Staff Experiences of Working with Individuals with Acquired Brain Injury:

A Qualitative Study

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Thesis portfolio abstract

Purpose: The overall aim of this thesis portfolio is to investigate the wider systemic effects of acquired brain injury (ABI); on how family members cope following their loved one experiencing brain injury, and the experiences of healthcare professionals working with survivors of ABI in neurorehabilitation.

Design: The structure of this project is presented in a portfolio format: a brief introduction, a systematic review of the literature on the coping styles of family caregivers following traumatic brain injury (TBI), a qualitative paper regarding the experiences of professionals working in a UK neurorehabilitation context, an extended methodology chapter, an overall discussion and a critical evaluation.

Findings: The systematic review found coping styles in adjusting to a family member with a TBI included avoidance coping and approach coping. These coping styles had psychosocial and emotional outcomes for caregivers, including distress, stress, burden, pessimism and worry. Additionally, types of family functioning impact upon the coping styles of caregivers.

The empirical paper utilised interpretative phenomenological analysis to explore the experiences of a range of professionals working with survivors of ABI. Three main themes were identified: personal emotional experience, the impact of meanings in personal lives, and frustrations towards the organisation.

Value of the study: The review confirms the importance of family needs in rehabilitation or support services. Better quality research is needed to investigate caregiver outcomes and coping styles. Qualitative research provides insight into the emotional experiences of a small group of professionals working in neurorehabilitation. This can be used to guide and support the well-being or supervision of professionals working with this complex client group. Areas of future research are considered.

Contents

Acknowledgements

Firstly, I would like to thank both of my supervisors, Fergus Gracey and Paul Fisher who have been supportive throughout the thesis project. I would also like to thank the service managers who supported the project so that I was able to recruit participants. Most importantly, I would like to thank the healthcare workers who took the time to share their experiences and participate in this research study, without whom this project would not have been possible. Finally, I would like to thank my family and friends for their unconditional support and encouragement throughout.

Introduction to Thesis Portfolio

Acquired brain injury (ABI) includes all forms of brain injury which are sustained after a period of normal development, including traumatic brain injury, strokes, and hypoxic brain injury (The Brain Injury Association of America, 2012). The consequences that ABI can have on survivors are dependent on the type and severity of the injury; including significant physical, cognitive, emotional and behavioural effects (British Society of Rehabilitation Medicine, 2003). ABIs are usually sudden, one off events that can change an individual's potential to reach their goals, and can often require specialist rehabilitation (Pagan et al., 2015). The consequences of brain injury on survivors' family members may place pressure to care and support the injured person (Bowen, Yeates & Palmer, 2010).

In recent years, there has been a shift from a medical approach to a more relational approach to rehabilitation. The consequences of brain injury can be understood to be more prominent when people are with others, rather than in isolation (Yeates, 2009). This relational approach does not focus just on survivors of brain injury; but the impact on survivors' relatives and communities. In other words, considering the 'brain-injured relationships and systems' (Bowen et al., 2010).

Successful rehabilitation can be influenced by family caregivers; and there has been increasing evidence that family's emotions are important in contributing to successful rehabilitation (Anderson, Parmenter, & Mok, 2002; Douglas & Spellacy, 1996; Rivera, Elliott, Berry, Grant, & Oswald, 2007).

This thesis portfolio focuses on the consequences of brain injury upon the wider system, which has been described by many informally as creating a "ripple effect," impacting not only the individual with the ABI, but beyond, including families, friends, colleagues (although it is not possible to identify by whom the phrase was coined).

The first chapter is a systematic review which aims to scope the coping styles of family caregivers following their loved one surviving a traumatic brain injury (TBI). There is a large body of literature in this area, and consideration is given to the effects of coping styles upon psychosocial and emotional outcomes for family caregivers of TBI survivors. A bridging chapter connects the papers.

The third chapter is the empirical paper, exploring healthcare workers' experiences of working within community neurorehabilitation settings. Current literature focuses on survivors' experiences of having an ABI, as well as family and carers' experiences of ABI. There is little information regarding staff experiences, therefore this study aims to address this gap in the literature. A key rationale for this study is to explore the lived experiences of working with individuals with ABIs to allow us to develop an in-depth understanding of the experiences for this group of healthcare workers. An extended methodology chapter outlines the background of IPA research and the implications for this study.

This study may also provide a basis for future research with an understanding of well-being, supervision, support or training needs, as well as motivations of professionals to work in this specialist field of brain injury rehabilitation. A final discussion chapter draws together findings from both studies.

Chapter 1.

Systematic review prepared for submission to: Neuropsychological Rehabilitation

Coping Styles of Family Caregivers for Adult Survivors of Traumatic Brain

Injury: A Systematic Review.

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Abstract

Introduction: Traumatic brain injury (TBI) often occurs unexpectedly, causing a range of cognitive, behavioural, emotional and physical sequalae. The majority of sufferers of TBI are relatively young, and the role of caregiver often falls onto families. There is substantial research investigating the emotional impact of adult TBI on caregivers, but no reviews look more broadly into the coping styles of TBI caregivers.

