll be so, I'll be very worn out.'

Participant C1 (P2:L21)

The three participants who reflected upon their cognitive abilities all expressed concern about their current cognitive functioning particularly in relation to short term memory and word finding difficulties. One participant described it as:

'... my brain is, it functions slightly differently on some wave that I don't know.'

Participant A1 (P7:L29)

'[Pause] in the hospital all that time then when I came out, I wasn't right when I came out, but I thought I was basically, you know. See when I think back on it now [I: Yea] I just, I couldn't tell you the name of a table at certain points, and all that kinda stuff [I: Ok], I mean I still get that every now and again. I can look at something, and I just don't know the name of that now [I: Yea]. But it will come to me eventually.'

Participant B1 (P7:L16)

This caused them anxiety in daily life and hampered their perception of recovery. One participant described concerns about cognitive abilities several years after injury, with a sense that they required to seek reassurance regarding this, to allow them to move on from this preoccupation. Following an assessment he recognised that his cognitive abilities were not as bad as he perceived them to be. The three participants, who recognised that their injury had impacted upon their daily

functioning, also made reference to adaptations they had been required to make to live with these changes. In relation to this two participants discussed a need to slow down their thought processes, and take more time to think things through.

Two participants mentioned changes in their personality in the first few months following their injury. This related to being somewhat more aggressive or irritable with others:

'Really, I was very [pause] I wouldn't say aggressive but very narky. You would say something, say something nice but I wouldn't take it as the right kind of way, and bark back at, bark back at you.'

Participant C1 (P5:L14)

Impact of Injury

Secondary Participants: One relative referred to the rapidity of physical recovery and the slower pace and on-going recovery of cognitive abilities and confusion. Another relative made reference to having to wait and being patient to see what the outcome would be:

'It was just a matter for time, from then on in to see how things go, progressed for him. He didn't do bad, he still, he still forgets things [pause] or he'll come and tell me about dozen times the same story [both laugh].'

Participant C2 (P1:L20)

Relatives did not mention the on-going tiredness indicated by the head injured participants however, were aware of personality changes in the initial stages of recovery:

'He, he is quite an impulsive person and doesn't suffer fools [pause] and he can have a short temper at times. And I thought that was exacerbated after the accident, very much so. Intolerant. You know, his prejudices were more [I: Mhmm] or more enhanced [pause] after the accident. That has settled down again but certainly in the short term after it, it was really bad ...'

Participant A2 (P5:L17)

1.4. Alcohol

Primary Participants: All participants made reference to alcohol during their narrative, with some placing more emphasis on it than others. Three of the four participants said that they reduced their alcohol intake significantly after their head injury, and all made reference to a change in the way alcohol affects them since their injury. One participant acknowledged that prior to his accident he used alcohol as a way of coping with his depression but now was able to recognise that this was not helpful. He said that he continues to drink, but much less now and does so more in a social context with friends one day a week rather than as a coping mechanism:

'... I think I was just kinda blocking everything out by getting drunk.'

Participant B1 (P2:L37)

Alcohol

Secondary Participants: Three relatives also made reference to the head injured individual's alcohol intake. One relative made particular reference to this, and felt that alcohol drinking reflected a negative strategy for coping with the emotional impact of the injury:

'She had, definitely had issues with alcohol. I don't for a second think she was dependent on alcohol, I don't. I think she used it is as a [pause] a blocking out tool.'

Participant D2 (P3:L42)

Another participant highlighted the stress that his attempts to drink after the accident had on her:

'Because I was going through a bit of a nightmare, it's very stressful [I: Yea]. You know, he was just wanting to go out to the pubs all the time, and [pause] you know start, thinking he could start where he finished off, do you know but [pause] your trying to tell him, no you need to change ...'

Participant B2 (P3:L28)

Theme 2 - Relationships

The super-ordinate theme of relationships was identified in the narratives of all four participants who had sustained a head injury, and they spent a considerable

amount of time focusing on this theme. Relationships with both family and friends were something identified by the majority of participants as an important factor in their quality of life. This theme indicated that the head injured participants were insightful to the impact of their injury on their family as well as themselves. Within the theme of relationships, two sub-ordinate themes emerged: support, and challenges for family.

2.1. Support

Primary Participants: There was a strong sense from all the participants that the support that they received from family and friends was of great importance and that they had a greater appreciation of these relationships post injury. For one participant there was acknowledgement that friends were very supportive however, they also recognised that their friends' lives were continuing:

'... obviously you don't expect them to stop because I've stopped.'

Participant D1 (P7:L1)

One participant indicated that there were friends in his life whom he would have expected to have been supportive who were not. This was difficult for him to understand; however, he did not dwell upon these friendships and focused more on those who were supportive. All participants also made reference to the support that they had received from the person they had asked to participate in this study.

Every participant also commented on the professional support that they had received, particularly from community head injury teams. They also greatly appreciated the community support networks, particularly those who felt that the follow up care after leaving hospital was not present.

Support

Secondary Participants: All of the secondary participants also indicated how important the support of family and friends was for their relative. Some were also able to recognise improvements in these relationships:

'[Pause], I think he has become a lot closer to his family as well, you know. Because of it.'

Participant B2 (P5:L35)

One relative also recognised the negative impact that the injury may have had on some of the head injured individual's relationships with family and friends. This linked to the theme of alcohol as she attributed the affect alcohol had on their behaviour post injury to cause embarrassment for others resulting in them not having as close a relationship as they might have had.

2.2. Stress for Family

Primary Participants: The head injured individuals' recognised the challenges and stress that their injury placed upon their close relatives, particularly in the acute phase of their injury. For some this was related to the changes that they witnessed in them, as well as the emotional impact:

'Her emotions have been changed to [pause] be nice to people and say, 'blah blah blah' but not be emotionally distracted to them anymore because she has done all that with me. She was very very distracted with me. She spoke to my lawyer, and accountant, and business people and they all came up to see me as well. And said [pause] she was very very upset because she thought I was, she didn't she thought I could have died ...'

Participant A1 (P12:L12)

Stress for Family

Secondary Participants: One participant noted the challenge of uncertainty with their relative being in hospital and medical staff being unable to provide any certainty with regard to their recovery, and experiencing feelings of hopelessness.

'And just as we got there they brought him in which was quite traumatic for me because, obviously he wasn't well at all.'

Participant A2 (P1:L23)

Another believed that the circumstances surrounding the injury were very stressful for the family, with having to deal with the grief associated with the death of a family member as well as support the head injured

participant. One participant also acknowledged how emotional it made them feel when they heard their relative talk to others about their journey since their head injury.

Theme 3 - Moving On

Within the final theme of 'moving on' four sub-ordinate themes were distinguished: memory of the event, sense of normality, attitude to life, and quality of life. Each of these sub themes reflects an aspect of the process of accepting, integrating, and continuing with their life despite the injury.

3.1. Memory of the Event

Primary Participants: All the participants identified that they had to rely on second hand information regarding the circumstances surrounding their head injury. For two of the participants not pursuing information about their injury appeared to be a way of coping to help them move on:

'You don't realise how lucky you are [I: Yea]. I think that [pause] head injury, and all that, and then [pause] a near death experience ... I didn't realise how bad it was, basically, know what I mean, it took me [pause] years to figure out. I never asked anybody, I didn't want to know.'

Participant B1 (P11:L36)

Memory of the Event

Secondary Participants: They also recognised the lack of memory of the circumstances surrounding the accident, with one relative in particular noticing the emotional impact this had:

'Yea, he can talk about it easier and he's, he's got it now in his mind. Whereas before, he kept saying, "tell me again", "tell me again", "tell me again". [I: So he was wanting you to go over, and over, and go through it with him?] Uh huh, who said what, who did what, and then because you had told him he started crying [I: Yea]. But that, I can understand that. It's understandable because he has no recollection of anything, none. He doesn't even remember than night at all, even going out.'

Participant A2 (P14:L17)

This also emphasised the importance felt about ease of talking about the event. One relative felt that the head injured participant had not fully processed what happened to him until he verbalised his story to others:

'Once he spoke about it, you could see the change the following day. He's now accepted he's got a problem, now it's up to him to sort his own problem out, and get on with, and get on with it. And that changed there, and that made a big difference to him. And I don't think if that, if he hadn't actually spoken out like that, I don't think he would be the same boy now.'

Participant C2 (P18:L43)

3.2. Sense of Normality

Primary Participants: For all participants there was a very strong sense of determination to recover and to not allow their life to be restricted by the head injury. There were frequent references in several narratives to 'moving on' from their injury, and 'getting on with life'.

'So the way I kind of looked at it was, "right. That's happened but [pause] I'm, I'm still here. I've still got to get on with it". And that was like the attitude I took really, towards everything and just basically got on with it ...'

Participant D1 (P5:L42)

One participant referred to this determination as:

'I've got the drive, [pause] I've got a sixth gear if you want. It keeps me going, won't stop until I [pause] until I have to stop.'

Participant C1 (P8:L8)

3.3. Attitude to Life

Primary Participants: Overall there was the sense from participants that they felt very fortunate to be in the situation they are in today, after having sustained a head injury:

'But luckily I was alright, and I was able to sort of just keep going, and forge on. And you know with all [pause] like my faculties and all that [I: Yea], I'm I'm fine, you know so it's not like I need any help, with like walking or anything like that. So, I was pretty, pretty lucky touch wood, you know, all round.'

Participant D1 (P8:L16)

'The thing is life never goes in one straight direction, it always goes off in off shoots, off cuts. So, mine's gone off in a strange off cut.'

Participant C1 (P11:L2)

'[Pause] my attitude to life has changed, it is quite mild. I just, I just know that I'm not trying to be some [pause] soldier of recovery, I'm just getting through life the way it comes to me and deal with it, that's all ...'

Participant A1 (P18:L12)

There was also the sense that for some, there was no point dwelling on what might have been, their attitude was to focus on where they are at the present time, and to be non-judgemental.

3.4. Quality of Life

Primary Participants: Overall, all the participants were positive about their quality of life. They recognised that this has not always been the case since the head injury due to the many challenges they had faced. However, at the present time they were feeling:

'[Pause] life is maybe not as bad as you think and it is, my quality of life is probably better now and [pause] better in a sense of [pause] my managing the quality of life, I can only manage things to suit myself, I can't manage my life to be better than I want it to be, it will be [pause] be what it is and I manage that and I keep quiet and I keep relaxed about that. That's probably, I'm more relaxed probably.'

