

**Factors influencing outcomes
and their measurement after brain injury**

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Declaration and signature of candidate	
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To Annabel and Iain
thank you for all your patience, support and belief.
I love you completely and totally,
forever and always.

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Thesis abstract

Acquired brain injury (ABI) is a major cause of morbidity and mortality, especially among younger people and the psychological sequelae can have chronic detrimental effects on patients' life and wellbeing. It is important to have clinically relevant, validated measures to be able to determine a person's psychological needs to structure interventions to improve outcomes. Measures designed for an ABI population have been developed but due to their rigid, closed question-based nature lived experience may not be captured. This means that an important source of clinically relevant information may be missed.

The available evidence on the effect of coping, efforts and strategies to reduce stress, on various outcome measures used in the brain injury population was collated and findings were synthesised. Results suggest that not one coping or quality of life measure is used consistently and that the majority of these measures are not specific to this population. In addition, the studies show that excessive use of coping strategies, or the use of emotionally focused strategies, may have a detrimental effect on quality of life.

The research paper addressed whether outcome measures miss clinically relevant information through their rigid structure. A mixed-methods analysis was used to compare information gathered from participants using an outcome measure (EBIQ) and that gained through analysis of semi-structured interviews. Ultimately, both methods have clinical value but the results from the outcome measure can be enriched through the use of qualitative information collected during interview.

These two papers show that, while outcome measures are valuable in assessing a person's needs and monitoring progress, there is a need for the more consistent use of outcome measures specific to the ABI population, in parallel with interviews to uncover issues which may otherwise be missed. A reflexive commentary on my journey through the research and thesis process is also presented.

Literature Review

The impact of coping style on quality of life following traumatic brain injury: a literature review

word count: 6659

Abstract

In addition to physical outcomes traumatic brain injury (TBI) has a large negative effect on a person's quality of life (QoL), which can lead to significant life-long disabilities. Coping, the cognitive and behavioural efforts to manage stressful situations, can affect outcomes following TBI. However, only a few studies have directly addressed the impact of coping on QoL post injury. This literature review assessed the evidence base for the influence of coping styles on QoL following a TBI. Included articles were published in English and examined the effect of coping style on QoL following a TBI in a community-based adult population. Ten articles were included in the review. These articles included a wide variety of QoL and coping outcome measures, and different severities of TBI were examined. The findings from most studies were consistent in that participants using high levels of coping overall, and in particular avoidant coping, have a poorer outcome in terms of QoL. These patients could need more support and training in using more productive coping strategies. Further prospective studies employing TBI- specific QoL and coping measures are required to confirm these results and to aid the design of population-specific interventions.

Introduction

Traumatic brain injury (TBI) is defined as 'an alteration in brain function, or other evidence of brain pathology, caused by an external force' (1). It is a global health problem (2), with an international pooled annual incidence rate for all ages of 295 per 100,000 population (3) and a pooled age-adjusted hospital discharge rate across Europe of 287 per 100,000 (4). Additionally, TBI has a large mortality and morbidity burden, and it is estimated that it will become the leading cause of death and disability by 2020 (2).

Not only can a TBI have an observable physical impact on an individual, it can also have a significant effect upon a person's overall quality of life (QoL). Quality of life is a dynamic concept involving subjective appraisal of an individual's health status, wellbeing and objective achievements (5) and can be separated into four main health dimensions: physical health (i.e. disease symptoms, side effects), mental health (i.e. positive feelings, psychiatric disorders), social health (i.e. connections, interactions) and functional health (i.e. self-care, mobility) (6). Each of these dimensions can be further split into predefined sets of domains that focus on the QoL measures specific to the tool used (7). Following TBI it has been shown that QoL may significantly decrease across all dimensions and that the size of the effect is related to the severity of the injury (8-10). However, while the physical aspects of a patient's QoL can improve over time, others, such as cognition, emotions, mental health and social function remain suppressed (8, 11). Thus, patients with a TBI can suffer from lasting disabilities that limit activities associated with daily living for the rest of their lives. This impact on QoL is evident even for people with mild, uncomplicated TBI (12).

One major factor that has been shown to affect outcomes following TBI is coping, the cognitive and behavioural efforts that people make to manage stressful situations (13). There are three ways in which coping can be conceptualised: situation-specific, dispositional or domain-specific. Situation-specific coping is a dynamic process and is defined as "the person's cognitive

and behavioural efforts to manage (reduce, minimize, master or tolerate) the internal and external demands of the person-environment transaction that is appraised as taxing or exceeding the person's resources" (14, 15). Coping can also be considered to be dispositional (or a style) whereby coping is not a stable trait but assumes that people prefer certain coping styles over others and that these may change over time. Finally, coping can also be considered to be domain specific in which different coping methods are used across different domains. Each of these concepts is based upon a different theoretical background and is associated with particular coping measures.

There are different coping models (16), which have been used in the TBI literature but the most common appears to be that of the cognitive theory of stress, appraisal and coping as proposed by Lazarus and Folkman (13). They defined two major coping strategies: emotion-focused coping, meaning the regulation of emotions generated by the appraisal of a perceived threat, and problem-focused coping which refers to the management of the problem itself (13). Within emotion-focused coping responses could be seen as maladaptive (avoidant coping) or adaptive (positive reappraisal). Problem-focused strategies consist of active efforts to change and solve the actual problem, whereas avoidant coping strategies involve emotional or behavioural efforts to escape the problem, for example through wishful thinking, the use of alcohol or drugs, or mental and social disengagement (13, 17).

Within the acquired brain injury (ABI) population, which includes TBI alongside strokes, hypoxia-related insults, and tumours, studies have consistently shown that avoidant coping is associated with negative outcomes such as depression, anxiety, emotional distress and lower productivity (18-24). The effect of problem-focused coping is less clear, with studies finding no effect or a negative effect on outcome (18, 19, 21, 23, 24). However, the relationship between coping and outcomes is complex as people can use different coping strategies throughout their recovery (25, 26). Other terms that are used are productive and non-productive coping: productive coping encompasses problem-focused strategies combined with positive emotional responses and social interaction, whereas non-productive coping is analogous to the use of avoidant strategies (27).

The distinction between productive and non-productive coping is not clear-cut and may depend on the individual's personality and socioeconomic status. For example, nicotine or alcohol use can be seen as a non-productive, avoidant, strategies however, this may also be conceptualized as means to achieve additional energy to address perceived threats, or as providing short term relaxation in stressful situations (Johnstone et al 2018). Hence these avoidant strategies could be viewed as productive, problem-focused, depending on an individual's environment. Or, if we view coping behaviours as threat-induced coping responses, in the terms of the Power Threat Meaning Framework (Johnstone et al 2018) 'What did you have to do to survive?'. For the purposes of this review, with the aim of simplifying the terminology used, the author will refer to productive and non-productive coping as defined above.

The purpose of the current literature review was to determine the level of evidence for the influence of coping styles on QoL for people with a TBI.

Methods

Search strategy

The databases of MEDLINE, PsychINFO, SPORTDiscus, AgeLine, CINAHL Plus, Academic Search Complete, eBook collection, AMED (all within EBSCO) and Web of Science were searched in September 2017 and March 2018. The free-text search combined the keywords of brain injury AND quality of life AND (outcome measure OR questionnaire) AND coping. The results from different databases were combined and duplicates were excluded.

Screening and selection of studies

The title and abstract of references returned by the above search strategy were screened for relevance and defined inclusion and exclusion criteria. If ambiguity remained following review of the title and the abstract of a reference, a review of the full text of the article was performed. The reference lists of all retrieved articles were also searched for suitable additional references.

Inclusion criteria

Peer-reviewed studies published in English that examined the effect of coping style on QoL following a TBI in an adult population in a community setting. The community setting was chosen to minimise the acute effects of TBI on behaviour and emotions and to allow the responses to injuries to be observed outside of hospital's support structures, providing a true picture of a person's coping style.

Exclusion criteria

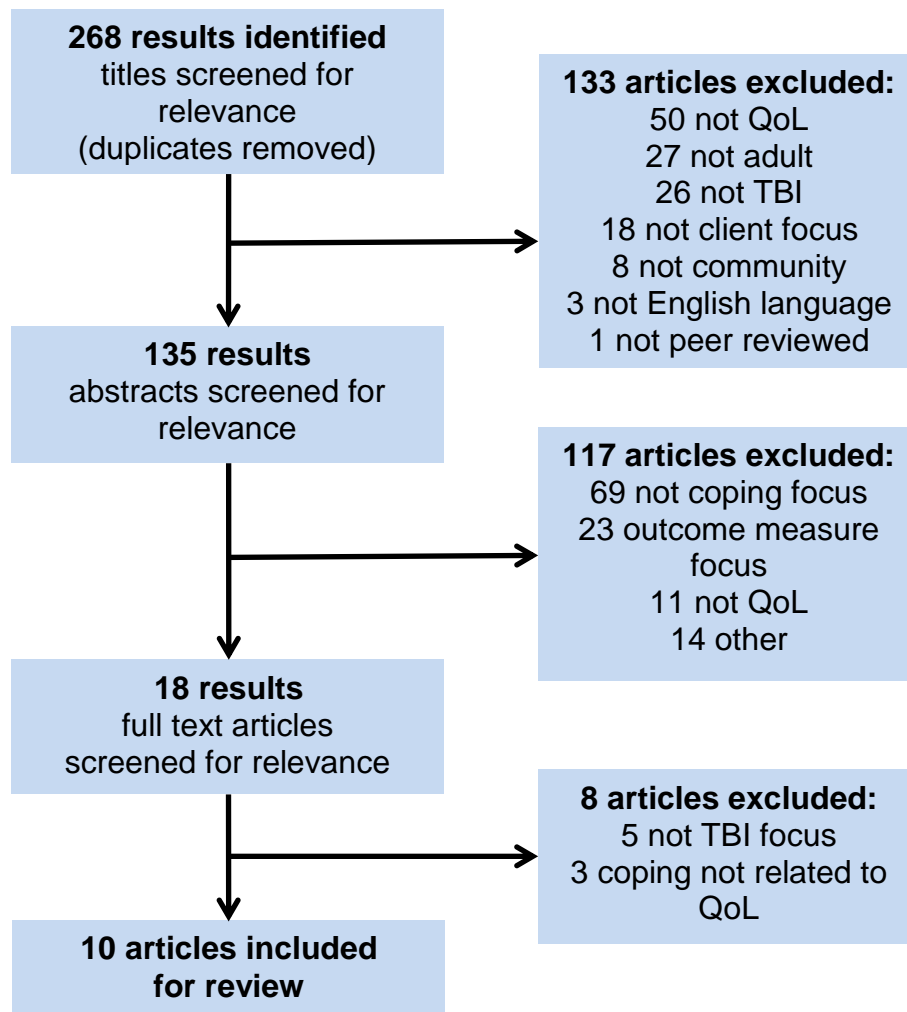
Studies whose population were not adult or involved non-TBI diagnoses or subjects in an inpatient setting.

Search strategy

The search strategy resulted in the retrieval of 268 references. Application of the inclusion and exclusion criteria to the information within the titles or abstracts resulted in 18 articles remaining. For each of these references the full article was obtained and reviewed. A further eight articles were rejected at this

stage, leaving a total of 10 for analysis. A diagram of this process is shown in Figure 1.

Figure 1. Flow diagram of studies through the review process.



Data abstraction and synthesis

A standardised data abstraction form was used to capture characteristics of the included studies that were felt to explore the possible influence of coping style on QoL following TBI. This included the following categories: study design and limitations, participant characteristics, cited coping tool, cited QoL tool, and findings that related coping data with QoL data.

Quality assessment

No reviewed checklist contained all of the elements that were considered critical for this analysis. Therefore a quality assessment checklist was developed, based upon the Cohort Study Checklist from the Critical Appraisal Skills Programme (CASP, 29; see Table 1). This was believed to be the most appropriate for the included studies. Ten of the included questions (1-4, 7-12) were adapted from the CASP checklist, while two (5 and 6) dealing with the QoL and coping tools used were added specifically for the purposes of this analysis. One point was given for each included element within an article and a quality score (out of 12) is given for each study in Table 2.

Table 1. Quality checklist criteria (adapted from the Cohort Study Checklist)

Criterion	Response		
	Yes (✓)	No (✗)	Uncertain (?)
1	Population clearly identified?		
2	Study design clearly presented?		
3	Participant selection described?		
4	Study objectives clearly presented?		
5	QoL tool cited?		
6	Coping tool cited?		
7	Clearly defined outcome measures?		
8	Minimised bias?		
8	Analysis fully described?		
9	Evidence sufficiently congruent with conclusions?		
10	Limitations reported and addressed		
11	Can the results be applied to the local population?		

Table 2. Summary of the quality criteria definitely met by included studies in the review

	1	2	3	4	5	6	7	8	9	10	11	12
Dawson, 2002 (30)	✓	✓	✓	✓	✓	✓	✓	?*	✓	✓	x	✓
Gould & Ponsford, 2014 (31)	✓	✓	✓	✓	✓	✓	✓	?*	✓	✓	✓	✓
Wolters Gregorio et al, 2014 (32)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Maestas et al, 2014 (33)	✓	✓	✓	✓	✓	✓	✓	?*	✓	✓	✓	✓
Moore et al, 1994 (34)	✓	✓	✓	✓	✓	✓	✓	?*	✓	✓	x	✓
Rutterford & Wood, 2006 (35)	✓	✓	✓	✓	✓	✓	✓	?*	✓	✓	✓	✓
Sasse et al, 2014 (36)	✓	✓	✓	✓	✓	✓	✓	?*	✓	✓	✓	✓
Snell et al, 2011 (37)	✓	✓	✓	✓	✓	✓	✓	?*	✓	✓	✓	✓
Tomberg et al, 2005 (38)	✓	✓	✓	✓	✓	✓	✓	?*	✓	✓	✓	✓
Tomberg et al, 2007 (26)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

x=no; ?=uncertain; ✓=yes

* Valid outcomes measures, but self-reporting

Results

Study characteristics

The characteristics of the included studies are shown in Table 3. The majority of studies (n=7) were cross-sectional in design, with three being longitudinal. One of the cross-sectional studies (26) was a follow up of a previous study in the same population (38), but for the purposes of this analysis has been considered as cross-sectional. Three of the studies (26, 30, 38) collected data from a comparator population (family and friends). Participant numbers ranged from 75 to 187 per study, with the exception of one study (26) that was a follow-up study of an established participant group (n=31 from n=85 in the original study [38]). All studies were of high quality (Table 2) as per the defined checklist. Bias was a potential issue for most studies due to the subjective nature of the questionnaires and the post-injury recording of pre-injury variables and characteristics.

Table 3. Characteristics of the studies included for analysis

Authors, year	Design	Control population?	Setting	n	Age (range)	Males (%)	Severity of TBI	Time post injury	Quality rating
Dawson, 2002 (30)	Prospective, cross-sectional	Yes Family and friends	Canada	94	28 (16–63)	58%	Mild Moderate Severe	4.3 years	10
Gould & Ponsford, 2014 (31)	Prospective, longitudinal	No	Australia	95	38 (17–76)	79%	Complicated mild Moderate Severe	Pre-injury 6 months 12 months 24 months 36 months 48 months	11
Wolters Gregorio et al, 2014 (32)	Prospective, longitudinal	No	Australia	147	34 (16–76)	80%	Mild=13% Moderate=21% Severe=41% Very severe=25%	Post-injury 6 months 12 months 24 months 36 months	12
Maestas et al, 2014 (33)	Prospective, cross-sectional	No	US	187	33 (SD=12)	76%	Uncomplicated mild=52% Complicated mild=48%	Pre-injury Post-injury 3 months	11

Authors, year	Design	Control population?	Setting	n	Age (range)	Males (%)	Severity of TBI	Time post injury	Quality rating
Moore et al, 1994 (34)	Prospective, cross-sectional	No	Canada	75	44 (19–84)	0% all female	Mild=36% Moderate=39% Severe=25%	63 months (9–98)	10
Rutterford & Wood, 2006 (35)	Prospective, cross-sectional	No	UK	131	48 (27–75)	65%	Mild=15% Moderate=21% Severe=10% Very severe=55%	15 years (10–31)	11
Sasse et al, 2014 (36)	Prospective, cross-sectional	No	Germany	141	17–30=25% 31–44=16% 45–68=58%	70%	Mild=31% Complicated mild=18% Moderate=20% Severe=23%	3 months–1 year=13% 1 to <2 years=18% 2 to <4 years=32% 4–15 years=36%	11
Snell et al, 2011 (37)	Prospective, Longitudinal	No	New Zealand	147	42 (16–78)	44%	Mild=100%	Post-injury 3 months	11
Tomberg et al, 2005 (38)	Prospective, longitudinal	Yes Family	Estonia	85	38 (14–66)	81%	Moderate=75% Severe=25%	2.3 years (9 months to 3 years)	11
Tomberg et al, 2007 (26)	Prospective, longitudinal	Yes Family	Estonia	31	44 (22–68)	81%	Moderate=81% Severe=19%	7.9 years (6–12)	12

Participant characteristics

The participants within the studies were recruited from Europe (n=4), North America (n=3), and Australia/New Zealand (n=3). Ages of participants ranged from 16–84 years with the mean age in most studies being approximately 40 years old: one study had an average age of 28 years (30) and another an average age of 33 (33). Most studies (n=8) had participant populations that were majorly male (58–81%); one study (37) had 44% males, and Moore et al, (1994) recruited solely female participants. The studies encompassed all levels of TBI from uncomplicated mild, complicated mild and moderate, through to severe and very severe, which were generally assessed using the Glasgow Coma Scale. Assessment time post injury for the cross-sectional studies ranged from an average of 3 months to 15 years with an upper limit of 31 years. Longitudinal studies assessed participants at 3, 6, 12, 24, 36 or 48 months.

QoL measurement and impact of TBI

A number of different tools for measuring QoL were used across the ten studies included in the analysis. They ranged from single item general questions (35), through general QoL questionnaires (n=8) and tools that were specific to the TBI population (QOLIBRI; 33). The Quality of Life Inventory (31, 32) and Short Form-36 (26, 33, 36; 38,) were used most often (n=2 and n=4 respectively). The structured tools had good internal consistency and test/re-test reliability (Table 4).

Table 4. Robustness of QoL measures used in the included articles

QoL measure	Abbreviation	Reference	Internal consistency	Test re-test reliability
Flanagan's QoL domains	-	Flanagan, 1982 (39)	-	-
Quality of Life Inventory	QOLI	Frisch, 1994 (40)	0.77–0.89	0.80–0.91
Short Form-36	SF-36	Ware et al, 1994 (41)	0.89–0.94	0.84–0.91
Sickness Impact Profile	SIP	Bergner et al, 1981 (42)	0.94	0.92
Single, general question	-	Dawson et al, 2002 (30)	-	-
Quality of Life after Brain Injury	QOLIBRI	von Steinbuchel et al, 2005 (43) von Steinbuchel et al, 2010 (44)	0.79–0.89	0.78–0.85
Rivermead Post-Concussion Symptoms Questionnaire	-	King et al, 1995 (45)	-	0.87–0.91
Rivermead Head Injury Follow-up Questionnaire	-	Crawford et al, 1996 (46)	-	0.56–0.67
Estonian version of RAND-36	RAND-36	Herodes et al, 2001 (47)	0.75–0.92	

Only five studies reported the effect of TBI on QoL separately from the effect of coping. In four studies QoL was lower post TBI when compared with controls or pre-injury measurements (30-32, 38). These effects were observed as early as 6 months post injury and as late as 48 months post injury, indicating that the reduction in QoL for those with a TBI was a chronic issue. The remaining study divided participants into those with good or poor outcome, defined by their overall QoL (37). The poor outcome group constituted approximately 50% of the overall population. The differences in QoL between participants was not analysed to any great length, but it was noted that QoL was affected across all domains including physical and emotional health, and functioning (38) and that the magnitude of changes in QoL did not change according to the severity of TBI (30).

Coping measurement and impact of TBI

Several different coping tools were used across the 10 studies included in this analysis (Table 5). These were the Ways of Coping Questionnaire (original and revised, n=3: 17), the Coping Scale for Adults (subscales or short version, n=2: 18, 27), the COPE-D inventory (Estonian version, n=2: 48, 49), the Brief COPE (n=2: 50), and the Freiburg Questionnaire of Coping with Illness (n=1: 51, 52).

Table 5. Robustness of coping measures used in the included articles

Coping measure	Abbreviation	Reference	Internal consistency across strategies	Test re-test reliability
Estonian COPE-D Inventory	–	Kallasmaa & Pulver, Personal Individual Diff 2000;29:881-894 (49)	0.49-0.95	-
Brief COPE	-	Carver. Int J Behav Med 1997;4:92-100 (50)	0.50-0.90	-
Coping Scale for Adults – short version	CSA	Frydenberg & Lewis. Am Educat Res Assoc 2000; presentation (53)	0.69-0.92	0.23-0.97
Ways of Coping Questionnaire	WOCQ	Rexrode et al. Educ Psychol Meas 2008;68: 262-280 (54)	0.60-0.75	-
Ways of Coping Checklist - Revised	WOCQ-R	Malia et al. Brain Inj. 1995;9:607-618 (21)	0.83-0.95	-
Freiburg Questionnaire of Coping with Illness*	FQCI	-	-	-
Coping Scale for Adults: 2 sub scales only	CSA – General Form	Frydenberg & Lewis. Am Educat Res Assoc 2000; presentation (53)	0.70-0.83	-

*Primary manuscripts are in German

Seven of the 10 studies describe coping separately from QoL to varying degrees (26, 30; 32-34, 36, 38). Coping styles used did not seem to be dependent upon the demographics of the participants (32), the severity of the TBI (30, 32), or age (38). In one study pre-injury coping styles positively correlated with the use of post-injury styles (32). Tomberg et al, 2007 (26) reported no increase or decrease in the use of productive or non-productive coping styles from an average of 2.3 to 7.9 years post-injury. However, Wolters Gregorio et al, 2014 (32) reported that the use of productive coping styles decreased within the first 6 months post injury and failed to return to pre-injury levels, even after 36 months. The use of non-productive coping styles also decreased initially, but increased thereafter to pre-injury levels or higher. Both Maestas et al, 2014 (33) and Tomberg et al, 2005 (38) noted that participants who used a more productive coping style tended to have more years of education compared with those who used more non-productive styles.