Methods: A systematic review of the literature was conducted using six electronic databases: AMED, EMBASE, MEDLINE, PsycINFO, BNI and CINAHL.

Results: The inclusion criteria found ten studies that were appropriate for the inclusion within the review. Data from each study was collated and the Quality Assessment Tool for Observational Cohort and Cross- sectional Studies was used to assess the studies. Nine of the studies were rated as 'poor' and one was rated as 'fair.' A range of coping styles of TBI caregivers were found, and predictors of emotional outcomes and mediators were found.

Conclusions: The review confirms the importance of family needs in rehabilitation or support services. Coping styles can have an effect on psychosocial and emotional outcomes of family caregivers. Better quality research is needed to investigate caregiver outcomes and coping styles.

Keywords: Family, traumatic brain injury, coping styles

Introduction

Acquired brain injury (ABI) includes all forms of brain injury that are sustained after a period of normal development, including traumatic brain injury, strokes, and hypoxic brain injury (The Brain Injury Association of America, 2012). Traumatic brain injury (TBI) is a major cause of mortality and morbidity (Lawrence et al., 2016), and is the most common cause of death for people under the age of 40 years old (National Institute of Clinical Excellence, 2014). There were 15,820 cases of TBI within England and Wales between April 2014 and June 2015 (Lawrence et al., 2016). The Brain Injury Association of America describes TBI as "an alteration of brain function, or other evidence of brain pathology, caused by an external force" (The Brain Injury Association of America, 2012). Common causes of TBI include road traffic accidents, assaults and falls (Headway, 2017).

The onset of TBI is typically sudden and is often followed by an intensive period of care, followed by rehabilitation (Vos, Diaz- Arrastia, 2014). This sequalae are often classed as 'hidden disabilities' (Gordon & Hibbard, 1998; Vos, Diaz- Arrastia, 2014) because there are often no physical indicators of brain damage, so cognitive difficulties can often go unnoticed (Simpson, Simons & McFadyen, 2002). However, TBIs often have substantial cognitive, behavioural and emotional sequalae following onset, which can cause life-long difficulties (Gordon et al., 1998, Simpson et al., 2002; Pondsford, Sloan & Snow, 2012). Survivors of TBI may suffer from cognitive impairments that may affect working memory, information processing, attention, and executive functioning (Azouvi, Allat-Azouvi & Belmont, 2009). These cognitive impairments are often associated with personality changes (Brooks & McKinlay, 1983) and poor self-awareness (Prigatano & Altman, 1990).

As the majority of TBIs occur in younger people who survive their injuries have a normal life expectancy (Morton & Wehman, 1995; Peterson & Sanders, 1995), they often rely upon life-long care provided from their family members (Pondsford, Sloan & Snow, 2012; Kozloff, 1987; Carnes & Quinn, 2005). The shift to a caring role for relatives with TBIs can be especially difficult when families may still be still adjusting to a new situation (Bowen, 2007). The emotional, personality and behavioural changes following brain injury are the most stressful changes for family members to manage (McKinlay, Brooks, Bond, Martinage & Marshall, 1981). It has been well established that this adjustment can cause increased levels of stress and subjective reports of burden amongst relatives in the long-term as well as immediately after the TBI occurred (Brooks, Campsie, Symington, Beattie & McKinlay, 1986; Lezak, 1978; Lewin, Marshall & Roberts, 1979; Ponsford & Schonberger, 2010).

Furthermore, the nature of this caring role for TBI survivors can also be associated with high levels of stress, burden, depression (Degeneffe et al., 2011), reduced perception of health-related quality-of-life (Volger, Klein & Bender, 2014) and grief (Pondsford et al., 2012). Longitudinal research has indicated that two years following TBI, compared to adults without the responsibilities of being a caregiver, family members of survivors often experienced reduced life satisfaction (Livingston et al., 2010).

Family functioning refers to the social and structural properties of the family environment, including interactions and relationships within the family. In particular, family functioning includes levels of conflict and cohesion, quality of communication, organization, and adaptability (Lewandowski, Palermo, Stinson, Handley & Chambers, 2010). The adjustment of families to their new roles and loved one with a TBI affects the way in which families function. It has been well documented that family functioning can significantly determine the family's adaptation to TBI of adults and children

(Curtiss, Klemz & Vanderploeg, 2000; Kozloff, 1987; Max et al., 1998). Sander et al. (2003) provided evidence to suggest that families of TBI survivors may have had higher rates of stress or unhealthy family functioning pre-injury, meaning they are less equipped to cope with the impact of injury in a family member (Ponsford et al., 2012). There is also substantial research that shows important factors in successful rehabilitation in TBI survivors are relative's emotions (Anderson, Parmenter, & Mok, 2002; Douglas & Spellacy, 1996; Rivera, Elliott, Berry, Grant, & Oswald, 2007), which might also impact upon their ability to cope following TBI of their family member.