Participant A1 (P17:L43)

'It has improved, it definitely improved. Now I'm working again, and all that, I'm a happier person [I: Yea]. You know, I really am, you know what I mean. I realise, I kinda look at things in a different, in a kinda [pause] every day is a kinda I'm still here basically, know what I mean.'

Participant B1 (P23:L21)

'It's great. When it's good it's fantastic, when it's bad it's "ach well" it's better tomorrow.'

Participant C1 (P22:L17)

'Aye, it's good. Yea, uh huh. There's, like a say, there's nothing that I can't do.'

Participant D1 (P16:L2)

Discussion

The aim of this study is to explore the subjective experience of quality of life following a severe head injury, and to compare self and proxy narratives. In the participants' narratives three super-ordinate themes emerged through their account of quality of life: 'daily functioning', 'relationships', and 'moving on'. Both groups of participants made explicit links between quality of life and their daily functioning, and relationships. In particular this focused on the importance of having a 'sense of purpose', involvement in 'hobbies and interests', and the recognition of 'support' from their family and friends. There was an overall sense from both the head injured individuals, and their relatives, that their current quality of life was good. This was something that had not been stable since their injury as most participants recognised times when their outlook on quality of life would not have been as positive.

This positive perception is in contrast to some of the existing quantitative literature on quality of life following head injury [7, 8]. Brown & Vandergoot [6] reported that more severe head injury was associated with poorer quality of life however, quality of life may be better for those who do not 'contrast between their "old" and "new" lives' [6, p.20]. This was reflected in the current study in the narratives relating to 'moving on' which suggests that this was an important factor in their experience of good quality of life. The reported variations over time in current participants felt quality of life, particularly early post-injury, related to the emotional impact of their injury and constraints on their independence. This is consistent with factors found to be associated with experienced quality of life in quantitative studies which included: the experience of symptoms of depression, and loss of physical and social independence [7, 13].

There is limited qualitative research in this area for direct comparison however, in their qualitative study of outcomes following head injury Morris, et al. [28] reported negative reactions of others and loss of a sense of self as two of the outcomes following head injury. In comparison, the present study's participants reported positive support from friends and family, and were able to maintain their sense of self by making adaptations in their life, and sustaining a positive attitude. The narratives did not only focus on themselves; each head injured participant also reflected on the impact and challenges faced by their family as a result of the accident. Recognising this helped them to appreciate the support they received and a greater value was placed on these relationships within their lives. The difference in findings may be reflective of Morris, et al.'s [28] sample having higher levels of disability following their head injury, and their sample including both individuals who had a head injury resulting from an external trauma source and also health conditions, such as stroke. In particular, they reported themes relating to changes in physical appearance, with a sense of loss, and negative reactions of others related to this which was not present for the current sample.

Existing quantitative literature suggests that poorer quality of life after a head injury is related to lifestyle changes and in particular social and leisure changes [10, 13]. The majority of participants in the current study viewed their lifestyle changes as a positive influence. This related to a change in their attitude towards life which aided them in 'moving on' from the head injury. For the most part, participants' social and leisure activities had not significantly changed following their injury and this may in part reflect their reported positive quality of life. The theme of 'sense of purpose' was something which every participant indicated as being closely related to their quality of life. When this was lost or altered following the head injury it resulted in a period of time where they saw their quality of life to be poorer. O'Neill, et al. [29] reported a similar finding where employment following head injury improved overall well-being. However, the narratives of participants in the present study indicated that having a sense of purpose through activities which were not paid employment also had a positive influence on quality of life. Tiredness was a

feature brought out under the theme 'impact of injury'. Fatigue has been shown to have a negative impact on reported quality of life [30]. They hypothesised that this was due to the impact that fatigue had on the quality of activities as they did not find those who were fatigued to be less active. Although one participant in this study reported elevated levels of fatigue since their injury, this did not seem to affect their overall perception of quality of life. Anxiety and depressive symptoms have also been found to be associated with a poorer quality of life [19, 29]. Participants reflected upon times when they had experienced such symptoms but, were not experiencing them at the time of the interviews. It is therefore not possible to conclude whether such symptoms would have impact on their overall rating of quality of life.

Both cognitive and communication difficulties have been identified as potential barriers to the head injured individual's ability to self-report [23]. This was not found in the present study. Despite the majority of participants making reference to and displaying cognitive difficulties in their narratives, they were able to give a good account of the negative impact of their injury on their daily functioning and of the adaptations they have had to make. Some of the head injured participants demonstrated insight into personality and emotional changes they had experienced. Self and proxy narratives largely raised the same themes in relation to quality of life and often made reference to the same stories and examples, to illustrate points being made. There was only one relative who more explicitly and frequently raised one theme in comparison to their head injured relative and this was related to 'alcohol'. The head injured individual and their relative identified the use of alcohol as a coping mechanism however, the head injured participant did not specifically identify the negative consequences of this behaviour, in contrast their relative did.

Strengths and Limitations

It would appear that the sample is largely representative of the severe head injury population. The majority of head injured participants were male and the majority of relatives were female, and the cause of injury reflected the reported three largest causes of injury: road traffic accidents, falls, and assault

[31]. A further strength of the current study is that it demonstrates the feasibility of conducting qualitative research in a head injured sample, and the ability to obtain clear narratives from this.

One of the limitations of the study is that all of the head injured participants were relatively high functioning, which may not be reflective of all of those living in the community with a head injury. It is also possible that those who chose to participate in the study may have different experiences and perceptions of quality of life, from those who chose not to participate. Reasons were not sought from those who chose not to participate and it is not possible to explore this further. Another potential limitation is that the head injured participants chose the relative they wished to contribute to the study which may potentially have introduced bias in the relative sample. However, the sample may have been more biased if the researcher had selected the relative since they may have selected a relative who did not know the head injured participant as well.

Clinical Implications and Future Research

It is hoped that the narratives from this study will raise awareness of areas to explore in discussions between clinicians and patients and their families. In particular, an understanding of whether they have a 'sense of purpose' through work or activity, and awareness of their support networks are likely to be important areas where quality of life may be improved. The ability of the head injured participants to self-report a range of both positive and negative factors impacting upon their quality of life, and the rich narratives which they provided demonstrates that qualitative methodology is a viable method for studies on a severely head injured population. Future research in key areas such as quality of life would benefit from further qualitative research, given the limited research evidence available currently. Specifically, further quality of life research may wish to: use a less high functioning group to explore their subjective quality of life, and compare the narratives of those with different injury severity.

Conclusions

This study found that following a severe head injury, individuals can experience good quality of life. The important factors identified for this are being able to adapt and manage daily functioning with a 'sense of purpose', supportive 'relationships', and a focus on 'moving on' from the injury. These findings support some of the existing quantitative research which has focused on factors which negatively impact on quality of life rather than the positive impact. The identification of factors associated with good quality of life sets it apart from existing literature which has tended to focus on factors which have a negative impact. This study has also shown the feasibility of conducting qualitative research with a head injury population, and convergence of quality of life themes between self and proxy reports. Thus indicating that head injured individuals are able to constructively reflect on their experiences despite cognitive difficulties.

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CHAPTER 3: Advanced Clinical Practice 1 - Reflective Critical Account

Multi-Disciplinary Team Working: A fragmented or collaborative
process?

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Abstract

Introduction: Clinical Psychologists have a specific skill set that can be valuable for multi-disciplinary team functioning if utilised effectively. However, pressures of workload and team dynamics may mean that such skills are not always utilised effectively. This reflective account aims to reflect upon my experiences of working in different multi-disciplinary teams during my Doctorate in Clinical Psychology training, and in particular working within an inpatient multi-disciplinary team.

Reflection: To structure and inform my reflection I drew upon Gibbs' (1988) model of reflection and Driscoll's 'What? Model of Structured Reflection' (2000). Prior to starting my placement at the inpatient unit I felt confident about working within a multi-disciplinary team, and with my role as Trainee Clinical Psychologist within teams. However, in the inpatient team I quickly became confused as to what my role was which initially felt quite deskilling. Although I felt I was part of a multi-disciplinary team with professionals working collaboratively, my lack of clarity around other professionals' roles and limited direct clinical work made the assessment process feel fragmented.

Reflective Review: Writing the reflective account was a useful learning experience and helped me to reflect upon the variety of multi-disciplinary teams in which I have worked, and the positive and negative elements of these. In my future professional development I hope to have the opportunity to work in a multi-disciplinary team where I can be involved in reflective practice discussions. I believe that such discussion enhances awareness of your clinical practice and can help build integrated team working.

CHAPTER 4: Advanced Clinical Practice 2 - Reflective Critical Account

Developing Training and Consultancy Competencies: A move away
from the evaluated mind-set

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Abstract

Introduction: The role of the Clinical Psychologist has developed beyond direct clinical work to encompass indirect clinical work including: teaching and training, consultancy, and supervision. This wider role has allowed for the development of psychologically informed skills and knowledge by other professionals. Opportunities for me to develop these indirect clinical skills have increased over the course of my Doctorate in Clinical Psychology training. Within this reflective account I plan to reflect on this skills development, particularly focusing on my competency in delivering consultation.

Reflection: I drew upon both Atkins & Murphy's (1994) cycle of reflection, and Driscoll's 'What? Model of Structured Reflection' (2000) to structure and inform my reflections. I was aware that as I progressed to third year training placements that training and consultancy would be a larger component of specialist service work. However, it was still initially a daunting prospect to lead a consultation. This initially led me to question my clinical competency in this area. Through reflection I appreciated that these emotions were reflective of a new learning experience rather than an all-encompassing lack of competency on my part. Overall, I found consultation to be a rewarding experiencing and recognise the need to move away from the mind-set that everyone is looking to evaluate your clinical skills. Which I feel is a by-product of clinical training.