The influence of coping style on QoL

The effect of coping style on QoL within the analysed studies can be seen in Table 6.

Table 6. Findings from the included articles relating to the effect of coping style on QoL following TBI.

Authors, year	QoL measure	Coping measure	Findings
Dawson, 2002 (30)	Flanagan's QoL domains (39)	Ways of Coping (17)	Participants with higher scores on a non-productive coping scale had a poorer outcome on the QoL measure, but this was not significant. Using hierarchical regression analysis non-productive coping was found to explain some of the variance in the psychosocial model, but not the QoL model.
Gould & Ponsford, 2014 (31)	Quality of Life Inventory (40)	Two subscales of Coping Scale for Adults (53,55)	Pre-injury coping style had no effect on the changes in QoL observed in the study. In addition, coping styles did not differ between the group experiencing decreases in QoL and the group experiencing increases in QoL. However, there was a tendency for the group exhibiting positive changes in QoL to use fewer non-productive coping strategies.
Wolters Gregorio et al, 2014 (32)	Quality of Life Inventory (40)	Coping Scale for Adults – Short Version (52)	Increased use of non-productive coping was correlated with significantly lower QoL at 1-year post injury. Increased use of productive coping has no effect on QoL.
Maestas et al, 2014 (33)	Short Form-36 (56)	Ways of Coping (17)	The participant cluster that used high levels of both productive and non-productive coping strategies had poorer mental health QoL when compared with clusters that

			used high productive and low non-productive, or low levels of both, coping strategies. Coping style had no impact on physical health QoL.
Moore et al, 1994 (34)	Sickness Impact Profile (57)	Ways of Coping Revised (58, 59)	The clusters of female participants who used either low levels of coping overall or productive coping strategies had better QoL outcomes than those clusters that used high levels of coping overall or non-productive coping strategies.
Rutterford & Wood, 2006 (35)	Single, general question (30)	Brief COPE (50)	No evidence was found to suggest that coping strategies affected QoL in this study. However, when productive coping style was combined with a 'personality' psychosocial component, it explained 43.5% of the variance in QoL.
Sasse et al, 2014 (36)	Short-Form 36 (56); Quality of Life after Brain Injury (43,44)	Freiburg Questionnaire of Coping with Illness (51, 52)	Non-productive coping strategies are associated with lower QoL across all domains with contribution to variance of 33-62%. Productive coping strategies are weakly but positively related to some QoL domains after TBI (18-22% variance).
Snell et al, 2011 (37)	Rivermead Post-Concussion Symptoms Questionnaire (45) Rivermead Head	Brief COPE (50)	Within the early stage of recovery following a TBI (within 3 months) there was a tendency for use of a productive coping style to be associated with poorer outcome for QoL

	Injury Follow-up Questionnaire (46)		
Tomberg et al, 2005 (38)	Estonian version of RAND-36 (47,60)	Estonian COPE-D inventory (48, 49)	At an average of 2.3 years post TBI, productive coping strategies were associated with improvements in QoL, whereas non-productive strategies had a weakly negative, but not significant, impact on QoL.
Tomberg et al, 2007 (26)	Estonian version of RAND-36 (47,60)	Estonian COPE-D inventory (48, 49)	From the first study period, use of a non-productive style had increased in those participants who had fewer problems with physical health and in those who had less support.

Table 7. Effects of subtypes of coping style on QoL domains following TBI.

Authors, year	QoL measure	Coping measure	Findings
Maestas et al, 2014 (33)	Short Form-36 (56)	Ways of Coping (17)	<ul style="list-style-type: none"> A cluster characterised by high overall use of coping strategies demonstrated significantly lower levels of mental health QoL than clusters that used high levels of problem-focused coping and low levels of avoidant coping, or low levels of all coping strategies
	Sickness Impact Profile (57)	Ways of Coping Revised (58, 59)	<ul style="list-style-type: none"> One analysis on a heterogeneous population showed that a cluster characterised by use of blame/avoidance coping strategies reported significantly greater psychosocial dimension difficulties compared to a cluster defined by use of a positive reappraisal strategy and cluster defined by low overall use of all coping strategies. A cluster characterised by high overall use of coping strategies had similar scores within the psychosocial domain compared to the blame/avoidance cluster Another analysis on a TBI population showed that a cluster characterised by high overall use of coping strategies reported significantly higher levels of psychosocial dimension disturbance compared to a cluster characterised by low overall use of coping strategies
Moore et al, 1994 (34)			
Sasse et al, 2014 (36)	Short-Form 36 (56); Quality of Life after Brain Injury (43, 44)	Freiburg Questionnaire of Coping with Illness (51, 52)	<ul style="list-style-type: none"> For a generic QoL tool (SF-36) moderate-to-weak negative correlations occurred between 'Trivialisation/Resignation' and the Physical component Summary and the Mental Component Summary For the TBI-specific QOLIBRI tool, significant moderate negative correlations between 'Trivialisation/Resignation' and the total score and all of the subscales was found Weak positive correlations were found between 'Action/Distraction' and the QOLIBRI subscales of 'Self' and 'Social relationships'

Tomberg et al, 2005 (36)	Estonian version of RAND-36 (47,60)	Estonian COPE-D inventory (48, 49)	<ul style="list-style-type: none"> • Analysis revealed a moderate positive relationship between the overall Task coping strategy and the Physical functioning QoL domain • The overall Social/emotional support and Avoidance coping strategies did not correlate significantly with any of the different health QoL domains • Weak positive relationships were noted between the Task coping strategy and the Emotional wellbeing, energy/fatigue, Social functioning and General health domains • The coping scales of Positive reinterpretation and growth, and Planning moderately correlated with the majority of health status QoL domains
Tomberg et al, 2007 (26)	Estonian version of RAND-36 (47, 60)	Estonian COPE-D inventory (48, 49)	<ul style="list-style-type: none"> • Use of an Avoidance coping strategy correlated with lower sociality, higher impact of the injury, and greater thinking about the injury • Use of the Avoidance coping strategy also significantly correlated to the presence of health complaints, especially self-reported memory disturbances

The effect of coping style on QoL was inconsistent across the ten studies. The majority of studies (n=6) found that non-productive coping strategies were associated with lower QoL at the time points studied (30-32, 33, 36, 38).

Accordingly, productive coping strategies were associated with improvements in QoL in five studies (33-36, 38), no change in one study (32) and a negative effect in one study (37). The size of the effect of coping style on QoL also varied across studies. In those studies using general QoL measures, and where it was reported, coping style contributed 15–30% of the total effect (30, 31, 38). When productive coping style was combined with personality, Rutterford & Wood (35) found that 43.5% of the variance was explained. Finally, use of a QoL measure specific for TBI increased the level of variance explained by coping to 33–62% for non-productive coping, and 8–22% for productive coping (35).

The two studies that used cluster analysis (33, 34) showed that participants who used high levels of coping in general (both productive and non-productive) had worse outcomes than those who used high levels of productive and low levels of non-productive coping, or those that used low levels of coping generally.

In the one study that examined the effects of pre-injury coping style on outcomes, pre-injury coping style had no effect on the changes in QoL observed in the study (31).

Of the studies that examined the longitudinal relationship of coping strategies with QoL, one (31) showed that coping strategies did not differ between groups (those showing increases in QoL versus those showing decreases in QoL) at 6, 12, 24, 36 and 48 months post injury. Tomberg et al, 2007 (26) showed that six years after initial assessment (itself 2.3 years after TBI on average) there was no change in the participants' use of productive or non-productive coping styles coupled with little change in QoL scores.

Five studies also reported the association of sub-types of coping with QoL (Table 7; 26, 33–38). High use of coping strategies in general resulted in worse outcomes in terms of mental health-related QoL from the SF-36 (33) and higher levels of psychosocial disturbance on the SIP (34) when compared with low use of coping strategies. Productive coping strategies had a weak-to-moderate positive effect on the physical functioning, emotional wellbeing, energy/fatigue,

social functioning and general health subscales of the RAND-36 measure (38), and on self and social relationship subscales of the QOLIBRI measure (36). In addition, use of the 'Positive reinterpretation and growth' and 'Planning' subscales from the COPE-D had a moderately positive correlation with all of the health status QoL domains for the RAND-36 (38). Conversely, use of maladaptive coping strategies resulted in weak negative correlations between the physical and mental components of the SF-36 and moderate negative correlations with all sub-scales of the QOLIBRI measure (36). Maladaptive coping strategies also correlated with lower sociality, higher impact of injury, greater thinking about the injury and the reporting of health complaints measured through the RAND-36 (26), although these relationships were not apparent in the same population 6 years earlier (38).

Discussion

The current literature review has found, from the small evidence base available, that the use of non-productive coping styles post TBI are associated with worse QoL for participants, and that these effects can be maintained up to 15 years. There is evidence that the use of positive coping styles post injury are beneficial, but it is inconclusive, and the changes observed are much smaller than those for non-productive coping strategies.

Coping is defined as “thoughts and behaviours used to manage internal and external demands or situations that are stressful” (13), while QoL is a dynamic phenomenon involving subjective appraisal of health status, well-being and objective achievements (31). Therefore it is reasonable to assume that the former will affect the latter. The results of the current analysis have shown that non-productive coping strategies are increased, and productive coping strategies decreased, in participants with varying severities of TBI and from short to long term post injury, leading to decreased QoL following TBI. However, it appears that coping style only explains a small proportion of the variance in QoL of those with a TBI; other factors that can affect QoL include functional outcome, age at trauma and time since trauma (61) and societal culture (62). Another factor that can affect QoL following TBI is community integration, which is an adaptive process of rehabilitation that is multidimensional, dynamic, personal, and culturally bound” (63) and that includes social, community and in-home participation, and participation in meaningful, productive activities (64). When additional factors such as personality, demographics or TBI severity are introduced into the regression models examining the relationship between coping and QoL, a greater degree of variance is explained (32, 33, 35).

Another approach is to use cluster analysis (33, 34) that identifies and analyses subgroups of participants based on their similar use of coping strategies rather than looking at coping strategies across an entire sample. Maestas et al (33) found that the cluster defined by high use of both problem-focused and avoidant coping strategies suffered significantly more depression and anxiety and had lower mental- health-related QoL compared with clusters that had low use of both coping strategies or high use of problem-focused strategies and low use of

avoidant strategies. Explanations for this include: 1, switching between coping strategies gives neither one sufficient time to produce an effect; 2, the avoidant coping strategy may be particularly maladaptive and so may override any impact of the problem-focused strategies (as suggested by the current review); and 3, high levels of overall coping reflect a scattergun approach whereby everything is tried and failure of these attempts leads to hopelessness, helplessness and associated sequelae (34).

Gender Difference

Three studies mention analysis of differences in coping styles between men and women (34, 36, 38). The study of Moore et al (31) only recruited female participants with moderate TBI and found that coping strategies used by women following a TBI are similar to those used by men. These findings were confirmed by Tomberg et al (38) and Sasse et al (36) who found no, or a very weak, link between gender and coping style employed. However, Moore et al noticed that women in their study did tend to use a coping strategy consisting of a combination of self-blame and escape avoidance resulting in poorer outcome.

Limitations of this analysis

When reviewing the findings of the current analysis, the size of the evidence base should be considered. Only 10 articles satisfying all of the inclusion and exclusion criteria were identified. Several candidate articles gave a definition of acquired brain injury (ABI) that included TBI in addition to injuries caused by strokes, tumours and hypoxia (65-67), but as the TBI results were not separated out they were discounted.

The demographics of the populations studied within the identified articles appear to be consistent with the general TBI population; that is 40-50 years of age and predominantly male (68). However, there was a great deal of variation between the studies with respects to the severity of injury, measurement of pre-injury characteristics, the time of follow up post injury, and the QoL and coping scales used within the studies, each of which could have affected the consistency of the results observed.

Severity of injury

The majority of studies included all types of TBI from the uncomplicated mild to the very severe, most of which were classified according to the Glasgow Coma Scale. An analysis of all of the populations contained within the studies shows that the majority of participants had mild TBI (~40%) followed by moderate (~30%), severe (~20%) and very severe (~10%), and in the majority of studies that included multiple severities these were not analysed separately. Thus, it is possible that the severity of TBI confounded the results.

A review of the literature up to 2004 found that although severity of TBI was linked to physical health and neuropsychological functioning, it was not necessarily a predictor of QoL (69), a result confirmed by Tomberg et al (38). However, a more recent study examining QoL in participants with varying degrees of TBI, as assessed by computerised tomography (CT), showed that QoL one year post injury was strongly related to CT findings on admission (70).

The other question pertinent to this review is whether an individual's coping style would be affected by the severity of TBI. In general it appears that the severity of TBI has no effect on the coping style of a participant (38) and that the coping style of the participant after injury is the same as that prior to the injury (32). In fact the coping style of the participant seems to depend on a large number of variables which can impact the participant including pre-injury mental health issues, social and socioeconomic status, cognitive functioning and emotional distress (26 and references therein).

Results from the two studies, of the current analysis, that recruited only participants with mild TBI are consistent with those of the other eight studies that recruited different severity types, in that participants who used non-productive coping strategies have a worse outcome (33, 37).

Measurement of pre-injury characteristics

In three of the 10 included studies (31-33) pre-injury measurements of QoL and coping styles were obtained through the use of retrospective questionnaires soon after injury (during admission or soon after discharge). However, all of these authors note this process as a limitation of their studies because

participants' ratings may have been affected by injury-related cognitive or mental health issues, or by idealised visions of their pre-injury selves. However, Maestas et al (33) note that these concerns may be minimised in their study as the patterns of pre-injury coping strategies reported were similar between participants with less versus more severe injuries. In addition, Wolters Gregorio et al (32) noted that, in their study, rates of identified depression were low.

Time of follow up post injury

The time-span of follow up across all of the studies was 3 months to 15 years and it is possible that a participant's perception of their QoL, or an assessment of their coping styles, would differ as more time passed since the injury. The three true longitudinal studies (31, 32, 36) and the extended study by Tomberg and colleagues (26, 38) shed some light onto this question. Participants' QoL decreases after TBI and reaches its nadir between 6 and 12 months. After this point it is relatively stable, with a possible slight improvement, through to four to eight years' post-injury. Hence, QoL seems to be depressed compared with pre-injury levels but stable in the long term. However, there is some disagreement as to whether coping styles change over time from within the identified publications. Wolters Gregorio et al (32) showed a significant decrease in the use of productive coping within the first 6 months which was followed by a slight increase, but levels were still depressed compared with pre-injury levels. A smaller decrease was observed in non-productive coping over the first 6 months with an increasing trend thereafter, resulting in higher level use of non-productive coping than pre-injury. Tomberg et al (26) noted that while the use of problem-solving and avoidance-oriented coping styles did not change significantly between 2 and 8 years post injury, the use of social/emotional support strategies did. Furthermore, compared to controls, active coping remained reduced and avoidance-oriented coping remained high in the late period following TBI. These outcomes could be explained by cognitive issues in the initial phase post TBI hindering all coping strategies, or the use of other coping styles such as seeking spiritual or social support. They could also be explained by the participants having limited insight into their situations immediately post TBI, and so have fewer issues identified as needing to be coped with. But as time goes on insight may increase, which coupled with a

decreasing support network, would lead to increased use of non-productive coping strategies in the post-acute and chronic phases (32).

However, Sasse et al (36) did not find a significant relationship between the time since injury and the coping styles employed after TBI with similar levels of adaptive and maladaptive styles being employed up to 15 years post injury. The reason for this is not evident but could be related to the use of different outcome measures between the studies.

The QoL measures used

In the 10 studies included in the current analysis eight different QoL measures were used, the majority of which had good internal consistency and test/re-test reliability (Table 5). This level of variation of QoL measure used within the TBI literature was also found by Polinder et al (71). They performed a systematic review of QoL measurement and outcome in the TBI population and found that in 49 papers reviewed 18 different QoL instruments were used. They stated that the choice of QoL measure was probably driven by a number of factors including instrument length, availability in the local language, availability of normative population values and cost. However different QoL measures assess different domains of health in different ways, which can make comparisons across studies difficult (71). Thus, it would be beneficial to have some guidelines as to the best instrument to use for the different populations studied.

The coping measures used

In the current analysis six of the coping measures were situation-specific, three were dispositional and one was domain specific. As with QoL measures, comparison of data from studies using different coping measures is difficult, and it is made more difficult by the different definitions and terminologies used within these measures (15)

Conclusion

The current literature review has shown that there is limited published evidence for the effect of coping on QoL following TBI. Within this literature a wide variety of QoL and coping measures are employed, in addition to different severities of TBI examined and analytical methods used. Despite this variability, it appears

that most studies were consistent in the findings that participants using high levels of coping overall, and in particular avoidant coping, have a poorer outcome in terms of quantified QoL. There may be benefit in being able to identify this proportion of those who have sustained a TBI in order to access support in using more productive coping strategies. Within a UK population this would be best accessed via community brain injury multi-disciplinary teams providing both neuropsychological and vocational interventions. Nevertheless, further prospective studies employing appropriate and specific QoL and coping measures for the TBI population are required to confirm these results and to aid the design of population specific interventions.

References

1. Menon DK, Schwab K, Wright DW, Maas AI. Demographics and Clinical Assessment Working Group of the International and Interagency Initiative toward Common Data Elements for Research on Traumatic Brain Injury and Psychological Health. Position statement: definition of traumatic brain injury. *Arch Phys Med Rehabil*. 2010; 91(11):1637–40. [PubMed: 21044706]
2. Hyder AA, Wunderlich CA, Puvanachandra P, Gururaj G, Kobusingye OC. The impact of traumatic brain injuries: a global perspective. *NeuroRehabilitation*. 2007; 22(5):341–53. [PubMed: 18162698]
3. Nguyen R, Fiest KM, McChesney J, Kwon CS, Jette N, Frolkis AD, Atta C, Mah S, Dhaliwal H, Reid A, et al. The international incidence of traumatic brain injury: a systematic review and meta-analysis. *Can J Neurol Sci*. 2016; 43(6):774–85. [PubMed: 27670907]
4. Majdan M, Plancikova D, Brazinova A, Rusnak M, Nieboer D, Feigin V, Maas A. Epidemiology of traumatic brain injuries in Europe: a cross-sectional analysis. *Lancet Public Health*. 2016; 1(2):e76–e83. [PubMed: 29253420]
5. Dijkers MP. Quality of life after traumatic brain injury: a review of research approaches and findings. *Arch Phys Med Rehabil*. 2004; 85(4 Suppl 2):S21–35. [PubMed: 15083419]
6. Post MW. Definitions of quality of life: what has happened and how to move on. *Top Spinal Cord Inj Rehabil* 2014 Summer; 20(3):167–80. [PubMed: 25484563]
7. Pietersma S, de Vries M, van den Akker-van Marle ME. Domains of quality of life: results of a three-stage Delphi consensus procedure among patients, family of patients, clinicians, scientists and the general public. *Qual Life Res*. 2014; 23(5):1543–56. [PubMed: 24241818]
8. Pagulayan KF, Temkin NR, Machamer J, Dikmen SS. A longitudinal study of health-related quality of life after traumatic brain injury. *Arch Phys Med Rehabil*. 2006; 87(5):611–8. [PubMed: 16635622]
9. Hawthorne G, Gruen RL, Kaye AH. Traumatic brain injury and long-term quality of life: findings from an Australian study. *J Neurotrauma*. 2009; 26(10):1623–33. [PubMed: 19317590]
10. Scholten AC, Haagsma JA, Andriessen TM, Vos PE, Steyerberg EW, van Beeck EF, Polinder S. Health-related quality of life after mild, moderate and severe traumatic brain injury: patterns and predictors of