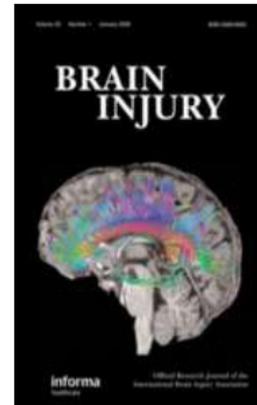
Reflective Review: Reflecting upon my competency development in different areas across clinical training has highlighted to me the competencies post-training I may benefit from developing further. In particular I hope that I have the opportunity to further develop my skills in the more indirect work undertaken by Clinical Psychologists.

Systematic Review Appendices (Chapter 1)

Appendix 1.1 - Manuscript Preparation Guidelines for the journal - Brain Injury

Brain Injury Instructions for Authors

Brain Injury publishes critical information relating to research and clinical practice, adult and pediatric populations. The Journal covers a full range of relevant topics relating to clinical, translational, and basic science research. Manuscripts address emergency and acute medical care, acute and post-acute rehabilitation, family and vocational issues, and long-term supports. Coverage includes assessment and interventions for functional, communication, neurological, and psychological disorders.



Manuscript Preparation

Authors should prepare and upload two versions of their manuscript. One should be a complete text, while in the second all document information identifying the author(s) should be removed from files to allow them to be sent anonymously to referees. When uploading files authors will then be able to define the non-anonymous version as "File not for review".

Brain Injury considers all manuscripts at the Editors' discretion; the Editors' decision is final.

Brain Injury considers all manuscripts on the strict condition that they are the property (copyright) of the submitting author(s), have been submitted only to *Brain Injury*, that they have not been published already, nor are they under consideration for publication, nor in press elsewhere. Authors who fail to adhere to this condition will be charged all costs which *Brain Injury* incurs, and their papers will not be published. Copyright will be transferred to the journal *Brain Injury* and Informa UK Ltd., if the paper is accepted.

General Guidelines

Please write clearly and concisely, stating your objectives clearly and defining your terms. Your arguments should be substantiated with well reasoned supporting evidence.

In writing your paper, you are encouraged to review articles in the area you are addressing which have been previously published in the Journal, and where you feel appropriate, to reference them. This will enhance context, coherence, and continuity for our readers.

For all manuscripts, gender-, race-, and creed-inclusive language is mandatory.

Use person-first language throughout the manuscript (i.e., persons with brain injury rather than brain injured persons).

Ethics of Experimentation: Contributors are required to follow the procedures in force in their countries which govern the ethics of work done with human subjects. The Code of Ethics of the World Medical Association ([Declaration of Helsinki](#)) represents a minimal requirement.

Abstracts are required for all papers submitted, they should not exceed 200 words and should precede the text of a paper. [See below](#) for further information.

Authors should include telephone and fax numbers as well as e-mail addresses on the cover page of manuscripts.

File preparation and types

Manuscripts are preferred in Microsoft Word format (.doc files). Documents must be double-spaced, with margins of one inch on all sides. Tables and figures should not appear in the main text, but should be uploaded as separate files and designated with the appropriate file type upon submission. References should be given in Council of Science Editors (CSE) Citation & Sequence format (see [References](#) section for examples).

Manuscripts should be compiled in the following order: title page; abstract; main text; acknowledgments; Declaration of Interest statement; appendices (as appropriate); references; tables with captions (on separate pages); figures; figure captions (as a list).

Title Page

A title page should be provided comprising the manuscript title plus the full names and affiliations of all authors involved in the preparation of the manuscript. One author should be clearly designated as the corresponding author and full contact information, including phone number and email address, provided for this person. Keywords that are not in the title should also be included on the title page. The keywords will assist indexers in cross indexing your article. The title page should be uploaded separately to the main manuscript and designated as "title page – not for review" on ScholarOne Manuscripts.

Abstract

Structured abstracts are required for all papers, and should be submitted as detailed below, following the title and author's name and address, preceding the main text.

For papers reporting original research, state the primary objective and any hypothesis tested; describe the research design and your reasons for adopting that methodology; state the methods and procedures employed, including where appropriate tools, hardware, software, the selection and number of study areas/subjects, and the central experimental interventions; state the main outcomes and results, including relevant data; and state the conclusions that might be drawn from these data and results, including their implications for further research or application/practice.

For review essays, state the primary objective of the review; the reasoning behind your literature selection; and the way you critically analyse the literature; state the main outcomes and results of your review; and state the conclusions that might be drawn, including their implications for further research or application/practice.

The abstract should not exceed 200 words.

Tables, figures and illustrations

The same data should not be reproduced in both tables and figures. The usual statistical conventions should be used: a value written 10.0 ± 0.25 indicates the estimate for a statistic (e.g. a mean) followed by its standard error. A mean with an estimate of the standard deviation will be written $10.0 \text{ SD } 2.65$. Contributors reporting ages of subjects should specify carefully the age groupings: a group of children of ages e.g. 4.0 to 4.99 years may be designated 4 +; a group aged 3.50 to 4.49 years $4 \pm$ and a group all precisely 4.0 years, 4.0.

Tables and figures should be referred to in text as follows: figure 1, table 1, i.e. lower case. 'As seen in table [or figure] 1 ...' (not Tab., fig. or Fig).

The place at which a table or figure is to be inserted in the printed text should be indicated clearly on a manuscript:

Insert table 2 about here

Each table and/or figure must have a title that explains its purpose without reference to the text. Tables and/or figure captions must be saved separately, as part of the file containing the complete text of the paper, and numbered correspondingly. The filename for the tables and/or figures should be descriptive of the graphic, e.g. table 1, figure 2a.

Tables

Tables should be used only when they can present information more efficiently than running text. Care should be taken to avoid any arrangement that unduly increases the depth of a table, and the column heads should be made as brief as possible, using abbreviations liberally. Lines of data should not be numbered nor run numbers given unless those numbers are needed for reference in the text. Columns should not contain only one or two entries, nor should the same entry be repeated numerous times consecutively. Tables should be grouped at the end of the manuscript on uploaded separately to the main body of the text.

Figures and illustrations

Figures must be uploaded separately and not embedded in the text. Avoid the use of colour and tints for purely aesthetic reasons. Figures should be produced as near to the finished size as possible. Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC). All files must be 300 dpi or higher.

Please note that it is in the author's interest to provide the highest quality figure format possible. Please do not hesitate to contact our Production Department if you have any queries.

Letters to the Editor

Letters to the Editor will be considered for publication subject to editor approval and provided that they either relate to content previously published in the Journal or address any item that is felt to be of interest to the readership. Letters relating to articles previously published in the Journal should be received no more than three months after publication of the original work. Pending editor approval, letters may be submitted to the author of the original paper in order that a reply be published simultaneously.

Letters to the Editor can be signed by a maximum of three authors, should be between 750 and 1,250 words, may contain one table/figure and may cite a maximum of five references. All Letters should be submitted via ScholarOne Manuscripts and should contain a Declaration of Interest statement.

Notes on Style

All authors are asked to take account of the diverse audience of *Brain Injury*. Clearly explain or avoid the use of terms that might be meaningful only to a local or national audience.

Some specific points of style for the text of original papers, reviews, and case studies follow:

- *Brain Injury* prefers US to 'American', USA to 'United States', and UK to 'United Kingdom'.
- *Brain Injury* uses conservative British, not US, spelling, i.e. colour not color; behaviour (behavioural) not behavior; [school] programme not program; [he] practises not practices; centre not center; organization not organisation; analyse not analyze, etc.
- Single 'quotes' are used for quotations rather than double "quotes", unless the 'quote is "within" another quote'.

- Punctuation should follow the British style, e.g. 'quotes precede punctuation'.
- Punctuation of common abbreviations should follow the following conventions: e.g. i.e. cf. Note that such abbreviations are not followed by a comma or a (double) point/period.
- Dashes (M-dash) should be clearly indicated in manuscripts by way of either a clear dash (-) or a double hyphen (- -).
- **Brain Injury** is sparing in its use of the upper case in headings and references, e.g. only the first word in paper titles and all subheads is in upper case; titles of papers from journals in the references and other places are not in upper case.
- Apostrophes should be used sparingly. Thus, decades should be referred to as follows: 'The 1980s [not the 1980's] saw ...'. Possessives associated with acronyms (e.g. APU), should be written as follows: 'The APU's findings that ...', but, NB, the plural is APUs.
- All acronyms for national agencies, examinations, etc., should be spelled out the first time they are introduced in text or references. Thereafter the acronym can be used if appropriate, e.g. 'The work of the Assessment of Performance Unit (APU) in the early 1980s ...'. Subsequently, 'The APU studies of achievement ...', in a reference ... (Department of Education and Science [DES] 1989a).
- Brief biographical details of significant national figures should be outlined in the text unless it is quite clear that the person concerned would be known internationally. Some suggested editorial emendations to a typical text are indicated in the following with square brackets: 'From the time of H. E. Armstrong [in the 19th century] to the curriculum development work associated with the Nuffield Foundation [in the 1960s], there has been a shift from heurism to constructivism in the design of [British] science courses'.
- The preferred local (national) usage for ethnic and other minorities should be used in all papers. For the USA, African-American, Hispanic, and Native American are used, e.g. 'The African American presidential candidate, Jesse Jackson...' For the UK, African-Caribbean (not 'West Indian'), etc.
- Material to be emphasized (italicized in the printed version) should be underlined in the typescript rather than italicized. Please use such emphasis sparingly.
- n (not N), % (not per cent) should be used in typescripts.
- Numbers in text should take the following forms: 300, 3000, 30 000. Spell out numbers under 10 unless used with a unit of measure, e.g. nine pupils but 9 mm (do not introduce periods with measure). For decimals, use the form 0.05 (not .05).

Acknowledgments and Declaration of Interest sections

Acknowledgments and Declaration of interest sections are different, and each has a specific purpose. The Acknowledgments section details special thanks, personal assistance, and dedications. Contributions from individuals who do not qualify for authorship should also be acknowledged here. Declarations of interest, however, refer to statements of financial support and/or statements of potential conflict of interest. Within this section also belongs disclosure of scientific writing assistance (use of an agency or agency/ freelance writer), grant support and numbers, and statements of employment, if applicable.

Acknowledgments section

Any acknowledgments authors wish to make should be included in a separate headed section at the end of the manuscript preceding any appendices, and before the references section. Please do not incorporate acknowledgments into notes or biographical notes.