- suboptimal functioning during the first year after injury. *Injury*. 2015; 46(4):616–24. [PubMed: 25476014]
11. Dikmen S, Machamer J, Temkin N. Psychosocial outcome in patients with moderate to severe head injury: 2-year follow-up. *Brain Inj*. 1993; 7(2):113–24. [PubMed: 8453410]
 12. Emanuelson I, Andersson Holmkvist E, Björklund R, Stålhammar D. Quality of life and post-concussion symptoms in adults after mild traumatic brain injury: a population-based study in western Sweden. *Acta Neurol Scand*. 2003; 108(5):332–8. [PubMed: 14616303]
 13. Lazarus RS & Folkman S. *Stress, Appraisal and Coping*. New York, NY. Springer 1984.
 14. Folkman S, Lazarus RS, Dunkel-Schetter C, DeLongis A, Gruen RJ. Dynamics of a stressful encounter: cognitive appraisal, coping and encounter outcomes. *J Pers Social Psychol*. 1986; 50(5):992–1003. [PubMed: 3712234]
 15. Wolters Gregório G, Brands I, Stapert S, Verhey FR, van Heugten CM. Assessments of coping after acquired brain injury: a systematic review of instrument conceptualization, feasibility, and psychometric properties. *J Head Trauma Rehabil*. 2014; 29(3):E30–42. [PubMed: 23640542]
 16. Krohne HW. Stress and coping theories. In: Smelser NJ, Baltes PB editors. *International Encyclopedia of the Social and Behavioral Sciences*. 2001. Elsevier.
 17. Folkman S, Lazarus RS. *Manual for the Ways of Coping Questionnaire*. Palo Alto, CA. Consulting Psychologists Press Inc, 1988.
 18. Anson K, Ponsford J. Coping and emotional adjustment following traumatic brain injury. *J Head Trauma Rehabil*. 2006; 21(3):248–59. [PubMed: 16717502]
 19. Curran CA, Ponsford JL, Crowe S. Coping strategies and emotional outcome following traumatic brain injury: a comparison with orthopedic patients. *J Head Trauma Rehabil*. 2000; 15(16):1256–74. [PubMed: 11056407]
 20. Dawson DR, Schwartz ML, Winocur G, Stuss DT. Return to productivity following traumatic brain injury: cognitive, psychological, physical, spiritual, and environmental correlates. *Disabil Rehabil*. 2007; 29(4):301–13. [PubMed: 17364780]
 21. Malia K, Powell G, Torode S. Coping and psychosocial function after brain injury. *Brain Inj*. 1995; 9(4):607–18. [PubMed:7581356]

22. Moore AD, Stambrook M, Peters LC. Coping strategies and adjustment after closed-head injury: a cluster analytical approach. *Brain Inj.* 1989;.3(2):171–5. [PubMed; 2730975]
23. Finset A, Andersson S. Coping strategies in patients with acquired brain injury: relationships between coping, apathy, depression and lesion location. *Brain Inj.* 2000; 14(10):887–905. [PubMed: 11076135]
24. Wolters G, Stapert S, Brands I, van Heugten C. Coping following acquired brain injury: predictors and correlates. *J Head Trauma Rehabil.* 2011; 26(2):150–7. [PubMed: 20535030]
25. Shotton L, Simpson J, Smith M. The experience of appraisal, coping and adaptive psychosocial adjustment following traumatic brain injury: a qualitative investigation. *Brain Inj* 2007; 21(8): 857-69. [PubMed: 17676443]
26. Tomberg T, Toomela A, Ennok M, Tikk A. Changes in coping strategies, social support, optimism and health-related quality of life following traumatic brain injury; a longitudinal study. *Brain Inj.* 2007; 21(5):479–88. [PubMed: 17522987]
27. Frydenberg E, Lewis R. Frydenberg's Coping Strategies. Adolescent Coping Scale Second Edition (ACS-2) Long Form. Published by the Australian Council for Educational Research 2012.
28. Johnstone L., Boyle M., Cromby J., Dillon J., Harper D., Kinderman P, Longden E, Pilgrim D, Read J. The Power Threat Meaning Framework: Towards the identification of patterns in emotional distress, unusual experiences and troubled or troubling behavior, as an alternative to functional psychiatric diagnosis. 2018; Leicester, England: British Psychological Society. Retrieved from www.bps.org.uk/PTM-Main
29. Cohort Study Checklist, Critical Appraisal Skills Programme (CASP) [cited 2017 Nov 10]: Available from <http://www.casp-uk.net/casp-tools-checklists>
30. Dawson DR. The determinants and correlates of outcome following traumatic brain injury: A prospective study. Dissertation. University of Toronto, Canada. 2002.
31. Gould KR, Ponsford JL. A longitudinal examination of positive changes in quality-of-life after traumatic brain injury. *Brain Inj.* 2015; 29(3):283–90. [PubMed: 25356859]
32. Wolters Gregório G, Gould KR, Spitz G, van Heugten CM, Ponsford JL. Changes in self-reported pre- to postinjury coping styles in the first 3 years after traumatic brain injury and the effects on psychosocial and

- emotional functioning and quality of life. *J Head Trauma Rehabil.* 2014; 29(3):E43–53. [PubMed: 23835873]
33. Maestas KL, Sander AM, Clarke AN, van Veldhoven LM, Struchen MA, Sherer M, Hannay HJ. Preinjury coping, emotional functioning, and quality of life following uncomplicated and complicated mild traumatic brain injury. *J Head Trauma Rehabil.* 2014; 29(5):407-17. [PubMed: 23535388]
 34. Moore AD, Stambrook M, Gill DG. Coping patterns associated with long-term outcome from traumatic brain injury among female survivors. *NeuroRehabilitation.* 1994; 4(2):122–9. [PubMed: 24525322]
 35. Rutterford NA, Wood RL. Evaluating a theory of stress and adjustment when predicting long-term psychosocial outcome after brain injury. *J Int Neuropsychol Soc.* 2006; 12(3):359–67. [PubMed: 16903128]
 36. Sasse N, Gibbons H, Wilson L, Martinez R, Sehmisch S, von Wild K, von Steinbüchel N. Coping strategies in individuals after traumatic brain injury: associations with health-related quality of life. *Disabil Rehabil.* 2014; 36(25):2152–60. [PubMed: 24579650]
 37. Snell DL, Siegert RJ, Hay-Smith JC, Surgenor LJ. Associations between illness perceptions, coping styles and outcome after mild traumatic brain injury: preliminary results from a cohort study. *Brain Inj.* 2011; 25(11):1126–38. [PubMed: 21870903]
 38. Tomberg T, Toomela A, Pulver A, Tikk A. Coping strategies, social support, life orientation and health-related quality of life following traumatic brain injury. *Brain Inj.* 2005; 19(14):1181–90. [PubMed: 16286333]
 39. Flanagan JC. Measurement of quality of life: current state of the art. *Arch Phys Med Rehabil* 1982; 63(2):56–9. [PubMed: 6460487]
 40. Frisch M. *Quality of Life Inventory*. Minneapolis, MN. BCDE, 1994. 77p
 41. Ware JE, Kosinski M, Keller SD. *SF-36 Physical and Mental Health Summary Scales: A User's Manual*. Boston, MA: The Health Institute; 1994.
 42. Bergner M, Bobbitt RA, Carter WB, Gilson BS. The Sickness Impact Profile: development and final revision of a health status measure. *Med Care.* 1981; 19(8):787–805. [PubMed: 7278416]
 43. von Steinbüchel N, Petersen C, Bullinger M, QOLIBRI Group. Assessment of health-related quality of life in persons after traumatic brain injury – development of the QOLIBRI, a specific measure. *Acta Neurochir Suppl* 2005; 93:43–9. [PubMed: 15986726]
 44. von Steinbüchel N, Wilson L, Gibbons H, Hawthorne g, Hofer S, Schmidt S, Bullinger M, Maas A, Neugebauer E, Powell J, et al. QOLIBRI Task Force. Quality of life after brain injury (QOLIBRI): scale development and

- metric properties. *J Neurotrauma*. 2010; 27(7):1167–85. [PubMed: 20486801]
45. King NS, Crawford S, Wenden FJ, Moss NE, Wade DT. The Rivermead Post Concussion Symptoms Questionnaire: a measure of symptoms commonly experienced after head injury and its reliability. *J Neurol*. 1995; 242(9):587–92. [PubMed: 8551320]
46. Crawford S, Wenden FJ, Wade DT. The Rivermead head injury follow up questionnaire: a study of a new rating scale and other measures to evaluate outcome after head injury. *J Neurol Neurosurg Psychiatry* 1996; 60(5): 510–4. [PubMed: 8778254]
47. Herodes M, Õun A, Haldre S, Kaasik AE. Epilepsy in Estonia: a quality-of-life study. *Epilepsia*. 2001; 42(8):1061–73. [PubMed: 11554894]
48. Carver CS, Scheier MF, Weintraub JK. Assessing coping strategies: a theoretically based approach. *J Pers Soc Psychol*. 1989; 56(2):267–83. [PubMed: 2926629]
49. Kallasmaa T, Pulver A. The structure and properties of the Estonian COPE inventory. *Pers Individ Dif* 2000; 29(5):881–94. [doi: 10.1016/S0191-8869(99)00240-8]
50. Carver CS. You want to measure coping but your protocol's too long: consider the Brief COPE. *Int J Behav Med*. 1997; 4(1):92–100. [PubMed: 16250744]
51. Hardt J, Petrack F, Egle UT, et al. Was misst der FKV? Eine Überprüfung des Freiburger Fragebogens zur Krankheitsverarbeitung bei Patienten mit unterschiedlichen Erkrankungen. *Zeitschrift für Klinische Psychologie und Psychotherapie* 2003;32:41–50.
52. Muthny FA. Freiburger Fragebogen zur Krankheitsverarbeitung. Manual. Weinheim: Beltz: 1989.
53. Frydenberg E, Lewis R. Coping scale for adults. Melbourne, The Australian Council for Educational Research, 1997. 20p
54. Rexrode KR, Petersen S, O'Toole S. The Ways of Coping Scale: A reliability generalization study. *Educ Psychol Meas*. 2008; 68(2):262–80. [doi: 10.1177/0013164407310128]
55. Anson K, Ponsford J. Evaluation of a coping skills group following traumatic brain injury. *Brain Inj*. 2006; 20(2):167–78. [PubMed: 16421066]
56. Ware JE, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). Conceptual framework and item selection. *Med Care*. 1992; 30(6):473–83. [PubMed: 1593914]

57. Bergner M, Bobbitt R, Pollard W. The Sickness Impact Profile: validation of a health measure. In: Coelho G, Hamburg D, Adams J, editors. Coping and adaptation. New York: Basic Books, 1976:p. 127–38.
58. Folkman S, Lazarus RS, Gruen RJ, DeLongis A. Appraisal, coping, health status, and psychological symptoms. *J Pers Soc Psychol.* 1986; 50(3):571–9. [PubMed: 3701593]
59. Moore AD, Stambrook M, Peters LC. Coping following traumatic brain injury (TBI): Derivation and validation of TBI sample Ways of Coping – revised subscales. *Can J Rehabil* 1994;7:193–200.
60. Hays RD, Sherbourne CD, Mazel R. The RAND 36-item health survey 1.0. Santa Monica, CA: RAND Corporation, 1993. <https://www.rand.org/pubs/reprints/RP247.html>.
61. Tsyben A, Guilfoyle M, Timofeev I, Anwar F, Allanson J, Outtrim J, Menon D, Hutchinson P, Helmy A. Spectrum of outcomes following traumatic brain injury – relationship between functional impairment and health-related quality of life. *Acta Neurochir* 2018; 160(1):107-115 [PubMed: 28988342]
62. Cnossen MC, Polinder S, Vos PE, Lingsma HF, Steyerberg EW, Sun Y, Ye P, Duan L, Haagsma JA. Comparing health-related quality of life of Dutch and Chinese patients with traumatic brain injury: do cultural differences play a role? *Health Qual Life Outcomes* 2017;15(1):72 [PubMed: 28410593]
63. Reistetter, TA; Abreu, BC. Appraising evidence on community integration following brain injury: A systematic review. *Occupational Therapy International* 2005; 12(4):196-217 [PubMed: 16485508]
64. Ritchie, L; Wright-St Clair, VA.; Keogh, J; Gray, M. Community Integration After Traumatic Brain Injury: A Systematic Review of the Clinical Implications of Measurement and Service Provision for Older Adults. *Archives of Physical Medicine & Rehabilitation* 2014; 95(1): 163-174 [PubMed: 24016401]
65. Wolters G, Stapert S, Brands I, van Heugten C. Coping styles in relation to cognitive rehabilitation and quality of life after brain injury. *Neuropsychol Rehabil.* 2010; 20(4):587–600. [PubMed: 20446171]
66. Boosman H, Winkens I, van Heugten CM, Rasquin SM, Heijnen VA, Visser-Meily JM. Predictors of health-related quality of life and participation after brain injury rehabilitation: The role of neuropsychological factors. *Neuropsychol Rehabil.* 2017; 27(4):581–98. [PubMed: 26609798]

67. Brands I, Bol Y, Stapert S, Köhler S, van Heugten C. Is the effect of coping styles disease specific? Relationships with emotional distress and quality of life in acquired brain injury and multiple sclerosis. *Clin Rehabil.* 2018; 32(1):116–26. [PubMed: 28691532]
68. Peeters W, van den Brande R, Polinder S, Brazinova A, Steyerberg EW, Lingsma HF, Maas A. Epidemiology of traumatic brain injury in Europe. *Acta Neurochirurgica.* 2015;157(10):1683–1696. [PubMed: 26269030]
69. Dijkers M. Quality of life after traumatic brain injury: a review of research approaches and findings. *Archives Of Physical Medicine And Rehabilitation.* 2004;85(4 Suppl 2):S21–S35. [PubMed: 15083419]
70. Prieto-Palomino MA, Curiel-Balsera E, Arias-Verdú MD, Der Kroft MD, Muñoz-López A, Fernández-Ortega JF, Quesada-García G, Sanchez-Cantalejo E, Rivera- Fernández R. Relationship between quality-of-life after 1-year follow-up and severity of traumatic brain injury assessed by computerized tomography. *Brain Inj.* 2016; 30(4):441–451. [PubMed: 26963562]
71. Polinder S, Haagsma JA, van Klaveren D, Steyerberg EW, van Beeck EF. Health-related quality of life after TBI: a systematic review of study design, instruments, measurement properties, and outcome. *Popul Health Metr.* 2015; 13:4. [PubMed: 25722656]

Empirical Report

Qualitative assessment of an outcome measure in a community ABI service

word count: 7212

Abstract

A variety of outcome measures are used to determine the extent of disability in patients following an acquired brain injury (ABI). While valid and reliable these quantitative questionnaires provide a rigid structure within which patients must respond and this may miss pertinent information. Alternatively, analysis of interviews allows patients to talk about topics that are of importance to them, but may miss clinically relevant issues. This study explored whether results from qualitative analysis of patient interviews accurately reflected results from a quantitative outcome measure. A quantitative questionnaire (EBIQ) and a semi-structured qualitative interview were given to five participants who had an ABI and three of their significant others. Both sets of results were then brought together and compared in a concurrent triangulation mixed-methods analysis. In the main qualitative themes did track quantitative domains, however some emergent themes in interview fell outside of the specific domains of the EBIQ. This pattern was also evident for the significant others. It appears that the addition of qualitative analysis of patients' narrative can enrich quantitative results from the EBIQ, which may lead to better clinical outcomes.

Introduction

An acquired brain injury (ABI) involves damage to the brain after birth and is not related to a congenital or degenerative disease (1). Impairments may be temporary or permanent and can cause partial or functional disability or psychosocial maladjustment (2). ABI is the most common cause of death and disability in young people with hospital admissions of 566 per 100 000 in the UK in 2013-14 (3), and 100-150 per 100 000 are likely to have an impairment that affects their life six months post injury (4). Ensuing disabilities are heterogeneous and complex, encompassing both physical and psychological changes; motor and sensory deficits, cognitive impairment, altered emotional response, and loss of behavioural control (5, 6). All of these factors can have a significant impact on the patient's personal and social life and quality of life (6). Thus, there is a clear need to determine the status and potential deficits of the patient as early as possible post-injury to guide treatment plans and to ensure that appropriate support is provided.

Global measures of disability, developed to estimate the overall level of handicap and social disadvantage of a patient, can be used to help evaluate a patient's situation upon initial referral to a service. These measures may be re-administered during on-going care to assess any improvement that the client may have made in reducing handicap and increasing quality of life and independence. The areas that such measures can inform include: service need, level of care, prognosis, length of hospitalisation, and potential financial recommendations (7). Furthermore, in an increasingly cost-conscious healthcare environment, quantitative outcome measures, whose results may be easily interpreted by commissioners, are used to provide evidence of the value of the service to the local population and the need for service evaluation, development and commissioning. The importance of measuring need and monitoring progress using outcome measures has been nationally identified within the UK (8).

The European Brain Injury Questionnaire (EBIQ) is one such measure and was designed to assess cognitive and social dimensions, together with basic activities of daily living in 9 domains: somatic, cognitive, motivation, impulsivity,

depression, isolation, physical, communication, and core symptoms (9). This is a reliable measure presented in a simple 63 item questionnaire which was specifically designed to address common issues stemming from brain injury: avoiding excessive exertion and tiring effects and avoiding semantic issues which may be problematic for those with dysphasia. Despite its brevity (compared to other measures assessing the sequelae of ABI), this measure still scores well for reliability and validity when tested internationally using nationally derived control data (9, 10). The EBIQ gains input from both the patient and a significant other (SO) providing a useful additional perspective which mitigates the possible lack of self-awareness and insight into their condition that a patient may have due to a moderate-to-severe brain injury (11).

However, by their nature, questionnaires such as the EBIQ require a person to categorise their experiences by predefined question and response sets. This may limit reporting of issues of concern and measurements of perceived improvement. Another approach is to perform structured or semi-structured interviews with patients, allowing them, with the use of open questions, to talk in-depth about topics using their own words and voice. These interviews can be analysed qualitatively, looking at the themes that emerge and what is important to the patient (12, 13). Thus, the questionnaire-based, hard-data, quantitative model may benefit from a richer qualitative evaluation. While there is research on qualitative experiences of having an ABI (12, 13, 14) and on developing valid quantitative questionnaire outcome tools for ABI (9, 15, 16), no literature can be found exploring how well these quantitative tools reflect clients' subjective experiences when being used in clinical settings.

The principal research objective of this study is to explore, in a community-based acquired brain injury population in the UK, whether results endorsed on a quantitative outcome measure accurately reflect a client's experience, as reported by themselves and a SO where available. A secondary research objective is to add to the debate around using quantitative assessment of quality of life. In summary: how well does a client's current experience relate, in their own words, and in the view of a SO where available, to what is endorsed on an outcome measure.

Method

Design

In order to explore the experiences of participants within this heterogeneous and complex client group a series of five single case studies were used. Each case study comprised a qualitative interview and a quantitative questionnaire from the participant and, where nominated, their significant other (SO). The interviews with the participant and SO were conducted separately and resulting qualitative (thematic analysis) and quantitative (EBIQ data) data were then brought together and themes of importance compared in a concurrent triangulation mixed-method analysis (17).

Limiting recruitment to five case studies (a maximum of 10 participants) allowed for a greater depth of individual qualitative analysis than in a larger study and was consistent with study populations in ABI (14) given the heterogeneity and small numbers of the population. In order to answer the relatively simple research question the sample size was determined by the preliminary nature of the enquiry, a number sufficient to be useful and available time and resources (18). It has been proposed research exploring multiple case studies should compose 4-5 cases with 3-5 interviewees per case study (19) or 15-30 interviews for single case studies (20). A single digit sample size (case studies) was decided appropriate (21) in consultation with the researcher's tutor and supervisor. It was decided a study at the upper end of this range, to a maximum of 5 case studies, with 2 interviewees the maximum per case study, was most appropriate to the resources available while still providing meaningful and informative results.

Epistemology

A post-positivism pragmatic approach was taken by the researcher. That is to say it was assumed that both the quantitative and qualitative data would provide acceptable knowledge but that they would be integrated to help interpret the data as a whole. However, both the interview and the questionnaire can only

approximate the truth, as the full reality of the personal experience of the consequences of the acquired brain injury may never be fully apprehended.

Recruitment

Approval from the University of Keele Independent Peer Review Committee (Appendix 1.1), NHS Research Ethics Committee (Appendix 1.2) and local NHS Research and Development department (Appendix 1.3) was obtained for this study. Clients attending a community NHS neuropsychology service and with a diagnosis of ABI were invited by their clinician to receive information about the study. The number of clients informed of the study was not recorded.

Participants' inclusion criteria mirrored the referral criteria to the team: 1) adult age, ≥ 18 years old; 2) with neurological problems from ABI. When meeting their clinician clients were provided with a letter of invitation (Appendix 1.4) and an information sheet (Appendix 1.5) describing the study and invited to consider participation within a 2 week period. When permission was granted, either in person to the clinician or by reply slip, the researcher followed up with a telephone call within the week. During this call a meeting was arranged at the clients' home to discuss participation in the study and, if applicable, arrange research meetings. All of the five clients who gave permission for this contact subsequently joined the study. Potential participants were also approached for permission to recruit a SO to the study. SOs were considered to be family members, close friends or carers identified by the client as a main source of day-to-day contact and support. All meeting with clients and SO took place on the same day, with participants' consent, to provide congruence in timelines and took place at the clients' home.

At each meeting only the individual participant and researcher were present. The order in which the client and SO were interviewed was directed by the participants' wishes to emulate clinical practice. At the first meeting the researcher explained the proposed study (with the information sheet, Appendix 1.5) and answered any queries before asking potential participants to sign informed consent forms (one to be kept by the participant and one by the researcher, Appendix 1.6).

From this point clients and SOs were considered as potential participants with consent and meetings completed individually. If one of the participants within a client/SO dyad withdrew the other was invited to continue.

Five clients who elected to receive information about the study subsequently completed participation. Three of these participants elected to invite significant others to join the study and this was also seen through to completion.

Table 1: Client demographics

Participant name	Gender	Age range	Initial severity of ABI
Anne	Female	60-65	severe
Cathy	Female	45-50	moderate
John	Male	50-55	severe
Helen	Female	35-40	moderate
Oliver	Male	55-60	severe

Ethical issues

The main ethical issues which arose from this study were obtaining informed consent from participants, participant confidentiality and the prevention of any distress being caused to any participant. Fully informed consent to participate in the study was sought by providing each potential participant, when meeting with their clinician, with an information sheet which clearly explained the purpose and involvement in the research project. This information was also described to the client by their clinician. The information provided explained that participants were free to decline, or opt out, of the study at any time without affecting their clinical treatment at any point now or in the future. There was no coercion to take part in this study.