Declaration of Interest section

All declarations of interest must be outlined under the subheading "Declaration of interest". If authors have no declarations of interest to report, this must be explicitly stated. The suggested, but not mandatory, wording in such an instance is: *The authors report no declarations of interest.* When

submitting a paper via ScholarOne Manuscripts, the “Declaration of interest” field is compulsory (authors must either state the disclosures or report that there are none). If this section is left empty authors will not be able to progress with the submission.

Please note: for NIH/Wellcome-funded papers, the grant number(s) must be included in the Declaration of Interest statement.

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Mathematics

Click for more information on the [presentation of mathematical text](#).

References

References should follow the Council of Science Editors (CSE) Citation & Sequence format. Only works actually cited in the text should be included in the references. Indicate in the text with Arabic numbers inside square brackets. Spelling in the reference list should follow the original. References should then be listed in numerical order at the end of the article. Further examples and information can be found in The CSE Manual for Authors, Editors, and Publishers, Seventh Edition. Periodical abbreviations should follow the style given by Index Medicus.

Examples are provided as follows:

Journal article: [1] Steiner U, Klein J, Eiser E, Budkowski A, Fetters LJ. Complete wetting from polymer mixtures. *Science* 1992;258:1122-9.

Book chapter: [2] Kuret JA, Murad F. Adenohypophyseal hormones and related substances. In: Gilman AG, Rall TW, Nies AS, Taylor P, editors. *The pharmacological basis of therapeutics*. 8th ed. New York: Pergamon; 1990. p 1334-60.

Conference proceedings: [3] Irvin AD, Cunningham MP, Young AS, editors. *Advances in the control of Theileriosis*. International Conference held at the International Laboratory for Research on Animal Diseases; 1981 Feb 9-13; Nairobi. Boston: Martinus Nijhoff Publishers; 1981. 427 p.

Dissertations or Thesis: [4] Mangie ED. *A comparative study of the perceptions of illness in New Kingdom Egypt and Mesopotamia of the early first millennium* [dissertation]. Akron (OH): University of Akron; 1991. 160 p. Available from: University Microfilms, Ann Arbor MI; AAG9203425.

Journal article on internet: [5] De Guise E, Leblanc J, Dagher J, Lamoureux J, Jishi A, Maleki M, Marcoux J, Feyz M. 2009. Early outcome in patients with traumatic brain injury, pre-injury alcohol abuse and intoxication at time of injury. *Brain Injury* 23(11):853-865. <http://www.informaworld.com/10.1080/02699050903283221>. Accessed 2009 Oct 06

Webpage: [6] *British Medical Journal* [Internet]. Stanford, CA: Stanford Univ; 2004 July 10 - [cited 2004 Aug 12]; Available from: <http://bmj.bmjournals.com>

Internet databases: [7] *Prevention News Update Database* [Internet]. Rockville (MD): Centers for Disease Control and Prevention (US), National Prevention Information Network. 1988 Jun - [cited 2001 Apr 12]. Available from: <http://www.cdcnpi.org/>

Appendix 1.2 - Quality Rating Criteria (modified Downs & Black checklist, 1998)

ALL CRITERIA	DESCRIPTION OF CRITERIA (with additional explanation as required, determined by consensus of raters)	POSSIBLE ANSWERS
1	Is the hypothesis/aim/objective of the study clearly described? Must be explicit	Yes/No
2	Are the main outcomes to be measured clearly described in the Introduction or Methods section? If the main outcomes are first mentioned in the Results section, the question should be answered no. ALL primary outcomes should be described for YES	Yes/No
3	Are the characteristics of the patients included in the study clearly described? In cohort studies and trials, inclusion and/or exclusion criteria should be given. In case-control studies, a case-definition and the source for controls should be given. Single case studies must state source of patient	Yes/No
4	Are the interventions of interest clearly described? Treatments and placebo (where relevant) that are to be compared should be clearly described.	Yes/No
5	Are the distributions of principal confounders in each group of subjects to be compared clearly described? A list of principal confounders is provided. YES = age, severity	Yes/No
6	Are the main findings of the study clearly described? Simple outcome data (including denominators and numerators) should be reported for all major findings so that the reader can check the major analyses and conclusions.	Yes/No
7	Does the study provide estimates of the random variability in the data for the main outcomes? In non normally distributed data the inter-quartile range of results should be reported. In normally distributed data the standard error, standard deviation or confidence intervals should be reported	Yes/No
8	Have all important adverse events that may be a consequence of the intervention been reported? This should be answered yes if the study demonstrates that there was a comprehensive attempt to measure adverse events (COMPLICATIONS BUT NOT AN INCREASE IN PAIN).	Yes/No
9	Have the characteristics of patients lost to follow-up been described? If not explicit = NO. RETROSPECTIVE – if not described = UTD; if not explicit re: numbers agreeing to participate = NO. Needs to be >85%	Yes/No
10	Have actual probability values been reported (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?	Yes/No
11	Were the subjects asked to participate in the study representative of the entire population from which they were recruited? The study must identify the source population for patients and describe how the patients were selected.	Yes/No/UTD
12	Were those subjects who were prepared to participate representative of the entire population from which they were recruited? The proportion of those asked who agreed should be stated.	Yes/No/UTD
13	Were the staff, places, and facilities where the patients were treated, representative of the treatment the majority of patients receive? For the question to be answered yes the study should demonstrate that the intervention was representative of that in use in the source population. Must state type of hospital and country for YES.	Yes/No/UTD
14	Was an attempt made to blind study subjects to the intervention they have received? For studies where the patients would have no way of knowing which intervention they received, this should be answered yes. Retrospective, single group = NO; UTD if > 1 group and blinding not explicitly stated	Yes/No/UTD
15	Was an attempt made to blind those measuring the main outcomes of the intervention? Must be explicit	Yes/No/UTD
16	If any of the results of the study were based on "data dredging", was this made clear? Any analyses that had not been planned at the outset of the study should be clearly indicated. Retrospective = NO. Prospective = YES	Yes/No/UTD
17	In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls? Where follow-up was the same for all study patients the answer should yes. Studies where differences in follow-up are ignored should be answered no. Acceptable range 1 yr follow up = 1 month each way; 2 years follow up = 2 months; 3 years follow up = 3months.....10years follow up = 10 months	Yes/No/UTD
18	Were the statistical tests used to assess the main outcomes appropriate? The statistical techniques used must be appropriate to the data. If no tests done, but would have been appropriate to do = NO	Yes/No/UTD
19	Was compliance with the intervention/s reliable? Where there was non compliance with the allocated treatment or where there was contamination of one group, the question should be answered no. Surgical studies will be YES unless procedure not completed.	Yes/No/UTD
20	Were the main outcome measures used accurate (valid and reliable)? Where outcome measures are clearly	Yes/No/UTD

	described, which refer to other work or that demonstrates the outcome measures are accurate = YES. ALL primary outcomes valid and reliable for YES	
21	Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population? Patients for all comparison groups should be selected from the same hospital. The question should be answered UTD for cohort and case control studies where there is no information concerning the source of patients	Yes/No/UTD
22	Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same time? For a study which does not specify the time period over which patients were recruited, the question should be answered as UTD. Surgical studies must be <10 years for YES, if >10 years then NO	Yes/No/UTD
23	Were study subjects randomised to intervention groups? Studies which state that subjects were randomised should be answered yes except where method of randomisation would not ensure random allocation.	Yes/No/UTD
24	Was the randomised intervention assignment concealed from both patients and health care staff until recruitment was complete and irrevocable? All non-randomised studies should be answered no. If assignment was concealed from patients but not from staff, it should be answered no.	Yes/No/UTD
25	Was there adequate adjustment for confounding in the analyses from which the main findings were drawn? In nonrandomised studies if the effect of the main confounders was not investigated or no adjustment was made in the final analyses the question should be answered as no. If no significant difference between groups shown then YES	Yes/No/UTD
26	Were losses of patients to follow-up taken into account? If the numbers of patients lost to follow-up are not reported = unable to determine.	Yes/No/UTD
27	Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance <5% Sample sizes have been calculated to detect a difference of x% and y%.	1-5

Major Research Project Appendices (Chapter 2)

Appendix 2.1 - Ethical Approval Letters

WoSRES
West of Scotland Research Ethics Service



West of Scotland REC 3
Ground Floor – The Tennent Institute
Western Infirmary
38 Church Street
Glasgow G11 6NT
www.nhs.gov.uk

Professor Thomas McMillan
Professor of Clinical Neuropsychology
University of Glasgow
Institute of Health & Wellbeing
1st Floor Administration Building
Gartnavel Royal Hospital,
1055 Great Western Road
Glasgow G12 0XH

Date 8th March 2013
Your Ref
Our Ref
Direct line 0141 211 2123
Fax 0141 211 1847
E-mail Liz.Jamieson@ggc.scot.nhs.uk

Dear Professor McMillan

Study title: Quality of Life in Adults with a Head Injury living in the Community: A Qualitative Study
REC reference: 13/WS/0046
Protocol number: GN13CP069
IRAS project ID: 124326

The Research Ethics Committee reviewed the above application at the meeting held on 28 February 2013. Thank you and Miss Jemma Walker for attending to discuss the application.

We plan to publish your research summary wording for the above study on the NRES 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 Co-ordinator Mrs Liz Jamieson, Liz.Jamieson@ggc.scot.nhs.uk.

The following discussion took place:

- 1) The Committee had concerns about participants possibly becoming distressed and asked you to explain what arrangements were in place to deal with such distress. Miss Walker advised that she would in the first instance deal with what she could but would also involve the Carer or GP should this be necessary. She also commented that the Community Treatment Centre for Brain Injury did take direct telephone calls in an emergency.
- 2) The Committee noted that confirmation of the diagnosis was required and asked who would take responsibility for this. Miss Walker explained that the Centre staff would identify suitable participants and would also be able to confirm the diagnosis. The Relative/Carer would also be able to confirm this.
- 3) The Committee asked you to define 'secondary carer'. Miss Walker advised that this would be someone who was actively involved in the person's care. This person could also be a relative.

4) The Committee asked what arrangements were in place should there be a disclosure of any kind during the research. This refers to both the participant and carer. Miss Walker stated that she would follow NHS policy in this regard. The Committee commented that it was important should something come to light during the research that gave cause for concern then Miss Walker must be able to take appropriate prompt action. Miss Walker confirmed that she would be in a position to deal with anything like this in a sensitive manner. A statement on disclosure does however require to be in the Participant Information Sheet.

5) The Committee asked if a patient who had a history of alcohol abuse prior to the head injury would be included. Miss Walker confirmed that those who required care prior to the head injury would not be included in the study.

6) The Committee noted that the Centre Manager would identify suitable participants and wondered if this could possibly lead to selection bias. Miss Walker commented that this was possible. The Committee suggested that perhaps consideration should be given to some level of selection as this would lead to a more mixed group.

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.

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites 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).

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

OTHER CONDITIONS SPECIFIED BY THE REC

1) Participant Information Sheets for both the patient and the carer require to be amended as follows:

- At 'Do I have to take part?' the first word should be 'No'.
- A suitable disclosure statement requires to be added clearly stating that there is a duty of care to take appropriate action should something come to light that gives cause for concern. It is important that Participants and Carers are clear about this.

2) Confirmation in writing is required that should someone show any signs of distress then immediate appropriate action will be taken to ensure that this is dealt with promptly and not just left to the Carer to deal with.

3) It is suggested that consideration be given to some level of selection which would give a more mixed group.

It is 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).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Interview Schedules/Topic Guides	2	08 February 2013
Investigator CV		08 February 2013
Other: Primary Participant Demographic Information	2	07 February 2013
Other: Secondary Participant Demographic Information	2	07 February 2013
Other: Letter from University of Glasgow		08 February 2013
Other: CV - Dr Sarah Wilson		06 February 2013
Other: CV - Gemma Walker		06 February 2013
Participant Consent Form: Primary Participant	1	11 February 2013
Participant Consent Form: Secondary Participant	1	11 February 2013
Participant Information Sheet: Primary Participant	1	13 February 2013
Participant Information Sheet: Secondary Participant (Relative/Carer)	1	11 February 2013
Protocol	1	11 February 2013
REC application		12 February 2013
Summary/Synopsis	1	07 February 2013

Membership of the Committee

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

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 website.

Further information is available at National Research Ethics Service website > After Review

13/WS/0046	Please quote this number on all correspondence
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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



Liz Jamieson
Committee Co-ordinator
On behalf of Dr Adam Burnel, Chair

*Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments
"After ethical review – guidance for researchers"*

Copy to: Dr Erica Packard, NHS Greater Glasgow & Clyde, Research & Development Department

Miss Jemma Walker
Institute of Health & Wellbeing,
University of Glasgow,
1st Floor, Administration Building,
Gartnavel Royal Hospital,
1055 Great Western Road,
Glasgow

West of Scotland REC 3

Ground Floor - Tennent Building
Western Infirmary
38 Church Street
Glasgow
G11 6NT

Date 13 March 2013

Direct line 0141 211 2482
Fax 0141 211 1847
E-mail rose.gallacher@ggc.scot.nhs.uk

Dear Miss Walker

Study title: Quality of Life in Adults with a Head Injury living in the
Community: A Qualitative Study
REC reference: 13/WS/0046
Protocol number: GN13CP069
IRAS project ID: 124326

Thank you for your recent e-mail. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 08 March 2013

Documents received

The documents received were as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Participant Consent Form: Primary Participant	2	08 March 2013
Participant Consent Form: Secondary Participant	2	08 March 2013
Participant Information Sheet: Primary Participant	2	08 March 2013
Participant Information Sheet: Secondary Participant	2	08 March 2013
Protocol	2	08 March 2013

Approved documents

The final list of approved documentation for the study is therefore as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Interview Schedules/Topic Guides	2	08 February 2013
Investigator CV		08 February 2013
Other: Primary Participant Demographic Information	2	07 February 2013
Other: Secondary Participant Demographic Information	2	07 February 2013
Other: Letter from University of Glasgow		08 February 2013
Other: CV - Dr Sarah Wilson		06 February 2013
Other: CV - Gemma Walker		06 February 2013
Participant Consent Form: Primary Participant	2	08 March 2013
Participant Consent Form: Secondary Participant	2	08 March 2013
Participant Information Sheet: Primary Participant	2	08 March 2013
Participant Information Sheet: Secondary Participant	2	08 March 2013
Protocol	2	08 March 2013
REC application		12 February 2013
Summary/Synopsis	1	07 February 2013

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

13/WS/0046	Please quote this number on all correspondence
------------	--

Yours sincerely



Mrs Rose Gallacher
Committee Assistant Co-ordinator

Copy to: Professor McMillan, Erica Packard, NHS Greater Glasgow & Clyde, R&D

Coordinator/Administrator: Dr Erica Packard/Mrs Elaine O'Neill
Telephone Number: 0141 211 6208
E-Mail: erica.packard@ggc.scot.nhs.uk
Website: www.nhsggc.org.uk/r&d

9 April 2013

Miss Jemma Walker
Trainee Clinical Psychologist
Institute of Health & Wellbeing
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow G12 0XH

NHS GG&C Board Approval

Dear Miss Walker,

Study Title:	Quality of Life in Adults with a Head Injury living in the Community: A Qualitative Study
Principal Investigator:	Miss Jemma Walker
GG&C HB site	Community Treatment Centre for Brain Injury
Sponsor	NHS Greater Glasgow and Clyde
R&D reference:	GN13CP069
REC reference:	13/WS/0046
Protocol no: (including version and date)	V2; 08/03/2013

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

Conditions of Approval

1. **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
 - a. During the life span of the study GGHB requires the following information relating to this site
 - i. Notification of any potential serious breaches.
 - ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (www.nhsggc.org.uk/content/default.asp?page=s1411), evidence of such training to be filed in the site file.

2. **For all studies** the following information is required during their lifespan.
 - a. Recruitment Numbers on a monthly basis
 - b. Any change of staff named on the original SSI form
 - c. Any amendments – Substantial or Non Substantial
 - d. Notification of Trial/study end including final recruitment figures
 - e. Final Report & Copies of Publications/Abstracts
-

Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely,



Dr Erica Packard
Research Co-ordinator

Appendix 2.2 - Semi-Structured Interview Schedule



Institute of Health & Wellbeing
Administration Building, 1st Floor,
Gartnavel Royal Hospital,
1055 Great Western Road,
Glasgow, G12 0XH



Quality of Life in Adults with a Head Injury living in the Community:
A qualitative study

INTERVIEW SCHEDULE

General Introduction

The aim of the research is to find out how individuals, who have experienced a head injury, feel about their quality of life. We hope that this will identify important positive and negative factors that professionals and carers could be aware of. Our interview today will be recorded to allow me to listen to it later and identify key points that you made. I may take some quotes from our interview to include in the research paper however, all information will be anonymised. You have the right to withdraw from participation in the study, up until the research is written up in June.

If you would like to take a break at any time or feel unable to continue please let me know. If you disclose anything that gives me reason to believe you may harm yourself or others, I will have a duty to report this to your support staff and will discuss this with you before I do so. If you feel you need any additional support following the interview we would advise you to speak with a relative or carer who can help you access further support, if necessary.

[Gain verbal consent to continue with the interview]

Introduction to Interview

I am interested in finding out how you feel about your quality of life. This is something that is unique and different for everyone. It is influenced by the areas of life which are important to you. When we feel good about what is happening in these areas of our life we are more happy and satisfied, but when these areas are not going well we may feel unhappy or frustrated.

I am interested in finding out what is important in your life. We often notice what areas of our life important to us when a significant event changes them, such as experiencing a head injury. During the interview it will be helpful for you to think of important areas of your life which have changed, either positively or negatively, since your head injury. As well as, areas of your life which you value more now.

[Clarify understanding of the focus of the interview]

- * Are there areas of your life that you think are important for your current quality of life?

Exploration of Specific areas

- * What is happening in this area of your life currently?
- * How was this area of your life different before your head injury?
- * Overall how does this area of your life currently make you feel?

[If focus on only negative areas relating to quality of life, prompt for areas view as positive]

Area Prompts if Required

- * Ability to get out the house
- * Involvement in:
 - social activities
 - leisure activities within the community
 - domestic activities egg cooking
 - work/education
- * Relationships with:
 - family members
 - carers
 - friends
 - partner
- * Attitudes of others towards you
- * Perception of self
- * Opportunities for independence and freedom to make decisions
- * Impact of physical and cognitive difficulties
- * Achievements since the head injury
- * Looking forward to and hope for the future

Appendix 2.3 - Demographic Information Forms



Institute of Health & Wellbeing
Administration Building, 1st Floor,
Gartnavel Royal Hospital,
1055 Great Western Road,
Glasgow, G12 0XH



Quality of Life in Adults with a Head Injury living in the Community: A qualitative study

PRIMARY PARTICIPANT DEMOGRAPHIC INFORMATION FORM

Primary Participant ID No: _____ Current Age: _____

Sex: *Male* *Female* Written Consent Obtained:

Day Service Attending: _____

Current Living Arrangements: _____

Current Occupation/Employment Status: _____

Injury Information

Age at time of Injury: _____

Information on Severity of Head Injury: _____

Length of Time Spent in Hospital Following Head Injury: _____

Length of Time Spent in Care Home: _____

Pre-Injury Information

Living Arrangements: _____

Level of Education Obtained: _____

Occupation/Employment Status: _____



Institute of Health & Wellbeing
 Administration Building, 1st Floor,
 Gartnavel Royal Hospital,
 1055 Great Western Road,
 Glasgow, G12 0XH



**Quality of Life in Adults with a Head Injury living in the Community:
 A qualitative study**

**SECONDARY PARTICIPANT
 DEMOGRAPHIC INFORMATION FORM**

Secondary Participant ID No: _____

Corresponding Primary Participant ID No: _____

Sex: *Male* *Female*

Current Age: _____

Written Consent Obtained from Client to Interview Carer:

Relationship to Client: _____

Length of Time Known Client: _____

Frequency of Contact with Client: _____

Appendix 2.4 - Participant Information Sheets



Jemma Walker (Trainee Clinical Psychologist)
Email: j.walker.4@research.gla.ac.uk
Institute of Health & Wellbeing
Administration Building, 1st Floor,
Gartnavel Royal Hospital,
1055 Great Western Road,
Glasgow, G12 0XH



Quality of Life in Adults with a Head Injury living in the Community: A qualitative study

PARTICIPANT INFORMATION SHEET

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information, and talk to others about the study if you wish. One of the researchers can meet with you to talk about the study and answer any questions you may have.