Consent and participation was only to be sought if it was clear that the information presented had been understood. Confidentiality was ensured by assigning each participant with a unique anonymised code on entry to the study. This code was used on all EBIQ sheets completed by the participant. On transcription all participants, and anyone mentioned in the interview, were allocated pseudonyms. Details of the anonymisation and pseudonyms were kept in a separate locked location from all research data. At no time was access

to case notes required for the purposes of this research. Additionally, data acquired during the study was not shared with the rest of the clinical team except in an anonymised form.

As this study presents a standard and widely used outcome measure to current clients of a neuropsychology service undue emotional distress was unlikely. If a participant had become distressed they would have been asked if they wish to stop and referred to a trained member of staff from their clinical team.

Outcome measure

The European Brain Injury Questionnaire (EBIQ, Appendix 1.8) is a valid and reliable outcome measure designed to subjectively assess cognitive and social dimensions, together with basic activities of daily living for people with an ABI (9, 10). These are measured in 9 domains: somatic, cognitive, motivation, impulsivity, depression, isolation, physical, communication, and core symptoms. Within each domain each question asks whether, within the last month, the issue has been experienced: 1 – 'Not at all', 2 - 'A little' or 3 - 'a lot'.

Both client and SO versions explore the client's recent experience of symptoms associated with ABI. The questions in each version mirror each other only differing by changing from second person to third person, respectively. When used by clinical services the EBIQ is usually presented as part of initial assessment and at the conclusion of planned intervention.

Semi-structured interview

The client and SO interviews were purposefully designed to explore all the domains covered by the EBIQ, from the client's and SO's perspective respectively, and to avoid bias which may result from an in depth discussion of a spontaneously arising single issue (Appendix 1.9). The interviews also included identical scope for open ended exploration of areas of importance to the participants (22). This ensured a full comparison of EBIQ data to interview transcripts was possible.

Research methodology

The appropriate client or SO version of the EBIQ was completed by each participant with the researcher available for assistance or clarification. After completion of the EBIQ a semi-structured interview was conducted without reference to the EBIQ data to allow for independent comparison of the data from the two different sources, qualitative and quantitative.

Data Analysis

This study used a convergent design to compare findings from the qualitative and quantitative data sources (23, 24). Both types of data were collected at the same time; analysed separately, and compared through joint displays of the data. In such a way the two types of data provide validation for each other and create a solid foundation for drawing conclusions about the intervention.

Thematic analysis was used to identify explicit descriptions of issues (25) arising within the transcribed interviews from each participant. Both a priori thematic categories/codes, based on the elements described in the EBIQ domains, and emerging themes outside those described by the EBIQ were identified to determine to what extent the EBIQ captured the participants' experience (26). This resulted in data organised to show patterns in semantic content and summarised (25).

The thematic analysis procedure was conducted based on a method proposed by Braun and Clarke (2006). This systematic method was applied rigorously in each case, in parallel with supervision, to enhance the quality of analysis. Each transcript was explored in six stages adapted from methodology suggested by Braun and Clarke (25):

1. The transcript was read and reread to allow the author to record any initial thoughts, reflections, or questions that were raised by the text
2. Initial coding was completed of participant discussion of issues resulting from ABI in each transcript and relevant data noted.
3. Coding was then collated against a priori EBIQ domain themes or in themes identified as falling outside the scope of the EBIQ.

4. The themes were re-checked against the coded extracts
5. Themes were refined and located within the client's overall story. Clear definitions and names for each theme falling outside the EBIQ domains were identified.
6. The coding for each theme was analysed for comparison against EBIQ quantitative data and presented graphically for each participant. Information for themes falling outside the EBIQ domains was collated to report for all participants.

NVivo 11 software (QSR International) was used to explore the transcripts, define codes and identify themes. When all coding in a transcript had been completed the software was used to analyse the percentage coverage for each identified EBIQ domain and for the themes falling outside the EBIQ, as described in step 6 above. The percentage coverage was calculated by comparing the amount of transcript coded for the domain in question against the total length of each transcript to obtain a percentage (using characters as the unit of measurement). This was performed for each domain and theme within each participant's interview. This measure of relative volume of text coded for each domain only provided a fixed numerical approximation for amount of each individual's interview coded to a domain (27).

As percentage coverage was only used within individual interviews this overcame the possible confounding variables of differing transcript length and verbosity which would be an issue with analysis between participants (28). The percentage coverage values were used in conjunction with the original coded material, and the researcher's contemporaneous notes, to identify influential themes and any impact of unexplored domains within each interview (24, 27). No previous studies using similar mixed methods could be identified in the literature: either when exploring an outcome measure or in quantifying structured-interview data with percentage coverage. The ensuing limitations with regard to reliability and validity will be discussed.

The percentage coverage data were moved to a Microsoft Excel spreadsheet in order to integrate and compare qualitative (percentage coverage) and quantitative (EBIQ results) data. As interviews and the resulting transcripts were of variable length the resulting percentages were presented in individual graphs for comparison with each participant's EBIQ scores rather than across the participant group. The percentage coverage was enriched with coded material and researcher observational notes. In combining the two data sets (17) in this way to explore EBIQ results a pragmatic approach was adopted for this analysis (27) as with the decision on sample size, above.

The reliability of coding was checked by an independent researcher with experience both in neuropsychological services and in thematic analysis.. An anonymised transcript was provided and coded in concordance with the above protocol. The independent researcher's coding was in 95% concordance with the primary investigator's coding of the same transcript. This was assessed by comparing coding for both a priori themes and emerging themes identified from hard copies of the same transcript.

In line with a concurrent triangulation design (as this is independent assessment of the same phenomena) after analysis of each participant's EBIQ and interview data the resulting qualitative and quantitative information was given equal status for integration. Graphs were plotted showing percentage coverage of coded data within each interview, for each domain, against EBIQ domain score. These graph plots were visually inspected to explore concordance between their profiles in parallel with reference to raw interview and EBIQ data. This allowed exploration of any divergence in observed peaks and troughs of the plots. This concurrent use of raw data and researcher notes was considered to give greater depth to the qualitative nature of percentage coverage measure. This qualitative consideration is reported along with the graphical representations.

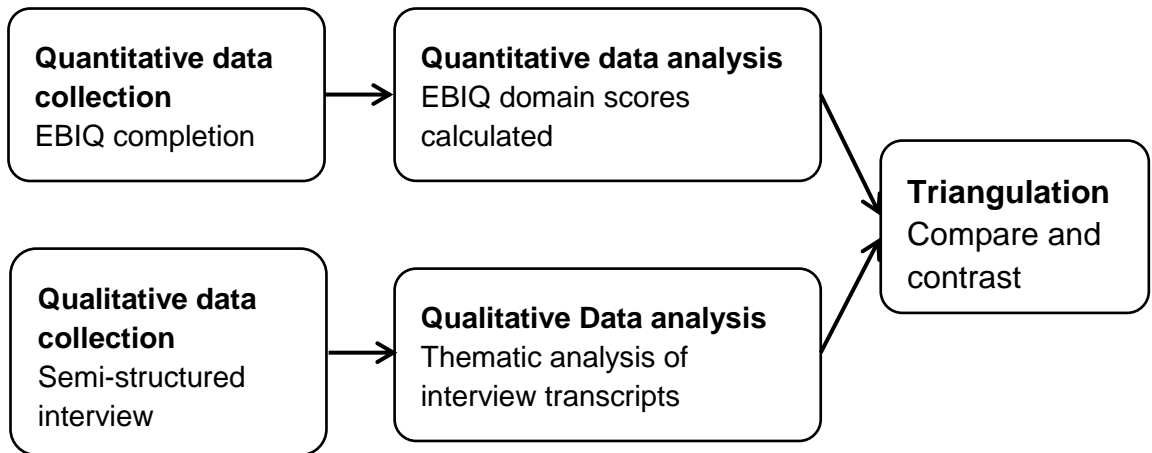


Figure 1: Analysis of quantitative and qualitative data

Results

Domains described in the EBIQ are represented by participant and SO pair or by sole participant where an SO was not available. The interview data and EBIQ domain scores are represented graphically. Each graph represents data from a single participant with average EBIQ domain scores represented by filled bars against the left-hand axis. For interview data the percentage coverage identified for each domain, as coded in the transcript, is shown by a line plot against the right-hand axis. Any divergence between the most richly described issues on interview (high points on the line plot) and EBIQ scores for that domain were explored.

Themes identified, from the transcripts, which fell outside the described EBIQ domains are categorised as 'other' on the graphs and are discussed later across all participants.

Anne and Stephen

Anne and Stephen (SO, partner) described a similar spectrum of difficulties in their interviews. However Stephen's pattern of response between the interview and EBIQ results showed some divergence in some domains.

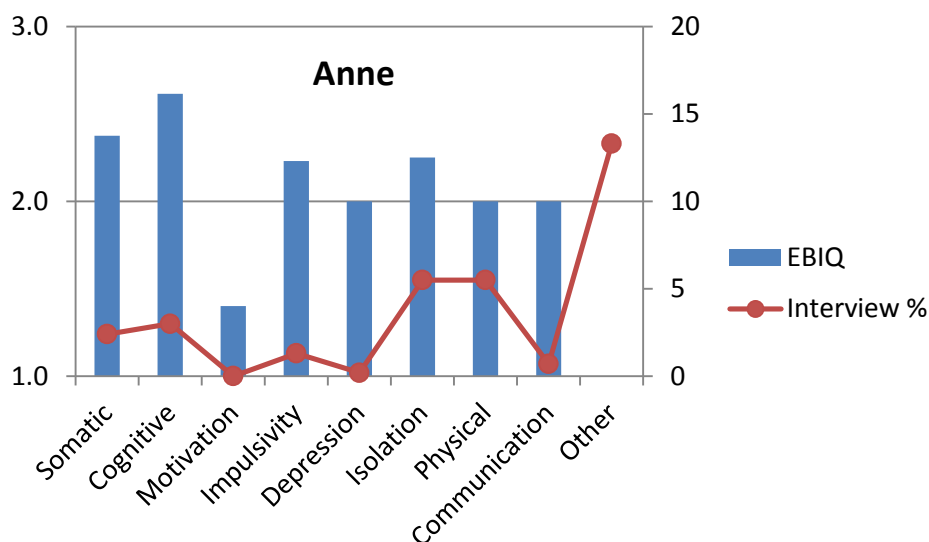


Figure 2. Anne's EBIQ score by domain and related percentage coverage in interview.

Anne spoke of cognitive issues but the resultant loss of independence and isolation formed the predominant themes within her interview. Isolation was spoken of as the most significant cause of Anne’s distress impacting on multiple domains. Isolation was described as encompassing: cognitive issues not being understood, and lack of social contact due to limitations in being able to travel independently, due to both cognitive and physical issues. However the scoring of the EBIQ placed the emphasis on the causative issues which resulted in high EBIQ scores in both isolation and cognitive domains.

Anne: ‘Memory is a nightmare. Remembering names ...’, ‘I know what people are saying to me, but within a flash it’s gone.’

‘I feel that there isn’t anybody there I can go and talk to, that they’ll think I’m silly’

‘I think [relative] thinks I’m deaf, not daft, because s/he tends to shout loud at me when s/he’s talking to me – oh dear!! But yeah, I think people think I’m not all there, because I am, I am all there’

‘Well I’m stuck in here [the house], I’m not allowed to go out’

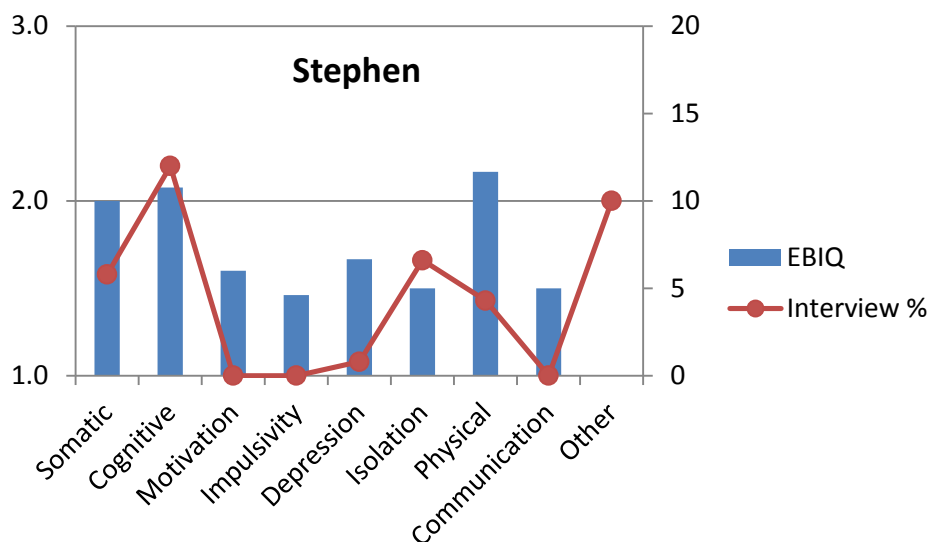


Figure 3. Stephen’s EBIQ score by domain and related percentage coverage in interview.

In interview with Stephen cognitive issues were noted as the theme of primary concern to him regarding Anne's ABI, with emphasis placed on these issues. The connection with the resultant isolation was also discussed and reflected in the domain score for his SO version of the EBIQ.

Stephen: 'Short term memory, I'll probably in a day or two have to remind her that you've been today. I know it sounds, you know, perhaps a bit too...but she is like that, she forgets things. But long term she'll remember.'

Stephen also identified Anne's isolation as a significant issue within interview. However the highest domain score in Stephen's EBIQ was recorded for physical issues. Inspection of raw data showed three of the six items within this domain were scored at a '3 - a lot' and one at a '2 - a little'. These items reflected issues, including one relationship issue, which were only mentioned briefly in interview.

The relatively low percentage coverage for EBIQ domains within Anne's interview may be correlated to 13.3% of the themes being identified as outside the scope of the EBIQ. Themes Anne and Stephen brought up included issues with independence, mood, cognition, relationship issues and communication.

Cathy and Richard

In the graphs plotting interview versus EBIQ data for both Cathy and Richard (SO, partner) initial visual inspection of their respective peaks in the plot profiles suggested divergence in their respective response sets.

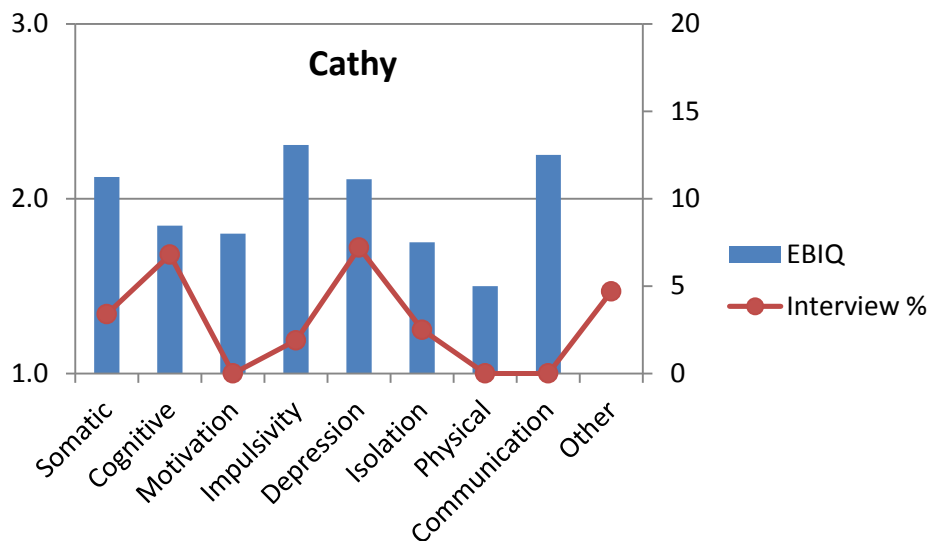


Figure 4: Cathy's EBIQ score by domain and related percentage coverage in interview.

Cathy's interview data showed peaks for cognitive and depression domains. However her EBIQ data did not show the same pattern with 4 domains averaging greater than '2 – a little': somatic, impulsivity, depression and communication. Examination of the EBIQ raw data identified Cathy scored domains described in the interviews as issues with changes in personality. The EBIQ items associated with impulsivity, which were rated as 3 – 'A lot', broadly encompassed being quick to both get frustrated with others and upset by others. When compared to the interview transcript this was briefly referred:

Cathy: 'Because on a day to day basis I forget such specific things, ..., but I get quite cross quite quickly'

'I try to keep it in, but sometimes it just bursts out of me and I shout'

These issues were also referred to in the interview in the context of issues within the context of dynamics with the family and in the third extract referring to using strategies such as a calendar:

*Cathy: ‘after my brain injury, I couldn’t concentrate and focus the same’
‘I find it more difficult to concentrate. I struggle to concentrate anyway
and I think a lot of that is from being in the house on my own, doing
house chores and general things and it’s easy to wander from one thing
to another’*

So it appears some of the high scoring EBIQ domains were only addressed briefly in interview.

Cathy’s interview data suggest a focus on cognitive issues which again did not tally with EBIQ data. Examination of the interview coding showed that cognitive issues were discussed in detail, and as a significant issue, both due to the brain injury and as a result of loss of valued roles following the injury e.g. reducing voluntary work and difficulty managing around the home. For Cathy the impact of the cognitive issues led to clearly expressed feelings of low self-esteem and self-worth which had a significant impact on day-to-day, and family, life since her ABI.:

Cathy: ‘I feel inferior that way and I feel it’s never good enough’

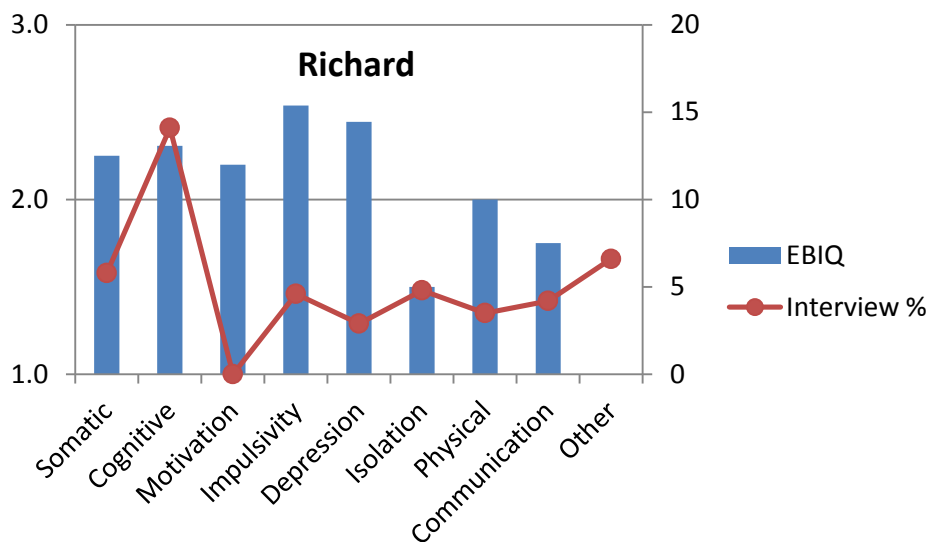


Figure 5: Richard’s EBIQ score by domain and related percentage coverage in interview.

Richard also showed divergence between the pattern of results from the EBIQ and interview data. Cognitive issues were the predominant issue discussed within interview and these were also scored highly by Richard on the EBIQ. Richard spoke of the impact of slowed processing speeds and decision making (cognitive) on the completion of tasks.

Richard: '... does do things slowly, she has to do things one thing at a time, sort of multitasking, I mean she does multitask, but multitasking is difficult for her.'

'But there's a huge amount of uncertainty actually, yeah there is ... but she will always look for reassurance in terms of any decision that she makes ... every decision is a challenge'

However other domains with attracted high score on EBIQ completion, though discussed, were spoken of more briefly, as in Cathy's report. When prompted with questions on other domains the transcript showed brief responses.

Richard scored the motivation domain highly for lack of interest in activities and completing tasks. However this was not directly addressed in the semi-structured interview. Within both Cathy's and Richard's interviews these issues were addressed as consequences of cognitive issues which then limited independence.

John and Fiona

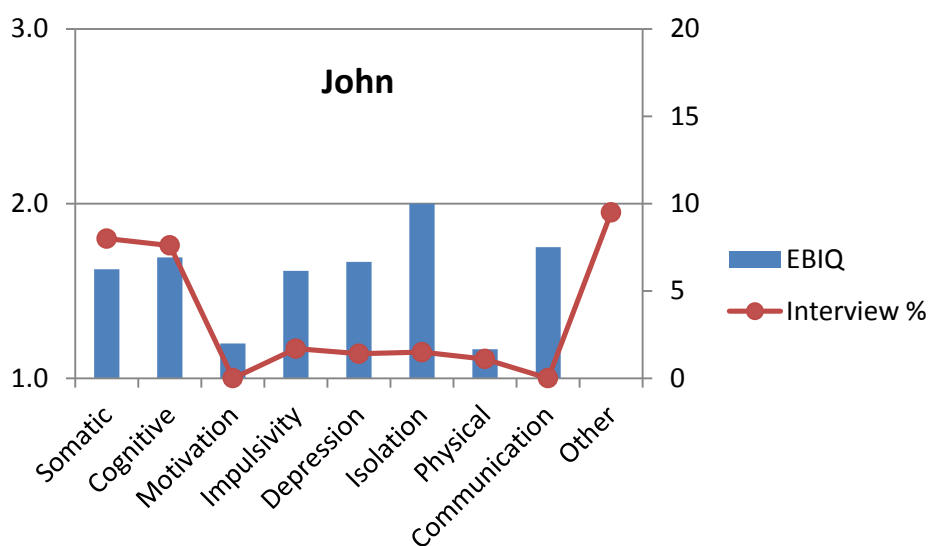


Figure 6: John's EBIQ score by domain and related percentage coverage in interview.