Who is conducting the research?

The research is being carried out by Jemma Walker (Trainee Clinical Psychologist) and is being supervised by Professor Tom McMillan and Dr Sarah Wilson from the University of Glasgow.

What is the purpose of this study?

The aim of the research is to find out how individuals, who have experienced a severe head injury, feel about their quality of life. We hope that this will identify important positive and negative factors that professionals and carers could be aware of. In addition, we want to know whether a relative and a carer have similar views about quality of life as those who have experienced a head injury.

The study will be submitted as part of the main researcher's (Jemma Walker) portfolio for examination by the University of Glasgow, as part of the Doctorate in Clinical Psychology.

Why have I been invited?

We are looking for people who are aged between 18 and 65 years, who have had a severe head injury. We believe that you might fit this criteria and this is why we have invited you to take part.

Do I have to take part?

No, it is up to you to decide. If you are interested we will meet with you to describe the study, and go through the information sheet. If you agree to take part, you will be asked to sign a consent form to show you have agreed to take part in the study. You are free to withdraw from the research until the research is written up in June 2013, without giving a reason. This would not affect the standard of care you receive or your future treatment.

What does taking part involve?

If you agree to take part in the study then we will ask you to meet with one of the researchers (Jemma Walker). The study involves you talking to the interviewer about what quality of life means for you. It is anticipated that this discussion will last up to one hour, during which you can have breaks if required. The interview will be audio recorded to allow the researcher to listen to the discussion and identify key points that you made. Some quotes from your interview may be included in the research paper however, all information will be anonymised. You will also be asked to provide details of the study to a relative or carer whom you feel knows you will. The researcher will invite your relative or carer to participate in a separate discussion similar to the one you have participated in.

If you disclose anything that gives me cause for concern, such as reason to believe you may harm yourself or others, I will have a duty to report this but will discuss this with you before I do so.

What happens to the information?

Your identity and personal information will be completely confidential and known only to the researchers. The information obtained will remain confidential and stored within a locked filing cabinet. The data will be held in accordance with the Data Protection Act, which means that we keep it safely and cannot reveal it to other people, without your permission. The interview you take part in will be audio recorded to allow the researchers to listen to it later and identify key points that you made. The recordings will be destroyed at the end of the study.

What are the possible benefits of taking part?

It is hoped that by taking part in this research, you will be providing valuable information regarding both positive and negative life experiences post head injury, and how these experiences relate to quality of life.

If for any reason you experience any distress after the interview we would advise you to speak with a relative or carer who can help you access further support, if necessary.

Who has reviewed the study?

This study has been reviewed by the West of Scotland Research Ethics Committee, and the NHS Greater Glasgow & Clyde Research and Development Department.

If you have any further questions?

We will give you a copy of the information sheet and signed consent form to keep. If you would like more information about the study and wish to speak to someone **not** closely linked to the study, please contact:

Dr Sue Turnbull (Research Tutor)
Institute of Health and Wellbeing, University of Glasgow
Email: Sue.Turnbull@glasgow.ac.uk
Telephone Number: 0141 211 3920

Researcher Contact Details

Jemma Walker (Trainee Clinical Psychologist)
Email: j.walker.4@research.gla.ac.uk
Institute of Health and Wellbeing, University of Glasgow,
First Floor, Administration Building, Gartnavel Royal Hospital,
1055 Great western Road, Glasgow, G12 0XH

Professor Tom McMillan (Professor of Clinical Neuropsychology)
Email: Thomas.McMillan@glasgow.ac.uk
Telephone Number: 0141 211 3920
Institute of Health and Wellbeing, University of Glasgow,
First Floor, Administration Building, Gartnavel Royal Hospital,
1055 Great western Road, Glasgow, G12 0XH

If you have a complaint about any aspect of the study?

If you are unhappy about any aspect of the study and wish to make a complaint, please contact the researcher in the first instance but the normal NHS complaint mechanisms is also available to you.

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



Jemma Walker (Trainee Clinical Psychologist)
Email: j.walker.4@research.gla.ac.uk
Institute of Health & Wellbeing
Administration Building, 1st Floor,
Gartnavel Royal Hospital,
1055 Great Western Road,
Glasgow, G12 0XH



Quality of Life in Adults with a Head Injury living in the Community: A qualitative study

RELATIVE & CARER INFORMATION SHEET

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information, and talk to others about the study if you wish. One of the researchers can meet with you to talk about the study and answer any questions you may have.

Who is conducting the research?

The research is being carried out by Jemma Walker (Trainee Clinical Psychologist) and is being supervised by Professor Tom McMillan and Dr Sarah Wilson from the University of Glasgow.

What is the purpose of this study?

The aim of the research is to find out how individuals, who have experienced a severe head injury, feel about their quality of life. We hope that this will identify important positive and negative factors that professionals and carers could be aware of. In addition, we want to know whether a relative and a carer have similar views about quality of life as those who have experienced a head injury.

The study will be submitted as part of the main researcher's (Jemma Walker) portfolio for examination by the University of Glasgow, as part of the Doctorate in Clinical Psychology.

Why have I been invited?

Your relative or client would like to take part in the study. However, we also need a relative or carer to participate to allow for a comparison of views on their quality of life. Your relative/client has identified that they feel you know them well and would like the researcher to invite you to take part in the study.

Do I have to take part?

No, it is up to you to decide. If you are interested we will meet with you to describe the study, and go through the information sheet. If you agree to take part, you will be asked to sign a consent form to show you have agreed to take part in the study. You are free to withdraw from the research until the research is written up in June 2013, without giving a reason. This would not affect the standard of care your relative/client receives or their future treatment.

What does taking part involve?

If you agree to take part in the study then we will ask you to meet with one of the researchers (Jemma Walker). The study involves you talking to the interviewer about what you think quality of life means for your relative/client, and important factors which affect their current quality of life both positively and negatively. It is anticipated that this discussion will last up to one hour, during which you can have breaks if required. The interview will be audio recorded to allow the researcher to listen to the discussion and identify key points that you made. Some quotes from your interview may be included in the research paper however, all information will be anonymised.

If you disclose anything that gives me cause for concern, such as reason to believe you may harm yourself or others, I will have a duty to report this but will discuss this with you before I do so.

What happens to the information?

The identity and personal information of yourself and your relative/client will be completely confidential and known only to the researchers. The information obtained will remain confidential and stored within a locked filing cabinet. The data will be held in accordance with the Data Protection Act, which means that we keep it safely and cannot reveal it to other people, without your permission. The interview you take part in will be audio recorded to allow the researchers to listen to it later and identify key points that you made. The recordings will be destroyed at the end of the study.

What are the possible benefits of taking part?

It is hoped that by taking part in this research, you will be providing valuable information regarding both positive and negative life experiences post head injury, and how these experiences relate to quality of life.

Who has reviewed the study?

This study has been reviewed by the West of Scotland Research Ethics Committee, and the NHS Greater Glasgow & Clyde Research and Development Department.

If you have any further questions?

We will give you a copy of the information sheet and signed consent form to keep. If you would like more information about the study and wish to speak to someone not closely linked to the study, please contact:

Dr Sue Turnbull (Research Tutor)
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Researcher Contact Details

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If you have a complaint about any aspect of the study?

If you are unhappy about any aspect of the study and wish to make a complaint, please contact the researcher in the first instance but the normal NHS complaint mechanisms is also available to you.

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

Appendix 2.5 - Participant Consent Forms



Jemma Walker (Trainee Clinical Psychologist)
Email: j.walker.4@research.gla.ac.uk
Institute of Health & Wellbeing
Administration Building, 1st Floor,
Gartnavel Royal Hospital,
1055 Great Western Road,
Glasgow, G12 0XH



Quality of Life in Adults with a Head Injury living in the Community: A qualitative study

PRIMARY PARTICIPANT CONSENT FORM

Please initial
the BOX

I confirm that I have read and understand the information sheet dated 08/03/2013 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw at any time until the point at which the research is written up. I understand that I do not need to give a reason for withdrawing, and my medical care and legal rights will not be affected.

I understand that the interview I participate in will be audio recorded and that anonymised quotes may be included in research paper.

I understand that NHS Greater Glasgow & Clyde, sponsor of the study, may require access to data collected during this study for the purposes of audit only.

I agree that a relative/carer identified by myself can participate in the study. I can be contacted at the number _____ to facilitate arrangements for my relative/carer to meet with the research team, should they wish further information about the study.

I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

If the person is unable to provide written consent then a witness must sign on behalf of the participant confirming that verbal consent has been given.

Witness (where appropriate)

Date

Signature

1 copy to the participant, 1 Original for the Researcher



Jemma Walker (Trainee Clinical Psychologist)
 Email: j.walker.4@research.gla.ac.uk
 Institute of Health & Wellbeing
 Administration Building, 1st Floor,
 Gartnavel Royal Hospital,
 1055 Great Western Road,
 Glasgow, G12 0XH



**Quality of Life in Adults with a Head Injury living in the Community:
 A qualitative study**

SECONDARY PARTICIPANT CONSENT FORM

Please initial
the BOX

I confirm that I have read and understand the information sheet dated 08/03/2013 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw at any time until the point at which the research is written up. I understand that I do not need to give a reason for withdrawing, and that my relative/client's medical care and legal rights will not be affected.

I understand that my relative/client has provided written consent indicating that they agree to my participation in this study.

I understand that the interview I participate in will be audio recorded and that anonymised quotes may be included in research paper.

I understand that NHS Greater Glasgow & Clyde, sponsor of the study, may require access to data collected during this study for the purposes of audit only.

I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

1 copy to the participant, 1 Original for the Researcher

Appendix 2.6 - Sample of Analysed Transcript

Participant A1 (Pages 11-12)

P Christmas Eve, and then, so we'll need to go down and look at the house we liked, it's a house with a wee garden because I needed a house with garden, and <wife>, <wife> was the one that [pause] engineered it all because she knew I needed a house with a garden, I couldn't, the flat was stairs up and stairs down, and my ability wasn't as good as it used to be so we needed to move. So we got the house we wanted, we sold the house we had got and then we got this new house and <wife> said I'll need this dog. So we got that. I think she got the dog [pause] probably because we had always talked about the dog and couldn't work it but she's thought well, 'I'm going to relax a bit more now, so there might be more opportunity for me to work with the dog.' So we've got this wee dog, he is lovely, good fun. Put me in <pond> tomorrow, yesterday for some reason. I went to get him and I slipped and fell, which I shouldn't have done because one of my, my knees is not as good as it should be. Slipped and fell in the water, completely washed out, the dog was out, happy [both laugh].

Comment [JW1]: Stairs challenging.
Physical Ability (Impact of Injury)

Comment [JW2]: Change in Lifestyle
(Hobbies & Interests)

I And would you ever have thought that you would have, had a dog and had time to spend ...

P We would have had time to spend, to have dog if we could, we were working out how we could do it. But [pause] well two things happened, out of hospital I had changed my business partner ... two things happened, people, my lawyer and my accountant said to me, '<A> you need to change out of this business, you can't deal with this so called partner of yours who doesn't, went to <Europe> and didn't do anything'. So I changed the whole, declined from the partnership, created my own partnership on my own, took him out of the situation and took all the other things out, the tax situation and took the company out. And [pause] that has helped me as well because I had a lot of, I had a lot of time working [pause] for a partnership that, I worked 80 - 90% of partnership and the other partner did 10% so all my time was spent making money for him effectively. So [pause] the first thing I did was ... just changed the business, changed my attitude to business and do my own business and do my own thing, and I managed to keep a client on board for that, which was quite good [*I: Mhmm*] and we, we got the dog as well because we thought that was good for, because I was now more in <home> rather than <England> most of the time, and <wife> also took another day off her work, so she only works four days a week now. So [pause] its, its [pause] suited us in a funny sort of way probably things we wouldn't have done if [pause] I hadn't had the problem, we might have just worked on. We thought to ourselves five years from now we need to do it, rather than me

Comment [JW3]: Changes to Business
(Daily Functioning)

Comment [JW4]: Unsatisfied with
work?

Comment [JW5]: Change in attitude to
work.
(Sense of Purpose/Adaptation)

Comment [JW6]: Change in Lifestyle
(Hobbies and Interests)

work for another ten years. There is no doubt that I'm 60 plus and my wife's not far behind me, but no doubt that we decided that in five years time if I can retire, I'm going to retire there is no point in trying to keep on working for a living because all you do is keep working. So, that's the hope to get through the next four or five years, and get retired and enjoy life because really after, after <wife> says after my accident her assumptions about people's lives, we've got somebody who was killed recently and somebody else, and somebody else, and she is a very emotional person but her emotions are now judged on the fact that whatever anybody has been through, and she knows about it, it can't be anything as bad as what I've been through. Her emotions have been changed to [pause] be nice to people and say, 'blah blah blah' but not be emotionally distracted to them anymore because she has done all that with me. She was very very distracted with me. She spoke to my lawyer, and accountant, and business people and they all came up to see me as well. And said [pause] she was very very upset because she thought I was, she didn't she thought I could have died, if I didn't come off the machine [I: Uh huh] So she was all upset about that, so we have both changed our life a bit.

Comment [JW7]: Lifestyle changes (Hobbies and Interests)

Comment [JW8]: Emotional impact on wife (Challenges for Family)

I So it sounds like, you have shifted the balance slightly. It used to be more work, and now ...

P Yea, it used to be more work and activity, now we've got a wee bit more time off during the week and we've got a dog to look after. So [pause] I'm only doing things that I need to do. Whether it is good or bad I don't know but there is a bit of me that says well [pause] whatever difference it makes to me that's all I can cope with really, I can't really, I can't really deal with any emotional stress of a business anymore like I used. So, I've just come out, and I really needed to do it a long time ago anyway because the only reason I was still working the business the way it was, was because of my position down in <England> three or four days a week trying to keep it going [I: Mhmm], and you can't do that all your life. Can't do it [I: Yea]. So that's what I have decided to do.

Comment [JW9]: Lifestyle changes (Hobbies and Interests)

Comment [JW10]: Ambivalence about changes?

Comment [JW11]: Under pressure with work?

Comment [JW12]: Pre-injury workload unsustainable? (Adaptation/Lifestyle Changes)

I So in some ways it sounds like you're saying it was a positive?

P Aye it is a positive, yea it is a positive thing because otherwise we would work every, every year for the next five years, get to a point with retirement but we might not get there because one thing we've said to ourselves, you never know what is in front of you. That day was the last day ... I've done a lot of things in my life but I never thought I would come to a position that my life's shortened myself, and that's what happened. So, if your life, if your life happens like that you say to yourself well the only point in life is your, is your

Comment [JW13]: Unexpected, shock? Re-evaluated point in life? (Attitude to Life)

Appendix 2.7 - Major Research Project Proposal

Title:

Quality of Life in Adults with a Head Injury living in the Community: A qualitative study

Abstract

Background: Head injury is a common cause of disability in young adults creating challenges for the development of their independence, and potentially altering their perception of quality of life. The current literature with the head injury population has indicated the experience of poorer quality of life in comparison to the general population. This has been attributed to a reduction in the quantity and quality of social relationships, reduced leisure activities, experiencing depressive and anxiety symptoms, and low self-efficacy. Over recent years this area of literature has been growing, and there has been some development in head injury specific health-related quality of life outcome measures. However, the qualitative research contributing to this has to date been limited.

Aims: The aim of this study is to explore the subjective experience of quality of life following head injury and to explore similarities and differences between related self and proxy reports.

Methods: Participants will include adults with a severe head injury who are significantly disabled and as a result receive a community care package, and a relative or carer who knows them well. An Interpretative Phenomenological Analysis (IPA) approach will be implemented; with participants and their carers taking part in semi-structured interviews to explore how they perceive the quality of life of the individuals with severe brain injury.

Applications: It is hoped that this study will inform future research and clinical outcome measures developed relating to quality of life following a head injury. Clinically, it is also hoped that the findings can inform clinical practice through providing insights into the positive and negative life experiences that affect an individual's quality of life post injury.

Introduction

The Scottish Intercollegiate Guidelines Network (SIGN 110, 2009) utilises a broad definition of head injury as, “a history of a blow to the head or with altered consciousness after a relevant injury, or with a scalp or forehead laceration” (Jennett & MacMillan, 1981, p.102). The prevalence of head injuries is difficult to estimate as minor head injuries may not be reported to healthcare providers. Therefore, prevalence estimates of head injuries are often based on attendance rates at emergency departments. In Scotland, this is estimated at around 100,000 yearly attendances (Jennett, 1996, cited in SIGN 110, 2009). Experiencing a head injury can have a long lasting effect on several different areas of an individual’s life, and is a common cause of death and disability in young adults (Maas, Stocchetti & Bullock, 2008).

Quality of Life

Quality of life is a difficult concept to define which means it is often interpreted by individuals in different ways. The World Health Organization Quality of Life (WHOQOL) Group (1995) defined quality of life as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHOQOL Group, 1995, p.1405). This definition outlines quality of life as a subjective experience resulting from various positive and negative aspects of the individual’s experiences. Given that following a severe head injury the individual is likely to have experienced both physical and psychological changes in functioning it is also possible that they will experience a change in the perception of their position in life and their views on the quality of their life. Although there is vast literature on outcomes following head injury, only a small proportion of this literature is focused on quality of life. Within this literature there is a general consensus that health related quality of life is significantly lower for those who have experienced a severe head injury, when compared with healthy controls (Emanuelson, Andersson, Björkland & Stålhammar, 2003).

Head Injury in Young Adults

For young adults (aged between 18 and 65 years) living with a disability post head injury can present many challenges as it is a time of life when important life decisions are made about relationships and career choices in developing independence (Turner-Stokes, Nair, Sedki, Disler & Wade, 2005; Truelle, et al., 2010). “Physical, cognitive, emotional, and behavioural impairments” (von Steinbüchel, et al., 2010, p.1167) may limit the life choices a young adult with a head injury has, and potentially may affect their perception of quality of life. Cognitive deficits following head injury have been identified as being more challenging for head injured individuals and their carers than physical deficits and emotional difficulties (van Zomeren & van den Burg, 1985). Such changes often include a reduction in attention span, memory and learning difficulties, and low motivation. Cognitive deficits combined with a lack of insight, and difficulties adjusting to their experience of a head injury often result in a significant change in lifestyle for the individual. It has therefore been suggested that one of the goals of post injury rehabilitation should be to assess and maximise the individual’s quality of life as far as possible (Koskinen, 1998; Cicerone & Azulay, 2007; Truelle, et al., 2010). Community based rehabilitation programmes have been identified as key in the facilitation of this (Powell, Heslin & Greenwood, 2002) since living within the community is likely to maximise potential opportunities for social inclusion and leisure activities.

Quality of Life after Head Injury

Severe head injury is associated with poorer family, social, work, and leisure outcomes all of which are influential factors on quality of life (Truelle, et al., 2010). Both demographic and injury characteristics show weak relationships with quality of life outcomes (Kalpakjian, Lam, Toussaint & Merbitz, 2004; Mailhan, Azouvi & Dazord, 2005), whilst changes in social and sexual relationships, and leisure activities have stronger relationships (Koskinen, 1998; Truelle, et al., 2010). “Perceived self-efficacy for the management of cognitive symptoms” (Cicerone & Azulay, 2007, p.264) has also been recognised as influential on the individual’s experience of quality of life. This may link to findings on the importance of relationships and leisure activities, since adjusting to cognitive limitations following head injury may affect willingness to actively make changes and maintain these

areas of their life. Cognitive limitations pose challenges for therapeutic work in addressing areas which may impact on the individual's quality of life. However, with adaptations they can be effective (Judd & Wilson, 2005).