Visual inspection of John's graph data suggests a trough in interview data in domains showing moderate EBIQ results. On inspecting the raw data, in interview and EBIQ responses, somatic problems were identified as significant issues impacting on John's quality of life: fatigue in particular. This was described as exacerbated by sleep issues. While this focus on fatigue was not reflected by the percentage coverage of coded material in John's interview it was made clear in his spoken emphasis.

John: "It's the fatigue one, the tiredness, that's the biggest ... [issue]"

Three domains' results were not comparable between EBIQ and interview for John. In the impulsivity domain bossy and annoyance scored highly whereas on interview impulsivity was described only briefly

John: 'If I've got any mood swings and it's not violent or anything like that, but an argumentative thing, it's always at Fiona, always. It's not with anybody else or whatever.'

'I just say something out of the ordinary – why would I say that ... and then 5 minutes later I start, what have I done. And I come back "I'm so sorry, I didn't mean that, didn't mean that in any way". I'm not that kind of person, not argumentative person.'

EBIQ depression was scored 'a lot' only for "feeling hopeless about future".

Again depression items were discussed in interview but succinctly and without emphasis

The greatest disparity was observed in the results for the isolation domain. On the EBIQ items describing "others don't understand problems" and "hiding feelings from others" were scored 'a lot' elevating the 4 item domain score. Within the interview John described only discussing feelings of isolation with his neuropsychologist. John reports when Fiona was told about these feelings she described being surprised he had not shared them (corroborated by Fiona in her interview). This lack of discussion on the topic appeared to be repeated within the research interview.

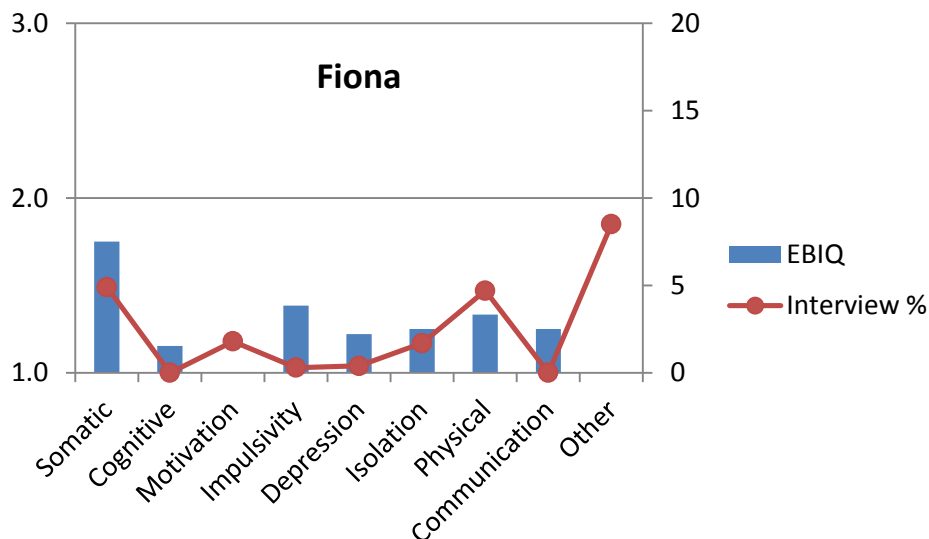


Figure 7: Fiona's EBIQ score by domain and related percentage coverage in interview

Fiona was also brief in her description of difficulties but somatic issues also featured prominently in descriptions of John's current issues.

Fiona: 'He gets very tired easily, fatigued'

The only other prominent issue, within EBIQ domains, identified by Fiona was within the physical EBIQ domain and focused on feeling uncomfortable in crowds. This was in agreement with scores on items within the EBIQ.

Fiona: Yeah he does, I mean he still doesn't want to go out into big busy crowded places. I mean he'll go up to [local area] and walk around, but if you were to go out to a pub or something like that, if it was too crowded it'd be a bit no I'll go. But he doesn't tend to put himself in those sort of situations.

When describing difficulties with crowds Fiona went on to describe how this issue led to John's perceived loss of motivation to engage with previously valued social activities. This was not the only area where interview and EBIQ results were seen to diverge in Fiona's report. Though the impulsivity and depression domains were scored quite lowly on the EBIQ they were only very briefly discussed in interview.

Helen

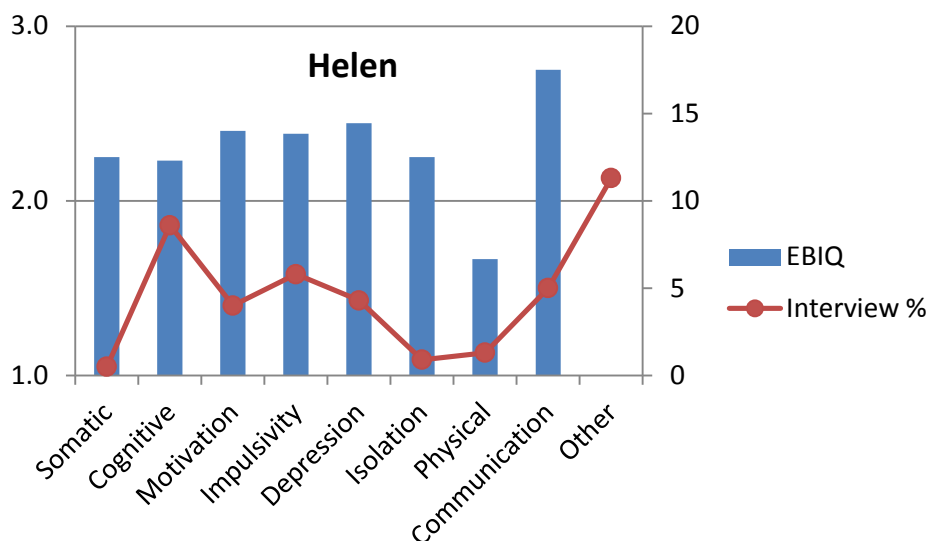


Figure 8: Helen's EBIQ score by domain and related percentage coverage in interview

Helen's responses to the EBIQ resulted in mean scores above 2 (a little) for 7 of the 8 domains. This high profile for the majority of domains was reflected in the plot describing interview data in cognitive, motivation, impulsivity, depression and motivation. Helen's description showed a focus on cognitive issues and clearly described struggles which have impacted on communication and loss of social contact:

*Helen: "“Yes in thinking skills and communicating with people, I do struggle ... because I'm not very quick at thinking “
[Planning and memory] “That's very stressful now, I don't always do things in the right order and I get side-tracked.”*

However somatic and communication domains appear to diverge. On inspection of the raw data scores of sleep issues were mentioned in interview but not discussed. Other areas marked as 3 (a lot) on the questionnaire were not acknowledged in discussion. Though the EBIQ result for 'communication' domain (4 items) appears greater than coded interview coverage the emphasis placed on the issue within her spoken description redressed this balance.

Helen: “Just listening and I might give my little penny worth here and there, but I’ll just tend to sit there and let everybody else get on with it

As with other participants, the majority of coded material, 11.3%, fell outside the EBIQ domains.

Oliver

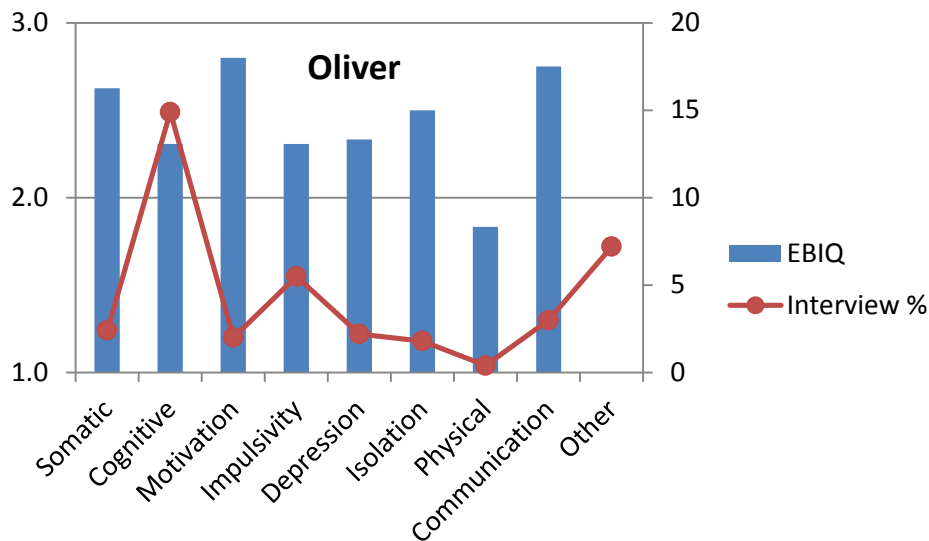


Figure 9: Oliver’s EBIQ score by domain and related percentage coverage in interview

Oliver’s interview data, when plotted, showed a clear peak in percentage coverage for cognitive issues and lower percentage coverage for other domains. Visually this was at odds to the relatively flat, but elevated, profile of EBIQ results. Inspection of raw interview coded data clearly shows a focus on discussing cognitive issues in relation to valued activities with practical analogies. For example memory and concentration issues:

Oliver: “So imagine you’re standing in your kitchen and you’ve got 4 saucepans on 4 hobs and you haven’t got to let them boil over. Now imagine that you’ve got 4 kitchens in a row along a corridor, each with a cooker in, each with one saucepan in. So when I’m in kitchen 1 I’ve got no idea what’s happening in 2, 3 and 4.”

These full descriptions impacted on the pattern of percentage coverage. Examination of EBIQ responses and other interview domains indicated a similar profile of response.

'Other' themes lying outside the EBIQ domains

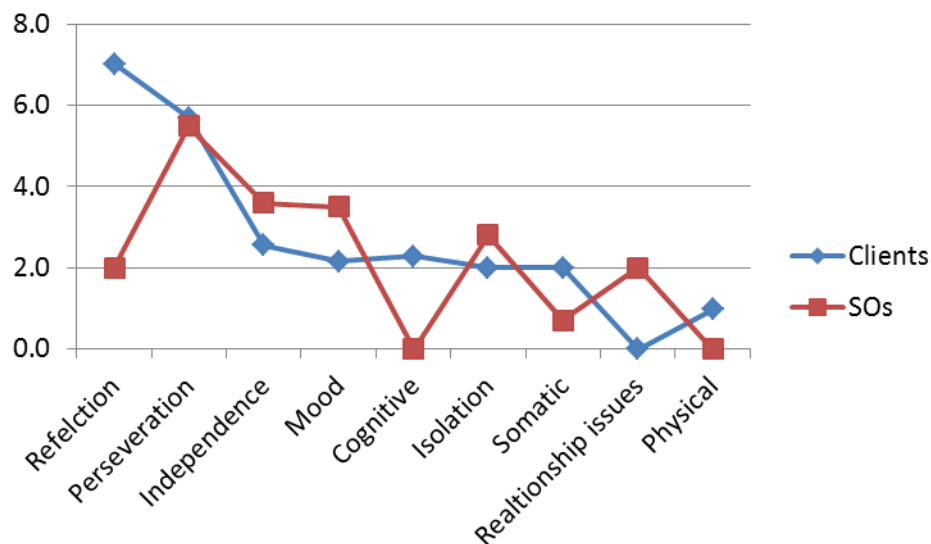


Figure 10: Average percentage coverage, across participants, for themes which were not covered by the EBIQ

In each interview issues were spoken of and coded which did not fall within the a priori thematic EBIQ categories. Ten themes were identified: reflection, perseveration, independence, mood, cognitive issues, isolation, somatic, relationship issues, physical.

Reflection

Reflection on improvement and use of effective coping strategies was a theme in most of the client interviews and some SO interviews. This covered both practical strategies such as keeping diaries and cognitive rehearsal techniques. Added benefits from these improvements were also identified:

John: "A lot easier, yes. I'm believing I'm having confidence. One of the biggest things I lost was trust and confidence to do anything and that's coming back now"

Perseveration

This theme was identified as an issue of importance for one participant and was also reported by their SO. This comprised perseveration on both practical tasks and with trains of thought. This was seen as an issue regardless of encouragement or fatigue:

John: Fiona says will you leave it now, let's go to bed. I said Fiona 'I aint going anywhere until this is done and this will get done, this will get done'"

Independence

Anne and Stephen described in depth issues in relation to loss of independence in managing additional health related difficulties and the associated appointments and the resulting need to rely on others. These sentiments were recognised by Anne.

Anne: 'so many appointments for different things, that I find it causes a bit of aggravation in my life. Because I'm not able to go to these appointments myself'

'I feel I've got to ask somebody to take me and I don't want that, I want to be able to do things myself. And I find that very, very frustrating'

Mood

A theme emerged around mood issues which were not identified within the EBIQ. Frustration and low mood were identified as direct results of limitations due to cognitive or somatic issues. This appeared to lead to descriptions of issues with self-confidence which are not addressed by the EBIQ (items relating to inferiority and worthlessness) from four clients, for example:

Cathy: "I don't feel confident and I feel...I question myself all the time, I'm almost uncomfortable with myself sometimes"

Cognitive

In this situation the term cognitive was used to describe a theme of cognitive issues not directly explored within the EBIQ cognitive domain. For example repeatedly being aware of '*losing track*' of conversation (within the interview), issues with word construction (playing Scrabble) and sensitivity to loud or busy situations.

Isolation

Aspects of isolation not covered by the EBIQ were spoken of by 3 clients. These themes included: loss of valued occupation, avoiding new social contacts specifically to avoid having to explain the ABI, and feeling the need to avoid busy and emotive family activities.

Somatic

Within three client interviews additional somatic issues were spoken of including: hearing loss, loss of sense of taste and smell and health issues not related to an ABI.

Relationship issues

One client described issues with her SO being unable to understand her needs for assistance with balance issues when outside the house. This was spoken of as an additional problem 'in everyday life' which was caused additional unwanted stress.

Physical

Three clients also identified issues which could be described as in a physical theme and directly resulting from the ABI: weight gain (due to reduced activity), balance issue and clumsiness.

Discussion

The current study has shown that results from qualitative interviews of patients following an ABI did not directly mirror the results obtained from the quantitative EBIQ questionnaire. Themes arose in interviews which were not covered by the EBIQ and EBIQ domains were seen to identify clinical causes of issues identified as difficult in interview. Thus, the interview and questionnaire were seen to be synergistic, having benefits that complement each other. The questionnaire may be a good prompt and be an easier format for patients to disclose issues in sensitive areas, while the interview provides a greater depth of information, an opportunity for a patient's story to be heard, and identified areas which would have been missed by the EBIQ.

Considering the results of this study one might question whether the EBIQ is an appropriate choice as an outcome measure in the ABI population. It is useful in the early stages of rehabilitation as it accommodates frequently occurring needs and issues of patients, is brief and is easy to deliver – all of which are important for both face validity and service delivery. It also has a good test/re-test validity over a period of one month (10). Bateman et al (29) explored the validity of the EBIQ sub-scales and proposed modifications, through Rasch analysis, for its use in research purposes. These modifications included the suggestion of adding a 'fatigue' subscale. However Bateman et al (29) also acknowledged the clinical utility of the full 63-item scale and promoted its continued day-to-day use across multiple service settings. However, in the long term does it capture a true picture of lived experience and the improvements that patients make? The structure of the EBIQ does allow free text at the end but does not prompt or the capture of positives such as the improved use of coping strategies, and may mask other issues.

Finally, when analysing data from the EBIQ the number of questions within each domain must be taken into account. These can vary from 4 to 13 so if using the means from a domain with a small number of questions, the weight of each individual question will be increased compared with a domain with a larger number of questions. In the current study the influence of individual question weights only became clear when the raw data was examined.

One could also question the validity of the analysis method in this study. While the structure of the interview aimed to avoid bias of discussion of one issue to the detriment of others one might also view this as moving away from the participants' true account. So although the interview was constrained by design (necessary to answer research question), it still led to a richer description of lived experience than questionnaire. Then thematic analysis was used and driven by the objective to explore a specific research question i.e. EBIQ domains. By its nature this resulted in a shallower description of the participants' descriptions but a more thorough exploration of the EBIQ domains (25).

In all of the interviews themes were identified which were not captured by the EBIQ. Missing these themes could have a significant impact on both identifying appropriate interventions and on measuring accurate outcomes for clients. However this may also reflect clients', and families' categorisation of issues in meaningful terms within their lives rather than clinical definitions. This issue may be unique to the research setting as more exploration of issues would be possible in a clinical interview. In addition evidence of reflection and improvement found on interview, but not identified by EBIQ, would have missed a valuable positive opportunity to reflect on recovery and the service may not have received positive qualitative feedback. Indeed, from a metasynthesis of 23 qualitative studies Levack et al (14) identified eight inter-related themes describing the enduring experience of TBI some of which were not covered by existing outcome measures. They suggested that new outcome measures may be required to evaluate experiences of loss of personal identity, satisfaction with reconstructed identity and sense of connection with one's body and one's life following TBI. A similar finding was reported by Carlozzi et al (30) who found that generic quantitative measures of health-related quality of life only partially captured the complex concepts reported by individuals during semi-structured interviews. This suggests that though the EBIQ is attractive as an easy-to-complete patient-reported outcome measure for a busy service setting it may not record some significant issues of importance to intervention, feedback and service evaluation.

It should also be asked whether outcome measures used have function and relevance to the clients. While this question was not addressed in this study monitoring and feeding back on more gradual improvement, as seen in the rehabilitation phase, is useful to track progress (31). However in more problematic recovery greater benefit may be derived from a more client defined qualitative construct. With benefits identified within both quantitative and qualitative approaches it appears a combination of the two would be optimal for clinical practice.

It could be concluded from the results of the current study that both quantitative outcome measures and a qualitative interview should be taken from each client to ensure that all aspects of their condition are captured. Other researchers have noted that no outcome measures can capture all of the aspects of a client's health status or quality of life. Additional information, captured through interviews with clients can add valuable context to outcome measure scores (32). In clinical practice the quantitative results of the EBIQ are rarely taken in isolation. Instead these are accompanied by a clinical interview and ongoing clinical contact. However with growing pressures on resources, measures such as the EBIQ are increasingly being used as patient reported outcome measures, filled in by clients independently, and potentially used for reporting to commissioners.

Limitations

There are several limitations to the current study. As suggested by Neale & Strang (32), perhaps the EBIQ questionnaire should have been administered and analysed first so that it could inform the structure of the interview. However, this would have meant a delay between the quantitative and qualitative measures, which all participants declined, and may have raised a question about comparability.

For this mixed methods research reliability and validity may be construed as, respectively: the consistency within the analysis used; and the integrity and application of methods used to accurately reflect agreement between the data and the real world experiences. (33). Reliability of this study was increased with experienced peer review of coding, use of standardised analysis software

(NVivo), submersion in the data during an extended period of data collection and consideration of the epistemology to enable reflection on possible researcher bias. The validity of this novel method of analysis has not been tested and two potential limitations stand out. Firstly with the small sample size it was not possible to undertake statistical exploration. Hence comparison of the two data streams was subjective and open to researcher bias. A larger study and sample size would allow greater objective analysis such as confirmatory cluster analysis to explore the conceptual integrity of a measure (34). Also within a larger study conventional content validity could be increased by exploring change over time, with participants being followed over the course of contact with the community ABI service to track change. This would also assist construct validity in providing an additional variable through which the qualitative and quantitative data could be compared. Secondly during all interviews gratitude to the clinical team was spontaneously reported by all respondents along with keenness to participate in the research. This may have biased verbal accounts of difficulties leading to greater disparity from the more objective qualitative data. This possible bias would be overcome with greater perceived distance of the researcher from the clinical team. It is hoped enough description has been provided for the reader to determine the transferability of these findings to their settings.

Conclusion

It appears that qualitative analysis of interviews with ABI service clients can provide added value to quantitative assessment by outcome measures such as the EBIQ. An interview uncovers clinically relevant themes that are outside the outcome measure's rigid structure. However, performing the interviews and analysis may not meet the needs for rapid and succinct reporting required by the demands of the clinical setting. Practical demands may mean that the EBIQ alone has to suffice. A further, larger, multi-timepoint study needs to be performed to determine whether qualitative themes consistently fall outside of the quantitative measure, and if there is a pattern to these themes that could feed into the outcome measure to ensure rapid and thorough measure of patients' status.