Several studies have indicated that young adults with a head injury experience depressive and anxiety symptoms several years post injury which has been hypothesised as related to feelings of isolation (Morton & Wehman, 1995; Steadman-Pare, Colantonio, Ratcliff, Chase & Vernich, 2001). A recent study exploring the self-reported quality of life of individuals living within the community and nursing homes also found a significant relationship between high depressive symptoms and lower quality of life (Best, 2012). They also found a significant relationship between low self-esteem and lower self-reported quality of life within the community sample. These studies indicate that the individual's emotional state can have a significant impact on their experience of quality of life and it has been recommended that qualitative research to further explore related psychosocial factors would be beneficial (Best, 2012).

Measurement of Quality of Life after Head Injury

Although, there are now several clinical outcome-related measures for the head injury population measures specific to health-related quality of life are limited (Truelle, et al., 2010). The Quality of Life after Brain Injury Questionnaire (QOLIBRI) developed by von Steinbüchel, et al. (2010) has been identified as a useful tool in measuring aspects of health-related quality of life specific to the head injury population (Koskinen, Hokkinen, Wilson, Sarajuuri, von Steinbüchel & Truelle, 2011; Best, 2012). It was developed using pooled items from existing measures of quality of life in head injury and the views of members of the task force, who were all health professionals. Views of people with a head injury on what constitutes their "quality of life" were not sought. Despite the growing literature on quality of life and head injury this has largely focused on quantitative studies with participants who receive community care packages and qualitative research with this population is very limited.

Overall, the current literature would indicate that quality of life is poorer for adults with a head injury living in the community, compared with the general population.

However, there has been variability in the reported effects. This may be reflective of the use proxy reports, despite the subjective nature of quality of life and uncertainty as to how well proxy and self-reported quality of life relate. One of the main reasons for the use of proxy reports, with the head injury population, is the suggestion that cognitive difficulties and communication problems may cause individuals to struggle to self-report their cognitive, behavioural, and emotional difficulties (Sbordone, Seyranian & Ruff, 1998). Sbordone, Seyranian & Ruff (1998) therefore suggested that proxy reporting by a significant other may be valuable when exploring these areas with individuals who have sustained a head injury. As a reflection of this, it is not uncommon for proxy reports to be obtained from carers in relation to the head injured individual's quality of life. Judd and Wilson (2005) conducted a qualitative study with clinicians regarding challenges faced in the development of therapeutic relationships with head injury clients. The identified challenges included aforementioned cognitive, behavioural, and emotional difficulties. It is possible therefore, that uncertainty over the distinction between self and proxy-reports, and challenges faced in the development of a therapeutic relationship have limited the qualitative research with the head injury population. However, in a review of the quality of life research approaches and findings in the head injury population, Dijkers (2004) recommended that there was a need for further qualitative research in this area.

Aims

The primary aim of this study is to explore how young adults who have experienced a head injury subjectively experience quality of life through the use of qualitative research methods. Secondary to this, the study aims to examine similarities and differences between self and proxy reported quality of life within the young adult head injury population and their carers.

Plan of Investigation

Design

The study will have a qualitative research design inviting adults who have had a severe head injury and their carers to participate in a semi-structured interview.

The focus of these interviews will be to explore the experience of quality of life for the individual with a head injury. Interpretative Phenomenological Analysis (IPA) will be used to analyse the narratives obtained; this approach allows for the exploration of “lived experience” without constraint from “predefined categories” (Smith, Flowers & Larkin, 2009, p.32).

Participants

Recruitment will comprise adults who, as a result of severe head injury, are significantly disabled and receive care in the community (primary participants). Severe head injury is defined as those scoring 8 or less on the Glasgow Coma Scale (GCS) for more than 24 hours after their head injury. The GCS is a widely used measure of head injury severity based on three areas of functioning, eye opening, motor response, and verbal response (Jennett & Teasdale, 1981). In addition, a relative or carer for each primary participant will also be invited to participate for an additional perspective on the participant’s quality of life (secondary participants). Primary participants will be NHS Greater Glasgow & Clyde (GG&C) residents and will be identified through the NHS GG&C ECR Team for Brain Injury, Acquired Brain Injury Service West Dunbartonshire, Headway Glasgow, and the Community Treatment Centre for Brain Injury.

Primary Participant Inclusion Criteria:

- Aged between 18 and 65 years, receiving care within the community.
- English as first language to ensure interpretations of the discourse between participant and researcher are not compromised.

Primary Participant Exclusion Criteria:

- Significant comprehension or communication difficulties that may impact on the ability to participate in the interviews.
- History of severe challenging behaviour, to ensure the safety of the participant and the researcher.
- Current alcohol and/or drug related dependency due to the impact this may have on their quality of life.
- Unable to provide informed consent.
- If a related secondary participant could not be identified.

Secondary Participant Inclusion Criteria:

- A relative or carer of the primary participant who is believed to have a good perception of the primary participant's quality of life.
- English as first language to ensure interpretations of the discourse between participant and researcher are not compromised.

Secondary Participant Exclusion Criteria:

- Unable to provide informed consent.

Justification of Sample Size

Within qualitative research, small sample sizes are recommended to facilitate engagement with participants and to ensure in-depth analysis of individual experiences. It has been recommended within the IPA literature that a sample size of between four and ten interviews is appropriate for this type of qualitative research (Smith, Flowers & Larkin, 2009, p.52). Therefore, it is planned that between four and six primary participants will be recruited and a related secondary participant for each. Consequently, it is planned that between eight and twelve interviews will be conducted.

Materials

To facilitate the flow of the interviews, a semi-structured interview schedule will be devised based on areas of relevance from the literature relating to head injury and quality of life. In addition, a demographic information sheet will be developed to gather relevant background information. For primary participants this will include; current age, age at time of injury, past and current employment, past and current living arrangements, severity of head injury, and time spent in hospital/care home. For secondary participants this will include; information on their relationship with the primary participant, frequency of contact with the primary participant, and length of time known the primary participant.

Procedure

Potential primary participants who fulfil the study criteria will be approached by the manager of the service they attend (Community Treatment Centre for Brain Injury, Headway, or West Dunbartonshire Brain Injury Clinic) and provided with a participant information sheet. After having an opportunity to read the information

sheet, potential participants will be asked by the relevant team, if they would like to meet with the researcher to discuss the study further. For those who wish to meet with the researcher, an initial meeting will be arranged at the Community Treatment Centre for Brain Injury, Headway, or West Dunbartonshire Brain Injury Clinic. During this initial meeting the researcher will ensure that the potential primary participant has understood the information provided about the study, address any queries they may have, and obtain written informed consent for participation from the individual. If the individual is unable to provide written consent due to a physical disability, verbal consent will be sought and verified by a witness.

If the primary participant has consented to their involvement in the study, they will be provided with an information sheet for a relative or carer whom they would like to invite to participate in the study. The primary participant will be asked to provide a telephone number they can be contacted at to find out if their relative or carer would like to meet the researcher and discuss the study. For those relatives/carers who would like to meet with the researcher a meeting will be arranged via the primary participant, at the Community Treatment Centre for Brain Injury, Headway, or West Dunbartonshire Brain Injury Clinic. At this meeting the researcher will clarify with the potential secondary participant what is involved in the study, and obtain written consent for their participation. Consent from both the primary participant and secondary participant will be required before proceeding to the interview stage. Individual semi-structured interviews will then be conducted with primary and secondary participants, and digitally recorded by the researcher. Both primary and secondary participant interviews will be held in rooms provided by the service that they attend (Community Treatment Centre for Brain Injury, Headway, or West Dunbartonshire Brain Injury Clinic). The interviews will last up to one hour, and breaks will be provided as required. Interview recordings will be transferred to an encrypted laptop, then transcribed and anonymised for analysis.

Data Analysis

Interview transcripts will be analysed using IPA. Through exploring the reflections of individuals who have experienced a significant life event the researcher attempts to understand and make sense of the experience for the individual (Smith, Flowers & Larkin, 2009). The interview transcripts will be systematically analysed case by case with emergent themes being identified and connections between these explored. To ensure reliability of the themes identified by the researcher, a supervisor or colleague will conduct a blind second analysis of a random selection of the transcripts.

Practical Applications

There has been a gap identified in the research literature of qualitative analysis of the experience of quality of life for those who have experienced a severe head injury. It is therefore hoped that this study will inform both future research and clinical outcome measures developed within this area. Clinically it is hoped that this study will provide further insights into positive and negative life experiences post injury, and how these experiences relate to quality of life. The completed study will be available as a thesis from the University of Glasgow library in paper and electronic format. As well as, being submitted for publication in a scientific journal.

Project Considerations

Health & Safety Issues

To ensure both participant and researcher safety interviews will not be conducted within the participant's home. It is planned that both primary and secondary participant interviews will be conducted within the day centres that participants attend, during normal working hours. The manager and administrative staff within the centres will also be informed of when the interviews will be occurring. The standard health and safety procedures for each centre will be followed.

If a participant shows signs of distress during the interview the researcher will cease the interview and attempt to aid the participant in managing their distress. If

following this the participant continues to display signs of distress and is believed to be at risk of harming themselves or others, the researcher will seek further assistance from support staff within the centre, and contact appropriate mental health services.

Ethical Issues

Prior to conducting the study ethical approval will be obtained from the West of Scotland Research Ethics Committee and from NHS GG&C Research and Development. Participation in the study will be voluntary and participants will be made aware that they may withdraw from the study at any time until the final write-up. The researcher's contact details will be outlined in the information sheet provided to participants should they have any questions following their interview or wish to withdraw from the study. NHS Greater Glasgow & Clyde confidentiality guidelines will also be followed in relation to any identifiable information. Following the completion of the study participants will be written to thanking them for their participation and providing them with a summary of the findings.

Financial Issues

The study will require financial support for paper and photocopying costs as well as, the borrowing of a digital recorder, transcription equipment, and an encrypted laptop. These will be provided by the Institute of Health and Wellbeing at the University of Glasgow.

Timetable

Date	Task
January 2013	Submit proposal to University
January 2013	Proposal assessed
February - March 2013	Apply for ethical approval
March - May 2013	Recruitment
May 2013	Data analysis
June - July 2013	Write up the research
End of July 2013	Submit research to University
September 2013	Viva

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