References

1. Headway 2018.[cited 2018 February 27th]. Available from <https://www.headway.org.uk/about-brain-injury/individuals/types-of-brain-injury/>.
2. Finnerty F, Glynn L, Dineen B, Colfer F, MacFarlane A. A postal survey of data in general practice on the prevalence of Acquired Brain Injury (ABI) in patients aged 18–65 in one county in the west of Ireland. *BMC Fam Pract* 2009;10:36. [PubMed: 19454016]
3. Headway 2015 Statistics [cited 2018 March 21st]. Available from <https://www.headway.org.uk/about-brain-injury/further-information/statistics/>.
4. House of Commons Select Committee on Health. Third Report: Head Injury: Rehabilitation. London: Stationery Office; 2001
5. Tyerman A & King N editors. Psychological approaches to rehabilitation after traumatic brain injury. Malden, Leicester, England: Blackwell Publishing; 2008. 528p
6. Stocchetti N, Zanier ER. Chronic impact of traumatic brain injury on outcome and quality of life: a narrative review. *Crit Care*. 2016; 20(1):148. [PubMed: 27323708]
7. Ustun TB, Kostansjek N, Chatterji S, Rehm J (editors). Measuring health and disability. Manual for WHO disability assessment schedule – WHODAS 2.0. World Health Organization; 2010. 88p
8. Department of Health and Social Care..National Service Framework: long term conditions. London: DH Long-term Conditions NSF Team; 2005 March 10th
9. Teasdale TW, Christensen AL, Willmes K, Deloche, G., Braga, L., Stachowiak F, Vendrell JM, CastroCaldas A, Laaksonen RK, Leclercq M. Subjective experience in brain injured patients and their close relatives: a European Brain Injury Questionnaire study. *Brain Inj*. 1997; 11(8): 543–63. [PubMed: 9251864]
10. Sopena S, Dewar BK, Nannery R, Teasdale TW, Wilson BA. The European Brain Injury Questionnaire (EBIQ) as a reliable outcome measure for use with people with brain injury. *Brain Inj*. 2007; 21(10):1063–8. [PubMed: 17891569]

11. Prigatano GP. Impaired self-awareness after moderately severe to severe traumatic brain injury. *Acta Neurochir Suppl* 2005; 93:39–42. [PubMed: 15986725]
12. Fadyl JK, Theadom A, Channon A, McPherson KM. Recovery and adaptation after traumatic brain injury in New Zealand: Longitudinal qualitative findings over the first two years. *Neuropsychol Rehabil* 2017; doi: 10.1080/09602011.2017.1364653. [PubMed: 28829229]
13. Graff HJ, Christensen U, Poulsen I, Egerod I. Patient perspectives on navigating the field of traumatic brain injury rehabilitation: a qualitative thematic analysis. *Disabil Rehabil.* 2018; 40(8):926–34. [PubMed: 28129694]
14. Levack WM, Kayes NM, Fadyl JK. Experience of recovery and outcome following traumatic brain injury: a metasynthesis of qualitative research. *Disabil Rehabil.* 2010; 32(12): 986–99. [PubMed: 20450406]
15. Morris PG, Prior L, Deb S, Lewis G, Mayle W, Burrow CE, Bryant E. Patients' views on outcome following head injury: a qualitative study. *BMC Family Practice* 2005; 6:30. [PubMed: 16048645]
16. Bogner JA, Whiteneck GG, MacDonald J, Juengst SB, Brown AW, Philippus AM, Marwitz JH, Lengenfelder J, Mellick D, Arenth P, et al. Test-retest reliability of traumatic brain injury outcome measures: a traumatic brain injury model systems study. *J Head Trauma Rehabil.* 2017;32(5):E1–E16. [PubMed: 28195954]
17. Creswell JW, Plano Clark VL. *Designing and conducting mixed methods research.* Thousand Oaks, CA: Sage; 2006 296p
18. Patton, M. Q. *Qualitative Research & Evaluation Methods,* Sage, Thousand Oaks, CA, 2002.pg 243
19. Creswell, J. W. *Qualitative inquiry & research design: Choosing among five approaches* (2nd ed.). Sage, Thousand Oaks, CA, 2007
20. Marshall B, Cardon P, Poddar A, Fontenot R. Does sample size matter in qualitative research?: A review of qualitative interviews in IS research, *J Comp Inform Syst.* 2013;54(1):11-22, [DOI: 10.1080/08874417.2013.11645667]
21. Marshall, MN. Sampling for qualitative research. *Fam Pract.* 1996; 13(6), 522-5 [PubMed: 9023528]

22. Smith JA, Osborn M. Interpretative phenomenological analysis. In: Smith JA editor. *Qualitative psychology: a practical guide to research methods*. Sage: London; Thousand Oaks; New Delhi; 2003, p53–80
23. Creswell JW, Plano Clark VL, Gutmann M, Hanson WE. Advanced mixed methods research designs. In: Tashakkori A, Teddlie C editors. *Handbook of mixed methods in social and behavioral research*. Thousand Oaks, CA: Sage p209–240
24. Driscoll DL, Appiah-Yeboah A, Rupert DJ. Merging qualitative and quantitative data in mixed methods research: How to and why not. *Ecological and Environmental Anthropology*. 2007; 3, 19-28.
<http://digitalcommons.unl.edu/icwdmeea/18>
25. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006; 3(2): 77–101.
Doi:10.1191/1478088706qp063oa
26. Joffe H, Yardley L. Content and thematic analysis. In: Marks DF, Yardley L editors. *Research methods for clinical and health psychology*, Sage Publications Ltd; 2003 p56-68
27. Bazeley P. Issues in mixing qualitative and quantitative approaches to research Published in: R. Buber, J. Gadner, & L. Richards (eds) (2004) *Applying qualitative methods to marketing management research*. UK: Palgrave Macmillan, pp141-156.
28. Bazeley P. NVivo 11 Reference Guide [cited 2018 Dec 18]: Available from: http://www.researchsupport.com.au/NV_11_notes.pdf.
29. Bateman A, Teasdale TW, Willmes K. Assessing construct validity of the self-rating version of the European Brain Injury Questionnaire (EBIQ) using Rasch analysis. *Neuropsychol Rehabil* 2009; 19(6):941–54. [PubMed: 19626557]
30. Carlozzi NE, Tulskey DS, Kisala PA. Traumatic brain injury patient-reported outcome measure: identification of health-related quality-of-life issues relevant to individuals with traumatic brain injury. *Arch Phys Med Rehabil* 2011; 92 (10 Suppl): S52–60. [PubMed: 21958923]
31. Andresen R, Caputi P, Oades LG. Do clinical outcome measures assess consumer-defined recovery? *Psychiatry Res*. 2010; 177(3):309–17. [PubMed: 20227768]
32. Neale J, Strang J. Blending qualitative and quantitative research methods to optimize patient reported outcome measures (PROMs). *Addiction* 2015; 110(8): 1215–1216. [PubMed: 25845408]

33. Merriam, Sharan B.. *Qualitative Research: A guide to design and implementation*, Wiley, 2009..
34. Bazeley, P. (2010). Computer assisted integration of mixed methods data sources and analyses. In A. Tashakkori & C. Teddlie (Eds.), *Handbook of mixed methods research for the social and behavioral sciences* (2nd ed., pp. 431-467). Thousand Oaks, CA: Sage

Appendix 1: Study documentation

1.1 Independent peer review approval letter



RESEARCH AND ENTERPRISE SERVICES

28th February 2014

Caroline Anderson
The Science Centre
Leek Road
ST4 2DF

Dear Caroline,

Qualitative Assessment of an outcome measure in a community ABI service

As you know the above project was initially awarded a grade 2 but following assessment of your response to the issues raised the project now has received final approval from the Independent Peer Review Committee and can be submitted for ethical approval.

I am attaching a letter addressed to the Chair of the NHS REC along with the original peer review comments which you can enclose with your NHS REC application.

Management approval

You should arrange for all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research must obtain management approval from the relevant care organisation before commencing any research procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Clinical trial of a medicinal product

Please remember that, if your project is a clinical trial of a medicinal product, MHRA approval is required. You must submit a request for a clinical trial authorisation under the Medicines for Human Use (Clinical Trials) Regulations 2004. Further details can be found at <http://www.mhra.gov.uk/home/groups/l-unit1/documents/websiteresources/con2022633.pdf>

If you have any queries, please do not hesitate to contact Hannah Reidy on 01782 733588.

Yours sincerely

A handwritten signature in black ink, appearing to read 'K Wilde'.

Dr K Wilde
Vice Chair – Independent Peer Review Committee

Enc

CC R&D Office

Research and Enterprise Services, Keele University, Staffordshire, ST5 5BG, UK
Telephone: + 44 (0)1782 734466 Fax: + 44 (0)1782 733740

1.2 Research Ethics Committee Approval Letter



East of Scotland Research Ethics Service (EoSRES)

Research Ethics Service

Tayside medical Science Centre
Residency Block Level 3
George Pirie Way
Ninewells Hospital and Medical School
Dundee DD1 9SY

Dr Caroline Anderson
Trainee Clinical Psychologist
The Robert Jones and Agnes Hunt Orthopaedic
Hospital NHS Trust
Midlands Centre for Spinal Injuries
Oswestry
Shropshire, SY10 7AG

Date: 20 November 2014
Your Ref:
Our Ref: LR/14/ES/1077
Enquiries to: Mrs Lorraine Reilly
Direct Line: 01382 383878
Email: eosres.tayside@nhs.net

Dear Dr Anderson

Study Title: Qualitative assessment of an outcome measure in a community ABI service.
REC reference: 14/ES/1077
IRAS project ID: 159213

Thank you for your letter received on 19 November 2014, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

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 REC Manager Mrs Lorraine Reilly, eosres.tayside@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

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

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

Management permission ("R&D approval") should be sought from all NHS organisations



involved in the study in accordance with NHS research governance arrangements.

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

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

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

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

Registration of Clinical Trials

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

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

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

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

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

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, 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" above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	Version	Date
Covering letter on headed paper [Covering Letter]		18 September 2014
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Varification of Insurance]		28 July 2014
GP/consultant information sheets or letters [GP letter]	1	02 July 2014
Interview schedules or topic guides for participants [Client Interview Schedule]	2	02 July 2014
IRAS Checklist XML [Checklist_19112014]		19 November 2014



Letter from sponsor		23 September 2014
Letters of invitation to participant	1	10 November 2014
Other [SO Consent Form]	2	02 July 2014
Other [SO Interview Schedule]	2	02 July 2014
Other [Letter to Chair Keele Uni Ind Ethics Review]		06 January 2014
Other [Email with attached amended documentation]		19 November 2014
Participant consent form [Client Consent Form]	2	02 July 2014
Participant information sheet (PIS) [SO]	3	10 November 2014
Participant information sheet (PIS) [Client]	3	09 October 2014
REC Application Form [REC_Form_19112014]		19 November 2014
Referee's report or other scientific critique report [Letter from Keele University Independent Peer Review Committee]		28 February 2014
Research protocol or project proposal		10 November 2014
Response to Request for Further Information		17 November 2014
Summary CV for Chief Investigator (CI) [CV Caroline Anderson]		08 September 2014
Summary CV for student [CV Caroline Anderson]		08 September 2014
Summary CV for supervisor (student research) [CV Helena Priest]		02 September 2014
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Diagram of Protocol]	1	18 September 2014
Validated questionnaire [European Brain Injury Questionnaire]		

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

Feedback

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



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

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/>

14/ES/1077

Please quote this number on all correspondence

Yours sincerely



pp
Dr Carol Macmillan
Chair

E-mail: eosres.tayside@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: Ms Sue Wood, North Staffordshire Combined Healthcare NHS Trust



1.3 NHS Research and Development Department approval letter

RESEARCH AND DEVELOPMENT DEPARTMENT
Trust Headquarters (Lawton House)
Bellringer Road, Trentham, Stoke-on-Trent, ST4 8HH
Telephone: 01782 441687/651 : Fax: 01782 441637/624
Email: r&d@northstaffs.nhs.uk : Twitter: @nschtresearch

4 December 2014

R&D Ref: CHC0106/RD

Dr Caroline Anderson
Trainee Clinical Psychologist
RJAH Orthopaedic Hospital NHSFT
Oswestry
SY10 7AG

Dear Caroline

Study Title: Qualitative Assessment of an Outcome Measure in a Community ABI Service
Chief Investigator: Dr Caroline Anderson
Sponsor: Keele University

I can confirm that the above project (R&D application) has been reviewed and given NHS Permission for Research by the Research & Development Department for North Staffordshire Combined Healthcare NHS Trust, and the details have been entered onto the R&D database.

I note that this research project has been approved by East of Scotland Research Ethics Service [Ref. 14/ES/1077].

NHS permission for the above research has been granted on the basis described in the application and supporting documentation. The documents reviewed were:

Document	Version Number	Date
Protocol	2	10/11/2014
Protocol Diagram	1	18/09/2014
Patient Information Sheet: Client	3	09/10/2014
Consent Form: Client	2	02/07/2014
Patient Information Sheet: SO	3	10/11/2014
Consent Form: SO	2	02/07/2014
GP Letter	1	02/07/2014
Participant Invitation Letter	1	10/11/2014
Interview Schedule: Client	2	02/07/2014
Interview Schedule: SO	2	02/07/2014

Chairman: Mr Ken Jarrold CBE

Chief Executive: Mrs Caroline Donovan

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R&D-TMP-001

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The research Sponsor, Chief Investigator, or the local Principal Investigator at a research site, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety. The R&D Office should be notified of any such measures, the reasons for the action and any further action required. The R&D Office should also be notified within the same time-frame as that of the research ethics committee and other regulatory bodies.

Approval by the R&D Department therefore assumes that you have read, understand and agree to comply with the following:-

- ❖ Research Governance Framework (www.doh.gov.uk/research)
- ❖ ICH Guidelines on Good Clinical Practice
- ❖ Data Protection Act 1998
- ❖ Mental Capacity Act 2007
- ❖ Medicines for Human Use (Clinical Trials) Regulations 2004
- ❖ Human Tissue Act 2004
- ❖ All applicable Trust policies & procedures

In line with these requirements, may I draw your attention to the need for you to provide the following documentation/notifications to the R&D Office throughout the course of the study, and that all amendments (including changes to the local research team) need to be submitted to, and approved by R&D, in accordance with IRAS guidance:-

- ❖ Annual Progress Report (form sent by this R&D Office)
- ❖ End of Study Declaration Form (available via IRAS)
- ❖ End of Study Report (produced by the Chief Investigator)
- ❖ Changes to study start and end dates
- ❖ Changes in study personnel

Please note that this NHS organisation is required to monitor research to ensure compliance with the Research Governance Framework, and other legal and regulatory requirements. This will be achieved by random audit conducted by this department.

I would like to take this opportunity to wish you well with your research. If you need any further advice or guidance please do not hesitate to contact us.

Yours sincerely



Dr Richard Hodgson
Associate Director for R&D

Copies to:
Helena Priest, Academic Supervisor
Lesley Stewart, Clinical Supervisor

Chairman: Mr Ken Jarrold CBE

Chief Executive: Mrs Caroline Donovan

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1.4: Letter of invitation



Keele University

North Staffordshire 
Combined Healthcare
NHS Trust



**The Neuropsychology, Physical Health
and Older Adult Psychology Team**

The Bennett Centre
Richmond Terrace
Shelton, Stoke-on-Trent
ST1 4ND
Tel: 01782 275188

Invitation to take part in a research study: Qualitative assessment of an outcome measure

Dear *potential participant name*

We would like to invite you to take part in a research study. This study is looking at how well a person's answers to a commonly used 'quality of life' questionnaire reflects their current situation. You are being invited to take part as you are a client with the Neuropsychology Team.

We have enclosed an information sheet with further details. One of the team will go through the information sheet with you and answer any questions you have.

If you consider taking part in this study we will ask for your permission for the researcher to contact you. The researcher can also answer any questions you have about this study. If you decide to go ahead two meetings will be arranged, with the researcher, at a location convenient for you.

You do not have to take part in this study if you do not wish to do so.

If you would like to consider taking part please let us know by either: telling Dr Stewart, or phoning and leaving a message, or returning the attached reply slip.

Yours sincerely,

Dr Caroline Anderson
Trainee Clinical Psychologist

Dr Lesley Stewart
Consultant Clinical Neuropsychologist

Qualitative assessment of an outcome measure
Client Invitation Letter, version 1 (10.11.2014)



Reply Slip

Title of Project: Qualitative assessment of an outcome measure

Name of Researcher: Caroline Anderson

**Please initial
or tick box**

I **do** want to be contacted about taking part in this research study.

I **do not** want to be contacted about this research study.

Name

Date

Signature

If you would prefer to reply by telephone please call The Bennett Centre: 01782 275188

1.5: Information sheets

1.5.1: Client information sheet



QUALITATIVE ASSESSMENT OF AN OUTCOME MEASURE

Client Information Sheet

We would like to invite you to take part in a study. This study is trying to find out if a questionnaire used in the Neuropsychology Team gives a good picture of the difficulties people sometimes experience in their lives. This study is being carried out as part of an educational qualification.

Before you decide whether to take part it is important for you to understand why the research is being done, and what it will involve. **Please take time to read the following information carefully and discuss it with others if you wish.** Ask me anything that is not clear or if you would like more information. Take time to decide if you wish to take part.

What is the purpose of the study?

Neuropsychology teams use questionnaires to help measure the rehabilitation need and progress of clients. This study aims to help us see if a questionnaire, the European Brain Injury Questionnaire (EBIQ), accurately tells us about the difficulties a person may be experiencing that are important to them. We cannot promise the study will help you but the information we get from this study will help guide us in assessing rehabilitation progress in the future.

Why have I been invited?

You have been invited to join the study as you are a current client with the Neuropsychology Team. The project is open to 5 clients who are working with the Neuropsychology Team and wish to take part. We would also like to invite inviting someone who is close to each client to take part, and be interviewed separately, with the your consent.

Do I have to take part?

You do not have to take part if you do not wish to do so.

If you do decide to take part you will be given this information sheet to keep, and be asked to sign a consent form. **You will be free to withdraw from the study at any time, without giving a reason, and without affecting care from the Neuropsychology Team now or in the future.** Any data collected would be deleted from the study.

What would I have to do?

- If you would like to take part, we will make an appointment for you with the researcher, either at your home, the Bennett Centre, or a health service location near you.
- This first meeting will last around ½ hour. **If you wear glasses please have them with you.**
- At the meeting there will be time to discuss the project and any questions you have will be answered. You will then be asked if you consent to take part in the project. If so, the researcher will ask you to complete a consent form. We will also ask permission to tell your GP of your involvement in the study. We will then complete the EBIQ questionnaire and arrange a second meeting.
- At the second meeting the researcher will ask you some questions about difficulties you may have had over the last month. This interview will last around 1 hour and will be recorded on a digital voice recorder.

What happens to my information?

The recording of the interview will be typed up and analysed. The researcher will compare your interview results of EBIQ questionnaire you completed.

All the paperwork and results will be made anonymous. The recording will be stored at a secure location and erased after 10 years. If you withdraw from the study the recording and any other information will be destroyed.

What will happen to the results of the study?

A report will be written and we will send you a summary of the study findings with an invitation to a presentation of this research.

Who is funding the study?

This study is being carried out as part of a Doctoral degree. The researcher, Caroline Anderson, is studying for a Doctorate in Clinical Psychology at Staffordshire and Keele Universities and will use this study for the clinical research component.

What will happen to the results of the study?

A report will be written and we will send you a summary of the study findings with an invitation to a presentation of this research.

Who has reviewed this study and what is the complaints process?

The East of Scotland Research Ethics Committee REC 1, which has responsibility for scrutinising all proposals for medical research on humans in Tayside, has examined the proposal and has raised no objections from the point of view of medical ethics. It is a requirement that your records in this research, together with any relevant records, be made available for scrutiny by monitors from the Keele University and North Staffordshire Combined Healthcare NHS Trust, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

If you believe that you have been harmed in any way by taking part in this study, you have the right to pursue a complaint and seek any resulting compensation through the Keele University who are acting as the research sponsor. Details about this are available from the research team. Also, as a patient of the NHS, you have the right to pursue a complaint through the usual NHS process. To do so, you can submit a complaint to the PALS Lead, Patient Experience Team, Heartlands Hospital, Hilton Road, Stoke-on-Trent, ST4 6TH, email patientexperienceteam@northstaffs.nhs.uk or call by calling 0800 389 9676. Note that the NHS has no legal liability for non-negligent harm. However, if you are harmed and this is due to someone's negligence, you may have grounds for a legal action against North Staffordshire Combined Healthcare NHS Trust but you may have to pay your legal costs.

Contact for further information

Dr Caroline Anderson (Trainee Clinical Psychologist) or
Dr Lesley Stewart (Consultant Clinical Neuropsychologist)
Neuropsychology, Physical Health and Older Adult Psychology Team,
The Bennett Centre, Richmond Terrace, Shelton, Stoke on Trent, ST1 4ND
Tel: 01782 275188

**Thank you for reading this information sheet
and for considering taking part.**

1.5.2: SO information sheet



QUALITATIVE ASSESSMENT OF AN OUTCOME MEASURE

Significant Other Information Sheet

We would like to invite you to take part in a study. This study is trying to find out if a questionnaire used in the Neuropsychology Team gives a good picture of the difficulties people sometimes experience in their lives. This study is being carried out as part of an educational qualification.

Before you decide whether to take part it is important for you to understand why the research is being done, and what it will involve. **Please take time to read the following information carefully and discuss it with others if you wish.** Ask me anything that is not clear or if you would like more information. Take time to decide if you wish to take part.

What is the purpose of the study?

Neuropsychology teams use questionnaires to help measure the rehabilitation need and progress of clients. This study aims to help us see if a questionnaire, the European Brain Injury Questionnaire (EBIQ), accurately tells us about the difficulties a person may be experiencing that are important to them. We cannot promise the study will help you but the information we get from this study will help guide us in assessing rehabilitation progress in the future.

Why have I been invited?

You have been invited to join the study as someone close to you is a current client with the Neuropsychology Team. We have contacted you with their consent. The project is open to 5 clients who are referred to the Neuropsychology Team and wish to take part together with someone close to them. You will be interviewed separately with the client's consent.

Do I have to take part?

You do not have to take part if you do not wish to do so.

If you do decide to take part you will be given this information sheet to keep, and be asked to sign a consent form. **You will be free to withdraw from the study at any time**, without giving a reason, and without affecting care from the Neuropsychology Team now or in the future. Any data collected would then be deleted from the study.

What would I have to do?

- If you would like to take part, we will make an appointment for you with the researcher, either at your home, the Bennett Centre, or a health service location near you.
- This first meeting will last around ½ hour. **If you wear glasses please have them with you.**
- At the meeting there will be time to discuss the project and any questions you have will be answered. You will then be asked if you consent to take part in the project. If so, the researcher will ask you to complete a consent form. We will also ask permission to tell your GP of your involvement in the study. We will then complete the EBIQ questionnaire and arrange a second meeting.
- At the second meeting the researcher will ask you some questions about difficulties you may have had over the last month. This interview will last around 1 hour and will be recorded on a digital voice recorder.

What happens to my information?

The recording of the interview will be typed up and analysed. The researcher will compare your interview results of EBIQ questionnaire you completed.

All the paperwork and results will be made anonymous. The recording will be stored at a secure location and erased after 10 years. If you withdraw from the study the recording and any other information will be destroyed.

What will happen to the results of the study?

A report will be written and we will send you a summary of the study findings with an invitation to a presentation of this research.

Who is funding the study?

This study is being carried out as part of a Doctoral degree. The researcher, Caroline Anderson, is studying for a Doctorate in Clinical Psychology at Staffordshire and Keele Universities and will use this study for the clinical research component.

What will happen to the results of the study?

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Who has reviewed this study and what is the complaints process?

The East of Scotland Research Ethics Committee REC 1, which has responsibility for scrutinising all proposals for medical research on humans in Tayside, has examined the proposal and has raised no objections from the point of view of medical ethics. It is a requirement that your records in this research, together with any relevant records, be made available for scrutiny by monitors from the Keele University and North Staffordshire Combined Healthcare NHS Trust, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

If you believe that you have been harmed in any way by taking part in this study, you have the right to pursue a complaint and seek any resulting compensation through the Keele University who are acting as the research sponsor. Details about this are available from the research team. Also, as a patient of the NHS, you have the right to pursue a complaint through the usual NHS process. To do so, you can submit a complaint to the PALS Lead, Patient Experience Team, Heartlands Hospital, Hilton Road, Stoke-on-Trent, ST4 6TH, email patientexperienceteam@northstaffs.nhs.uk or call by calling 0800 389 9676. Note that the NHS has no legal liability for non-negligent harm. However, if you are harmed and this is due to someone's negligence, you may have grounds for a legal action against North Staffordshire Combined Healthcare NHS Trust but you may have to pay your legal costs.

Contact for further information

Dr Caroline Anderson (Trainee Clinical Psychologist) or
Dr Lesley Stewart (Consultant Clinical Neuropsychologist)
Neuropsychology, Physical Health and Older Adult Psychology Team,
The Bennett Centre, Richmond Terrace, Shelton, Stoke on Trent, ST1 4ND
Tel: 01782 275188

**Thank you for reading this information sheet
and for considering taking part.**

1.6: Consent forms

1.6.1: Client consent form



CLIENT CONSENT FORM

Title of Project: Qualitative assessment of an outcome measure

Name of Researcher: Caroline Anderson

I agree to take part in this project; my signature on the bottom of this form shows:

	Please initial or tick box
I have read / understood the information sheet provided and have had the opportunity to ask questions.	<input type="checkbox"/>
I understand that my taking part in this project is voluntary and that I can withdraw from the study at any time without giving a reason.	<input type="checkbox"/>
I understand that this will not affect care, now or in the future, from the Neuropsychology, Physical Health and Older Adult Psychology Team	<input type="checkbox"/>
I agree to my interview being recorded (audio only).	<input type="checkbox"/>
I understand that my participation is confidential and agree for anonymised quotes to be used in reports and publications.	<input type="checkbox"/>
I understand that participation in this study does not affect my rights to seek health care as and when I require.	<input type="checkbox"/>
I agree to my GP being notified of my participation in this project.	<input type="checkbox"/>

Name of Client

Date

Signature

Researcher

Date

Signature

Qualitative assessment of an outcome measure
Client Consent form, version 2 (02.07.2014)

1.6.2: Significant other consent form



SIGNIFICANT OTHER CONSENT FORM

Title of Project: Qualitative assessment of an outcome measure

Name of Researcher: Caroline Anderson

I agree to take part in this project; my signature on the bottom of this form shows:

Please initial
or tick box

I have read / understood the information sheet provided and have had the opportunity to ask questions.

I understand that my taking part in this project is voluntary and that I can withdraw from the study at any time without giving a reason.

I understand that this will not affect care, now or in the future, from the Neuropsychology, Physical Health and Older Adult Psychology Team

I agree to my interview being recorded (audio only).

I understand that my participation is confidential and agree for anonymised quotes to be used in reports and publications.

I understand that participation in this study does not affect my rights to seek health care as and when I require.

I agree to my GP being notified of my participation in this project.

Name of Significant Other

Date

Signature

Researcher

Date

Signature

Qualitative assessment of an outcome measure
SO Client Consent form, version 2 (02.07.2014)

1.7: Letter to client participant's GP



North Staffordshire
Combined Healthcare
NHS Trust



**The Neuropsychology, Physical Health
and Older Adult Psychology Team**
The Bennett Centre
Richmond Terrace
Shelton
Stoke-on-Trent
ST1 4ND
Tel: 01782 275188

Dear Dr *name*

re: *participant name, DoB*

I am writing regarding your patient, above. At present we are conducting a study 'Qualitative Assessment of an Outcome Measure'. *Participant name* has given informed consent to participate in this research and for us to inform you of their involvement.

The study comprises involvement in two meetings. An initial meeting to obtain the informed consent and complete the European Brain Injury Questionnaire (EBIQ) has been completed. A second meeting to conduct a semi structured interview on the areas covered by the EBIQ will be scheduled as soon as possible. Due to the standard and established nature of the EBIQ and its subject areas we do not anticipate that the presentation will engender any distress.

Please do not hesitate to contact us within this time if you have any queries or concerns regarding your patient's involvement with this project.

Yours sincerely,

Dr Caroline Anderson
Trainee Clinical Psychologist

Lesley Stewart
Consultant Clinical Neuropsychologist

Qualitative assessment of an outcome measure
GP letter, version 1 (02.07.2014)

1.8: EBIQ

EBIQ (European Brain Injury Questionnaire) - Self-Rating

Patient identification: _____

Date: _____

This questionnaire is concerned with a number of problems or difficulties that people sometimes experience in their lives. We would like to know how much you have experienced any of these **within the last month**. Please read each item in the questionnaire and respond by marking your answer in the circle under 'Not at all' or 'A little' or 'A lot'. Do not spend too much time on any item. Just give your most immediate response.

How much have you experienced the following?

	Not at all	A Little	A lot
01 Headaches	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
02 Failing to get things done on time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
03 Reacting too quickly to what others say or do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
04 Trouble remembering things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
05 Difficulty participating in conversations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
06 Others do not understand your problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
07 Everything is an effort	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
08 Being unable to plan activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
09 Feeling hopeless about your future	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10 Having temper outbursts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11 Being confused	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12 Feeling lonely, even when together with other people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13 Mood swings without reason	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14 Feeling critical of others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15 Having to do things slowly in order to be correct	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16 Faintness or dizziness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17 Hiding your feelings from others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18 Feeling sad	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19 Being 'bossy' or dominating	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

		Not at all	A Little	A lot
20	Needing to be reminded about personal hygiene	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21	Difficulty managing your finances	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22	Trouble concentrating	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23	Failing to notice other people's moods	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24	Feeling anger against other people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25	Having your feelings easily hurt	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
26	Feeling unable to get things done	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27	Annoyance or irritation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
28	Problems with household chores	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
29	Lack of interest in hobbies at home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30	Feeling lonely	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
31	Feeling inferior to other people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
32	Sleep problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
33	Feeling uncomfortable in crowds	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34	Shouting at people in anger	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
35	Difficulty in communicating what you want to say	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
36	Being unsure what to do in dangerous situations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
37	Being obstinate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
38	Lack of interest in your surroundings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
39	Thinking only of yourself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
40	Mistrusting other people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
41	Crying easily	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
42	Difficulty finding your way in new surroundings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
43	Being inclined to eat too much	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
44	Getting into quarrels easily	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
45	Lack of energy or being slowed down	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
46	Forgetting the day of the week	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
47	Feeling of worthlessness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
48	Lack of interest in hobbies outside the home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

		Not at all	A Little	A lot
49	Needing help with personal hygiene	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
50	Restlessness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
51	Feeling tense	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
52	Acting inappropriately in dangerous situations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
53	Feeling life is not worth living	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
54	Forgetting appointments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
55	Leaving others to take the initiative in conversations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
56	Loss of sexual interest or pleasure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
57	Throwing things in anger	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
58	Preferring to be alone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
59	Difficulty in making decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
60	Losing contact with your friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
61	Lack of interest in current affairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
62	Behaving tactlessly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
63	Having problems in general	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If you have a close relative who is also completing this questionnaire, then please answer the following questions about that person.

64	Do you think that his/her life has changed after you had the injury?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
65	Do you think that he/she is having problems due to your present situation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
66	Do you think that his/her mood has changed due to your present situation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Any other comments?

Thank-you for your cooperation

EBIQ (European Brain Injury Questionnaire) - Relative-Rating

Patient identification: _____

Relative identification: _____

Date:

This questionnaire is concerned with a number of problems or difficulties that people sometimes experience in their lives. We would like to know how much your brain-injured relative has experienced any of these **within the last month**. Please read each item in the questionnaire and respond by marking your answer in the circle under 'Not at all' or 'A little' or 'A lot'. Do not spend too much time on any item. Just give your most immediate response.

In your view, how much has he/she experienced the following?

	Not at all	A Little	A lot
01 Headaches	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
02 Failing to get things done on time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
03 Reacting too quickly to what others say or do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
04 Trouble remembering things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
05 Difficulty participating in conversations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
06 Others do not understand his/her problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
07 Everything is an effort	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
08 Being unable to plan activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
09 Feeling hopeless about his/her future	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10 Having temper outbursts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11 Being confused	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12 Feeling lonely, even when together with other people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13 Mood swings without reason	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14 Feeling critical of others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15 Having to do things slowly in order to be correct	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16 Faintness or dizziness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17 Hiding his/her feelings from others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18 Feeling sad	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19 Being 'bossy' or dominating	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

		Not at all	A Little	A lot
20	Needing to be reminded about personal hygiene	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21	Difficulty managing his/her finances	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22	Trouble concentrating	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23	Failing to notice other people's moods	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24	Feeling anger against other people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25	Having his/her feelings easily hurt	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
26	Feeling unable to get things done	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27	Annoyance or irritation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
28	Problems with household chores	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
29	Lack of interest in hobbies at home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30	Feeling lonely	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
31	Feeling inferior to other people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
32	Sleep problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
33	Feeling uncomfortable in crowds	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34	Shouting at people in anger	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
35	Difficulty in communicating what he/she want to say	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
36	Being unsure what to do in dangerous situations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
37	Being obstinate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
38	Lack of interest in his/her surroundings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
39	Thinking only of himself/herself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
40	Mistrusting other people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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42	Difficulty finding his/her way in new surroundings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
43	Being inclined to eat too much	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
44	Getting into quarrels easily	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
45	Lack of energy or being slowed down	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
46	Forgetting the day of the week	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
47	Feeling of worthlessness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
48	Lack of interest in hobbies outside the home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

		Not at all	A Little	A lot
49	Needing help with personal hygiene	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
50	Restlessness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
51	Feeling tense	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
52	Acting inappropriately in dangerous situations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
53	Feeling life is not worth living	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
54	Forgetting appointments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
55	Leaving others to take the initiative in conversations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
56	Loss of sexual interest or pleasure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
57	Throwing things in anger	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
58	Preferring to be alone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
59	Difficulty in making decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
60	Losing contact with his/her friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
61	Lack of interest in current affairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
62	Behaving tactlessly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
63	Having problems in general	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please answer the following questions about **yourself**.

- | | | | | |
|----|--|-----------------------|-----------------------|-----------------------|
| 64 | Has your life changed
after your relative had the injury? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 65 | Are you having problems
due to his/her present situation? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 66 | Has your mood has changed
due to his/her present situation? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Any other comments?

Thank-you for your cooperation

EBIQ Scales

The scales are computed as the average response values for the following questions.

	QR Item	
1	Somatic	01 07 16 32 43 50 51 45
2	Cognitive	04 46 54 22 02 08 21 59 15 11 36 23 42
3	Motivation	29 48 61 38 26
4	Impulsivity	03 10 13 24 25 27 34 37 44 57 62 14 19
5	Depression	09 12 18 30 31 41 47 53 58
6	Isolation	06 17 39 40
7	Physical	28 33 49 52 56 20
8	Communication	35 55 60 05
9	Core Symptoms	07 16 43 51 45 22 08 59 15 36 29 61 38 26 13 25 27 44 62 12 18 30 31 47 53 06 17 39 33 49 52 55 60 63

Where	Not at all	= 1
	A little	= 2
	A lot	= 3

References

- Teasdale, T. W., Christensen, A-L., Willmes, K., Deloche, G., Braga, L., Stachowiak, F., Vendrell, J., Castro-Caldas, A., L., Laaksonen, R. K. & Leclercq, M. (1997) Subjective experience in brain-injured patients and their close relatives: A European Brain Injury Questionnaire study. *Brain Injury*, 11. 543-563.
- Svendsen, H.Aa., Teasdale, T.W. & Pinner, M. (2004) Subjective experience in patients with brain injury and their close relatives before and after a rehabilitation program. *Neuropsychological Rehabilitation*, 14, 495-515.

1.9: Interview schedules

1.9.1: Client interview schedule



Keele University



Interview Schedule - Client

As the interviews will take a semi-structured format, this schedule outlines the general topics that will be covered in each interview and domain specific prompts that will be used. These questions, and their order, will be used as a guide to the researcher and tailored to suit the participant's communication needs.

If a topic has been covered earlier in the interview the domains will be explored by using general prompts e.g. "Could you tell me a bit more about ...?" or will be omitted.

Interview Questions

"I would like to ask you some questions about some difficulties that people sometimes experience in their lives. I would like to know how much you have experienced these over the last month.

Core symptoms

- Can I start by asking if you have experienced any problems or difficulties over the last month?
- Have there been changes in your quality of life because of your injury?

Somatic domain

- Over the last month have you had any difficulties due to feeling generally unwell or light headed?
- How has your eating and sleeping been?
 - *Prompt: Have you felt restless or tense?*
- Sometimes after a head injury people feel 'slowed-down' or lacking energy. Have you felt like this over the last month?

Cognitive domain

- How have your memory and concentration been over the last month?
 - *Prompt: Have you missed any appointments because you had forgotten about them?*
 - *Prompt: Have you been able to watch TV or read the paper as you normally would?*
- Have you had difficulty planning things?
 - *Prompt: Have you found difficulty getting things done on time?*

Qualitative assessment of an outcome measure
Client Interview Schedule, version 2 (02.07.2014)

- Do you find you need to do things slowly in order to get them correct?
- Have you felt confused?
 - *Prompt: Difficulty deciding what to do in a situation?*
 - *Prompt: Difficulty finding way in new surroundings*
- Over the last month do you feel like you have had any difficulty in telling how other people are feeling?

Motivation

- Have you felt disinterested in your usual pass-times?
 - *Prompt: Have to bee taking part in hobbies at home (e.g. TV) or with friends (e.g. sport)?*
- Have you felt able to get things done as you normally would?

Impulsivity

- In the last month have you experienced mood swings or found yourself getting angry?
 - *Prompt: Have you found yourself losing your temper easily with people*
 - *Prompt: Have you felt stubborn or got easily annoyed?*
 - *Prompt: Have you found yourself getting easily upset?*
- Do you think you have behaved critically or tactlessly to anyone?

Depression

- How do you view the future?
- Over the last month have you felt low or found yourself crying easily?
 - *Prompt: Have you felt inferior or worthless?*
 - *Prompt: Have you felt life wasn't worth living?*

Isolation

- In the last month have you felt you needed to hide your feelings?
- Do other people understand your difficulties?
- Do you find yourself not trusting others or thinking mainly of yourself?

Physical

- Have you needed help around the house over the last month?
 - *Prompt: Has someone needed to remind you about or help you with personal hygiene?*
 - *Prompt: Have you needed help around the house e.g. cleaning, washing up etc?*
- Have you had any difficulty being in crowded environments?
- Have you noticed a change in your sexual interest?

Communication

- Recently have you found communicating difficult?
 - *Prompt: Is this different when you are in a busy room compared to a quiet room*
 - *Prompt: Do you prefer to let others start a conversation?*
- Have you lost contact with friends recently?

General

- Are there any other difficulties you have experienced recently that you would like to tell me about?

End of the Interview

Those are all the questions I wanted to ask you today. Thank you for your time and for sharing your experiences with me. Do you have any questions you would like to ask me?

On the information sheet there are the Neuropsychology Team phone contact details. If you feel upset after our meeting today please contact someone at the Neuropsychology Team who will be able to support you.

As we discussed when we looked at the information sheet I will now go and transform the audio recording into a written format. I will make everything you have told me today anonymous. Are you still happy to take part in this study?

Would you like me to send you a summary of the findings from my research? If you have any questions in the meantime, please feel free to contact me.”

1.9.2: Significant other interview schedule



Keele University



Interview Schedule – Significant Other

As the interviews will take a semi-structured format, this schedule outlines the general topics that will be covered in each interview and domain specific prompts that will be used. These questions, and their order, will be used as a guide to the researcher and tailored to suit the participant's communication needs.

If a topic has been covered earlier in the interview the domains will be explored by using general prompts e.g. "Could you tell me a bit more about ...?" or will be omitted.

Interview Questions

"I would like to ask you some questions about some difficulties that people sometimes experience in their lives. I would like to know how much *[[client name]]* may have experienced these over the last month.

Core symptoms

- Can I start by asking if *[[client name]]* has experienced any problems or difficulties over the last month?
- Have there been changes in his/her quality of life because of his/her injury?

Somatic domain

- Over the last month has *[[client name]]* had any difficulties due to feeling generally unwell or light headed?
- How has *[[client name]]*'s eating and sleeping been?
 - Prompt: Has *[[client name]]* felt restless or tense?
- Sometimes after a head injury people feel 'slowed-down' or lacking energy. Do you feel *[[client name]]* has felt like this over the last month?

Cognitive domain

- How has *[[client name]]*'s memory and concentration been over the last month?
 - Prompt: Has *[[client name]]* missed any appointments because they had forgotten about them?

- *Prompt: Has [[client name]] been able to watch TV or read the paper as they normally would?*
- Has **[[client name]]** been having difficulty planning things?
 - *Prompt: Have you found difficulty getting things done on time?*
- Does **[[client name]]** find they need to do things slowly in order to get them correct?
- Has **[[client name]]** appeared confused?
 - *Prompt: Difficulty deciding what to do in a situation?*
 - *Prompt: Difficulty finding way in new surroundings*
- Over the last month do you feel **[[client name]]** has had any difficulty in telling how other people are feeling?

Motivation

- Has **[[client name]]** felt disinterested in their usual pass-times?
 - *Prompt: Has [[client name]] been taking part in hobbies at home (e.g. TV) or with friends (e.g. sport)?*
- Has **[[client name]]** felt able to get things done as they normally would?

Impulsivity

- In the last month has **[[client name]]** experienced mood swings or found themselves getting angry?
 - *Prompt: Have you found [[client name]] losing your temper easily with people*
 - *Prompt: Have you found [[client name]] stubborn or getting easily annoyed?*
 - *Prompt: Has [[client name]] got upset easily?*
- Do you think **[[client name]]** has behaved critically or tactlessly to anyone?

Depression

- How do you think **[[client name]]** views the future?
- Over the last month has **[[client name]]** felt low or have you found they crying easily?
 - *Prompt: Has [[client name]] felt inferior or worthless?*
 - *Prompt: Do you feel [[client name]] has felt life wasn't worth living?*

Isolation

- In the last month do you feel **[[client name]]** has hidden his/her feelings?
- Do you think **[[client name]]** feels other people understand his/her difficulties?
- Does **[[client name]]** find himself/herself not trusting others or thinking mainly of themselves?

Reflective commentary

Word count: 3255

Abstract

This thesis is comprised of a literature review of studies exploring coping strategies following an acquired brain injury and paper describing an empirical study exploring the correspondence between a quantitative outcome measure and a participants' spoken description of issues following an acquired brain injury. The process of designing and completing these papers has proven to be an interesting and enlightening journey which is explored in this reflective commentary. Personal reflections on parallel life experiences are also explored

Introduction

This thesis is comprised of three papers: a review of literature on coping styles and quality of life; a mixed method exploration of an outcome measure used to measure progress in a community setting; and this first person reflective commentary of the research process, completing the thesis and parallel personal development.

This commentary describes the researcher's influences and the process of designing and completing the two studies: which explore life after an acquired brain injury. While the development of these topics is the primary focus for reflection their development, and execution, cannot be separated from the concurrent lived experience of the researcher. Hence this commentary also presents a first person reflective account of some of the parallel personal journey interwoven with changes in roles, outlook and growth of the researcher. These changes are linked both to the research experience and personal lifelong learning.

Reflections on thesis from conception to reporting

Researcher Characteristics

Over the time taken to complete this thesis I have learnt from the research process, clinical training and parallel life events which I believe have changed my characteristics as a researcher.

Interest in ABI

My background may have influenced both my choice of research and learning experiences while studying for the DClinPsy. After pursuing a career in academic neuroscience I returned to psychology by securing assistant psychologist positions working in very supportive community acquired brain injury (ABI) and older adult teams. Neuropsychology and multidisciplinary services requiring insight into physiological issues seemed to maximise my

opportunity to use transferable skills giving me added confidence in the transition.

I also have a personal interest in ABI as my mother was involved in a traffic accident when I was 16 resulting in what we now recognise was probably a mild ABI. Personal experience of someone living with mild neuropsychological issues has perhaps not only influenced my interest in the specialty but also driven a wish to hear the lived experience from those it impacts on.

Interest in a mixed methods approach

My neuroscientific career involved analysis of very large quantitative datasets. As someone who had never felt comfortable with medical models of mental health issues it was during my time as an assistant psychologist I starting reading around systemic and social constructionist approaches. On starting the DClinPsy my first personal tutor noted the 'bench-science' and quantitative nature of my background and accurately commented 'so you won't have been encouraged to be reflective then?' This was true but the transition, which I was anticipating to be challenging, became a very welcome one. This was cemented during a first-year community adult mental health placement during which I joined my supervisor's client sessions as we worked from a Narrative perspective (1, 2). Observing, and being part of, sessions in which the impact of a Narrative approach appeared transformative for the client had a significant impact on my own clinical practice. This led to completing Level 1 training with the Institute of Narrative Therapy concurrently with the DClinPsy course. I also sought out further teaching in qualitative research techniques, completing a 2 day course in Interpretative Phenomenological Analysis (3).

While I had increased appreciation for the significance of a person's narrative the importance of quantitative service evaluation as requested by commissioners and payment-by-results (4) was also part of my professional education.

Personal influences

My personal journey has run in parallel to the above research experience and in some ways cannot be separated from it. During my time on the DClinPsy

course not only did my professional outlook develop, exploring new knowledge, models and techniques, but very importantly I also became a mother. I moved from being a career-focused striver to having my priorities re-focused onto my baby and their needs. This development was probably the biggest and most swift shift in focus I have experienced in my life. As I embedded myself within the course and my cohort further research planning took a back seat to accommodate academic work, clinical work and rest.

This shift in focus was intensified as it emerged my baby had additional healthcare needs. We experienced a prolonged struggle to have these needs recognised and met by professionals. Some of this struggle focused on arbitrary quantitative data which did not account for individual or familial differences. This was also my first intense experience of the double-edged sword of labelling, which I will explore later.

Learning style

From my previous experience in academia, both undergraduate and postgraduate, I was aware that my learning style is best facilitated within a collaborative learning environment (5). Being well aware of the challenging nature of the DClinPsy course I had looked forward to this exciting journey learning while embedded within a cohort of peers. Maternity leave and part-time working meant I left this fantastic and supportive group I had started the journey with and progressively join new cohorts which had formed their own bonds and group dynamic.

Achieving support to facilitate both my personal and professional roles was exceptionally challenging and allowed me to reflect on the personal and professional processes within complex environments. Subsequently my original research setting became unable to host my research which resulted in a delay until a new supervisor kindly agreeing to host the project. This occurred after I had concluded taught elements of the course and commenced paid employment. Hence the majority of this doctoral and research experience was spent moving forward with individual learning without the hoped for collaborative experience. On reflection I found this relative isolation challenging (6). Resilience is not a static concept and involves using dynamic planning for the

unpredictable to cope with adversity (7) However, I wonder whether it is possible that too much resilience may be unhelpful in exhibiting too much tolerance for adverse situations without adequate support. Conversely I believe I have derived additional pride in the persistence and resilience needed to achieve a conclusion.

Epistemological Position

When I started the process of developing this thesis my background had been in purely quantitative research and, as noted above by my tutor, reflection had not played a part in this (8). I had not previously understood or considered my ontological and epistemological positions. Through experience I have learnt to consciously reflect on my personal position both on the subject area and the research process.

Reviewing my previous quantitative bench-science experience it can be viewed as coming from a positivist model using objective observations to discover 'proven facts'. The assumption was that measurable relations between verifiable observations were being made without subjective conjecture. This would in part rationalise the lack of consideration for the influence of the researcher's personal position in the process. It follows that with a personal move to a more social constructionist clinical approach that there was a parallel adjustment in research perspective.

As described in the empirical paper I believe within this study, centred on the research question and requiring a mixed methods triangulation approach, took a post-positivism pragmatic approach. In other words both the quantitative and qualitative data were attributed equal value and integrated to look for agreement and discordance. In this way it was accepted in this problem-centred pragmatic approach, neither the interview nor the questionnaire could capture the individuals' full experience but only approximate the truth at the given time.

While I believe the epistemological position of this thesis as a post-positivism pragmatic approach I cannot claim that this is who I am as a researcher. On reflection this work, and previous research experience, I am still exploring more

constructionist approaches. Critical realism (9) is perhaps the next stage in my exploration of research. This may be seen as a way to explore individuals' personal views of reality which are by their nature fallible and provisional, but not simply cognitive constructions. This must be true for both participant and researcher.

As suggested above I am not sure if I have reached my final destination in my learning journey and epistemological position. However the process of exploring my beliefs, both academically and clinically is both central to a path of life-long learning and central to fulfil the role of reflective practitioner (10)

Project development and completion

Development of a research theme

I had remained in close touch with a community acquired brain injury service in which I had worked as an assistant. Though I had initially been invited to take charge of a part of a multi-centre study involving the service it was soon clear this would be too large an undertaking for a DClinPsy thesis. Chatting with a friend from that ABI service we were discussing the necessity of outcome measure data in the commissioning process. As noted, with experience of Narrative Therapy, I was interested in the difference between a person's description of the lived experience and what may be tracked on a quantitative outcome measure. This led me to wonder whether it would be possible to explore this in a more formal way with people who had experienced an acquired brain injury. Hence the seed of a plan to develop a mixed methods project comparing a qualitative outcome measure to a person's description of their current issues, following acquired brain injury, was born. My hope was to be able to explore whether a set of closed questions, converted into a numerical score could accurately reflect a client's experience.

While the empirical research area seemed to evolve naturally from my interest in work within an ABI community service, and the value of qualitative information gathering, the subject for a literature review eluded me for some time. During my period of data collection I was lucky enough to be working in a

service supporting people who had experienced spinal injuries. This was challenging clinical work and I found myself frequently exploring models of coping with both clients and colleagues. Curiosity led me to explore this subject in the brain injury area but I was unable to find a review of the literature focusing on ABI. Hence this was the start of my study to review the literature in this area.

Developing a realistic project

Initial grand designs for the research project of a longitudinal, large mixed-method project were streamlined with practical experienced input from my research tutor and clinical supervisor (Consultant Clinical Neuropsychologist). This would have aimed to explore, qualitatively, how the outcome measure reflected change over time against the participants' verbal accounts. Looking back at these initial hopes I realise I was enthusiastic to challenge myself with a methodology which was new to me (both qualitative and mixed methods) within the supportive learning environment of the DClinPsy course, my peer group, and a supportive clinical team hosting the project.

In discussion with my supervisors a more manageable and realistic project was proposed and as I was relatively inexperienced in qualitative, and clinical research, and I was very grateful for this guidance. The opportunity to receive guidance reminded me how essential I find an outsider perspective in tempering initial enthusiastic far-reaching goals to manageable and deliverable projects.

Due to the heterogeneity of the ABI population it was apparent that to allow direct comparison of a person's interview to outcome measure data a series of case-studies would be required. It was mutually decided, with advice from my clinical supervisor and research tutor, to recruit 5 clients giving a maximum of 10 participants if all elected to include a significant other (SO). This limit was to ensure qualitative analysis and reporting was of a manageable proportion for a single researcher. In addition it was necessary to develop a semi-structured interview to allow participants to describe issues as freely as possible while also prompting for information on all areas covered by the chosen outcome measure. This also served to minimise possible confounding variables due to neuropsychological issues such as perseveration.

Designing the process for analysis of the data was also subject to the need to facilitate data integration. Thematic analysis provided results which would be possible to be quantified for direct comparisons for each participant (11, 12). This also needed to be realistically reportable for a wide audience and publication.

I was aware as each research design decision was taken that this was moving from an idealistic notion of 'qualitatively validating a quantitative tool' to a realistic and pragmatic comparison of qualitative and quantitative data exploring similar themes.

Research implementation and conclusion

While the research project was going through ethical approval procedures the original host service became unable to continue with the project. Through previous contacts on clinical placement a new service and supervisor came on board. Recruitment started as soon as was feasible and progressed well but remotely. By this time I had completed the taught elements of the doctoral course and was employed in a Clinical Psychology service. Hence my contact with academic peer support had ceased. My research tutor and clinical supervisor became my contacts from hence forth.

Data collection also went very smoothly with all participants who had been recruited completing their involvement. It was when it came to data analysis, assimilation and reporting that I found myself reflecting on the progressive loss of hoped for support structures as something I found challenging.

Research Findings

The findings of the literature review provide limited evidence that positive coping styles are beneficial after a brain injury when using quality of life (QoL) measures. However there exists more robust data indicating that non-productive coping styles are unhelpful when considering longer term QoL. While these associations are what a common sense approach would expect the lack of evidence and small changes observed were interesting. Perhaps my long term focus on neuroscientific and neuropsychological research had skewed my perception of how much research was being pursued. However the difficulties I

experienced seeing this thesis to conclusion may also be reflected in the challenges others experience in facilitating research in busy clinical environments.

The empirical paper's findings suggest that neither a quantitative outcome measure nor a semi-structured interview can achieve a full understanding of a client's current lived experience. However the use of both in parallel appeared complementary. While combining a relatively simple measure and clinical interview may appear a standard clinical way of working in my experience, with increasing pressure on NHS community service resources, this does not always occur. So while the paper's findings may not be surprising hopefully it will serve as reinforcement for the importance of multiple information gathering streams being combined to facilitate a greater understanding of a person's lived experience.

Ethical considerations

In gaining ethical approval for the research study care was shown by all concerned regarding the recruitment process. This focused on who would be inviting service users to join the project. As I was not working in the team in which the study was hosted the clients' clinician was chosen to invite current service users when meeting at clinical appointments. Care was taken to minimise the possibility that there could be any feelings of responsibility to take part in the research. This need for this care was apparent when meeting with the potential participants describing enthusiasm to take part in gratitude for care they had received from the service. While this represents reports from a self-selecting sample it highlights the importance of taking all possible steps to avoid service users feeling obliged to take part in research embedded within a service which also provide care for them.

Within the research interviews clear research boundaries were also necessary when discussing clinical issues. As the interview so closely followed an outcome measure tailored for an ABI population questions participants posed questions which I felt fell outside the remit of a research interview. Having previously worked in a very similar clinical role I found myself remaining constantly aware of these boundaries. I believe this previous clinical experience

helped me to risk assess and where it was appropriate to either: move the discussion back to the research focus and when to address the client; or acknowledge the importance of an issue and ask for permission to relay an agreed message to their clinician.

Personal Reflections

During the course of this research journey my personal circumstances have changed greatly. I believe my previous clear goal-orientated career-driven focus suddenly became blurry as competing priorities appeared.

Personal professional development

Becoming a mother not only changed my role, it also gave me new experiences which I believe have directly influenced my professional and clinical practice.

Parenthood

I believe the knowledge I have gained through the doctoral course has positively impacted on my journey in learning to be a parent. This not only comes from acquired academic knowledge but also the need to accept that good-enough is good-enough. The overlap in caring roles, personal and professional can be seen as complimentary and as "*immersing ourselves in the processes of growth and development of other human beings*' (13). This is especially true when there is adequate support both in both workplace and home environments providing synergistic results (14). This synergism and a balance between the two caring roles of empathic practitioner and mother (13) is what I strive to achieve.

This reflection on, and greater understanding of, how my own life relates to my clinical and research has helped advance my personal professional development (15). For example both my child and I now have first-hand experienced both the positive and negative impact of labels. Achieving a defined label has allowed access to appropriate adjustments at school and with healthcare. However that label has been hard fight to attain and came at some ongoing personal cost us both. This has fed into my clinical practice working

with clients who have had unhelpful experiences with services or employers, along with reports of ongoing social stigma (16). I have noted myself reflecting more frequently when casual labels are attributed to someone and wondering about their validity and the effect of their use. This may also impact on deeper exploration of the client's experience and one can see the relationship between this and the empirical research hypothesis. This was a link I only came to recognise when reflecting on this research process.

While not confined to just the impact of labelling the personal professional development, and accompanying self-awareness, this has afforded me is central to the role of clinical psychologist as a reflective practitioner reducing the risk unresolved issues may impact negatively on clinical work (17) and possibly facilitating empathy and the therapeutic alliance. (7).

Summary

Despite limitations this thesis re-enforces the benefits of positive coping styles in long-term recovery following brain injury and for those assisting with this recovery both quantitative and qualitative exploration of neuropsychological issues are optimal.

This commentary reflects on a few brief portions of the research process including both achievements and challenges. This journey has included substantial learning and development, with significant changes in role and outlook. I was not expecting that the process had so positively fed into my clinical approach. The process of completing this project has also taught me about my own strength and weaknesses, some previously known, some previously unknown. This is actively helping me develop as a reflective scientist and practitioner.

References

1. Burr, V. Social constructionism. Second edition. London: Routledge, 2003. pp240
2. Morgan A. What is narrative therapy? An easy to read introduction. Adelaide: Dulwich Centre publications. 2000 pp
3. Smith JA, Osborn, M. Interpretative phenomenological analysis. In Smith JA editor. Qualitative psychology: a practical guide to research methods (second ed) London: Sage, 2007. p53-80
4. Department of Health. A simple guide to payment by results. London: DH, 2011. pp72
5. Lin L. Exploring collaborative learning: theoretical and conceptual perspectives. In: Investigating Chinese HE EFL classrooms. Springer-Verlag, Heidelberg, 2015. P11-28
6. Hawkey LC, Cacioppo JT. Loneliness matters: a theoretical and empirical review of consequences and mechanisms. *Ann Behav Med* 2010; 40(2): 218-227. PubMed [20652462]
7. Zhao-O'Brien J. The role of personal professional development in clinical psychology: A trainee's understanding and experience. *Clin Psychol Forum* 2011; 228: 45-48
8. Willig C. Introducing qualitative research in psychology (second edition). New York: Open University Press, 2008. pp248
9. Patomaki H, Wight C. After post-positivism? The promises of critical realism. *International Studies Quarterly* 2000; 44(2), 213-237.
10. British Psychology Society. Code of ethics and conduct. Leicester: British Psychological Society, 2009. pp31
11. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006; 3(2): 77–101. doi:10.1191/1478088706qp063oa

12. Driscoll DL, Appiah-Yeboah A, Rupert DJ. Merging qualitative and quantitative data in mixed methods research: How to and why not. *Ecological and Environmental Anthropology*. 2007; 3, 19-28.
<http://digitalcommons.unl.edu/icwdmeea/18>
13. Basescu C. The on-going mostly happy crisis of parenthood and its effect on the therapist's clinical work. In Gerson B editor. *The therapist as a person: life crisis, life choices, life experiences and their effect on treatment*. Atlantic Press: USA, 1996. p1010-118
14. Rupert PA, Stevanovic P, Hartman ET, Bryant FB, Miller A. Predicting work–family conflict and life satisfaction among professional psychologists. *Professional Psychology: Research and Practice* 2012; 43(4), 341-348. doi:10.1037/a0026675
15. Walsh S, Scaife J. Mechanisms for addressing personal and professional development in clinical training. *Clin Psychol Forum* 1998; 115:21 – 24.
16. Link BG, Cullen FT, Struening E, Shrout PE, Dohrenwend BP. A modified labeling theory approach to mental disorders: an empirical assessment. *American Sociological Review* 1989; 54(3): 400–423. doi:10.2307/2095613.
17. Hughes J. What is personal development and why is it important? In J. Hughes & S. Youngson (Eds.) *Personal Development and Clinical Psychology*. BPS Blackwell. Oxford, 2009. p24–45.

Appendix 2: Thesis appendix

2.1 Brain Injury instructions for authors

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Instructions for authors

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read and follow them as closely as possible, as doing so will ensure your paper matches the journal's requirements. For general guidance on the publication process at Taylor & Francis please visit our Author Services website.

This journal uses ScholarOne Manuscripts (previously Manuscript Central) to peer review manuscript submissions. Please read the guide for ScholarOne authors before making a submission. Complete guidelines for preparing and submitting your manuscript to this journal are provided below.

About the journal

Brain Injury is an international, peer-reviewed journal publishing high-quality, original research. Please see the journal's Aims & Scope for information about its focus and peer-review policy.

Peer review

Taylor & Francis is committed to peer-review integrity and upholding the highest standards of review. Once your paper has been assessed for suitability by the editor, it will then be double blind peer-reviewed by expert referees. Find out more about what to expect during peer review and read our guidance on publishing ethics.

Preparing your paper

All authors submitting to medicine, biomedicine, health sciences, allied and public health journals should conform to the Uniform Requirements for Manuscripts Submitted to Biomedical Journals, prepared by the International Committee of Medical Journal Editors (ICMJE).

Submission types

Brain Injury accepts the following types of submissions: original research and 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.

Structure

Your paper should be compiled in the following order: title page; abstract; keywords; main text; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list).

Formatting and templates

Papers may be submitted in any standard file format, including Word and LaTeX. Figures should be saved separately from the text. The main document should be double-spaced, with one-inch margins on all sides, and all pages should be numbered consecutively. Text should appear in 12-point Times New Roman or other common 12-point font. 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).

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 behaviourism 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).

Style guidelines

Submissions to *Brain Injury* should follow the style guidelines described in *Scientific Style and Format: The CSE Manual for Authors, Editors, and Publishers* (8th ed.). *Merriam-Webster's Collegiate Dictionary* (11th ed.) should be consulted for spelling.

References

References should be presented in a separate section at the end of the document, in accordance with Vancouver system guidelines (see *Citing Medicine*, 2nd ed.). The references should be listed and numbered based on the order of their first citation. Every reference should be assigned its own unique number. References should not be repeated in the list, with each

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<i>1 author</i>	Smith A
<i>2 to 10 authors</i>	Smith A, Jones B, Smythe C, Jonesy D, Smitty E, Jonesi F, Smithe G, Janes H, Smithee I, Junes J
<i>11 or more authors</i>	Smith A, Jones B, Smythe C, Jonesy D, Smitty E, Jonesi F, Smithe G, Janes H, Smithee I, Junes J, et al.

Models from US National Library of Medicine (NLM) resources (e.g., *MEDLINE*, *Index Medicus*), should be employed for abbreviating journal titles in the reference section. Examples of common reference types appear below.

Journal article

12. Taylor J, Ogilvie BC. A conceptual model of adaptation to retirement among athletes: a meta-analysis. *J Appl Sport Psychol.* 1994;6(1):1–20.
doi:10.1080/10413209408406462. Cited in PubMed; PMID:25888877.

Book

2. Duke JA. Handbook of phytochemical constituents of GRAS herbs and other economic plants. Boca Raton (FL): CRC Press; 2001. 676 p.

Book with titled volume and edition

18. Bowlby J. Attachment and loss. Vol. 3, Loss: sadness and depression . 3rd ed. New York (NY): Basic Books; 1982.

Edited book chapter

34. Gordon S, Lavalley D. Career transitions in competitive sport. In: Morris T, Summers J, editors. *Sport psychology: theory, applications and issues.* 2nd ed. Brisbane (Australia): Wiley; 2004. p. 584–610.

Edited book chapter with volume and edition

26. Remael A. Audiovisual translation. In: Gambier Y, van Dooslaer L, editors. Handbook of translation studies. Vol. 1. 2nd ed. Amsterdam (Netherlands): John Benjamins; 2012. p. 12–7.

Online/Website

8. United States Census Bureau: Census.gov [Internet]. Washington (DC): United States D; c. 2014. American housing survey: 2013 detailed tables; 2014 Oct 16 [cited 2014 Oct 21]; [1 screen and data files]. Available from: <http://www.census.gov/newsroom/press-releases/2014/cb14-tps78.html>.

Dissertation/Thesis

26. Allison N. Bacterial degradation of halogenated aliphatic acids [dissertation]. [Nottingham (UK)]: Trent Polytechnic; 1981. 120 p.

Conference presentation

4. Alfermann D, Gross A. Coping with career termination: it all depends on freedom of choice. Paper presented at: 9th Annual World Congress on Sport Psychology; 1997 Jan 23; Netanya, Israel.

Paper/Report

55. Grigg W, Moran R, Kuang M. National Indian education study. Washington (DC): National Center for Education Statistics; 2010 Jun 23. Report No.: NCES 2010-462.

Newspaper

22. Protzman, F. Clamor in the East: East Berliners explore land long forbidden. New York Times (Late ed.). 1989 Nov 10;Sect. A:1 (col. 2).

Patent

67. Pfeifer A, Muhs A, Pihlgren M, Adolfsson O, Van Leuven F, inventors; AC Immune S.A, Katholieke Universiteit Leuven, assignees. Humanized tau antibody. United States patent US 9,657,091. 2017 May 23.

Computer software with developer

10. Noguera J, Cumby C. SigmaXL. Version 8.0. [software]. Kitchener (Canada): SigmaXL, Inc; 2017 Feb 27.

Computer software without developer

76. SPSS Amos. Version 22.0 [software]. Armonk (NY): IBM; 2013 Aug 13.

Dataset

3. Wang G-Y, Zhu Z-M, Cui S, Wang J-H. Data from: glucocorticoid induces incoordination between glutamatergic and GABAergic neurons in the amygdala [dataset] . 2017 Aug 11 [cited 2017 Dec 22]. In: Dryad Digital Repository [Internet]. Available from: <https://doi.org/10.5061/dryad.k9q7h>.

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