A range of family interventions is often advocated by both researchers and clinicians, including, family education, family counselling and therapy, marital and sexual counselling, family support groups, family networking, and family advocacy (Rosenthal & Young, 1988). However, despite the well documented challenges that family caregivers of TBI survivors face following the TBI, there is limited evidence of family intervention studies (Boschen et al., 2007). Studies have suggested the possible usefulness of family education interventions psychoeducation of brain injury (Sanguinetti & Catanzaro, 1987; Sinnakaruppan, Downey & Morrison, 2005). Sinnakaruppan et al. (2005) found positive changes in general health as a result of a psychoeducation programme. Sanguinetti and Catanzaro (1987) found participants were more informed about behaviour following brain injury and felt better prepared to help the family member with cognitive difficulties. Singer, Glang and Nixon (1994) also found that two types of family support group reduced participants' levels of depression and anxiety. However, Singer et al. (1994) did not employ a control group.

Coping can be defined as a process that can take several years, and as continuously altering cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as exceeding a person's resources (Lazarus & Folkman, 1984). Coping is typically oriented towards solving problems, or emotion -

focused, towards reducing the stressful emotions. Lazarus & Folkman (1984) developed the stress, coping and appraisal model as a conceptual framework that has been utilised in understanding caregivers of TBI survivors' quality of life (Chronister, Chan, Sasson-Gelman & Yui Chun, 2010). Further, Chwalisz (1996) investigated the perceived stress model of caregiver burden amongst TBI caregivers and found coping and social support moderated the effect of perceived stress with both mental health and physical health.

There are many ways in which families adjust emotionally and functionally to having a loved one experience TBI. However, there is a lack of clarity regarding how families cope with their adjustment to TBI. A theory explaining the key factors involved in determining outcomes might help inform a model which could be used to guide psychological formulation and intervention. This scoping review aims to identify any studies addressing coping styles of family caregivers of TBI survivors. This may assist in determining any significant predictors or associations that might be of use clinically.

Method

Inclusion and Exclusion Criteria

A systematic review of the literature was conducted, using the PICO framework (Aslam & Emmanuel, 2010). Articles were included for review if they adhered to the following eligibility criteria:

- Population: Family members, no restriction to type of family members. The majority of the sample (at least 80%) includes adults aged over 18 who have experienced a traumatic brain injury

- Interest: Coping

- Comparison: No comparator restriction

- Outcome: Studies providing any psychosocial outcomes

- The majority of the sample (at least 80%) has moderate to severe TBI, no restrictions on definition

- Peer reviewed journals, written in English

Studies were excluded:

- If they were not written in English

- If they were mixed method or qualitative studies

- If they included interventions

- If the injured member of the family has mild TBI only

- If the injured family member was under 18 years of age

- All other forms of ABI including stroke

Search Strategy

The literature was searched using the following primary databases in June 2017: AMED, EMBASE, MEDLINE, PsycINFO, BNI and CINAHL. A search strategy using three components was run; including the following key terms; ("family caregivers" OR "informal caregivers" OR "relatives" OR "family" OR "family members" OR "carers" OR "caregivers"), AND ("acquired brain injury" OR "traumatic brain injury" OR "head injury") AND ("coping" OR "coping skills" OR "coping mechanisms"). All searches were combined, and any duplicates from the results were removed. For completeness, reference lists of the studies included were hand searched to incorporate any of relevance. The limiters applied were peer-reviewed studies, those written in English, and included adults.

Studies were reviewed until the end of June 2017 and were only included if they were published until this date and met the above criteria.

Search Results

The initial electronic search generated 872 articles. These were filtered using a stepwise approach to remove qualitative methodologies, non-English studies and included only peer-reviewed studies, 119 papers remained. Abstracts of these 119 papers were read and those that did not meet the eligibility criteria were excluded. Any studies that did not meet criteria at this stage were excluded, for reasons such as qualitative studies, paediatric brain injury studies or focusing on stroke rather than TBI. This left a total of 13 full text articles to be inspected closely for appropriateness to be included; which were hand searched for additional articles. Two additional studies were included, resulting in 15 full text articles that were assessed for their eligibility; figure 1 presents the PRISMA flow chart showing the process by which the final selection of articles was identified. A total of ten full text articles were selected to be reviewed. The final selection of ten studies will be described and evaluated.

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│ (n=2)        │   └─────────────────────────────┘  │  severity in sample (n=1)             │
└──────────────┘                 │                   │                                      │
                                 │                   │  Preliminary studies (from same       │
                                 ▼                   │  author with same measures, follow up │
                                                     │  included in review) (n=2)            │
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                                                     │  No clarity on age of TBI sample      │
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Figure 1: Flowchart to show selection of eligible studies.

Assessment of the Quality of Included studies

All studies were critically appraised using the Quality Assessment Tool for Observational Cohort and Cross- Sectional Studies (QATOCCS; National Heart, Lung and Blood Institute, NHLBI, 2014). This tool was selected as it was most appropriate because of its application to quantitative study designs, particularly for observational and cross-sectional studies. The QATOCCS tool was used to assess the studies methodological strengths and weaknesses by assessing the following domains: the research question, the study design, the selection bias, blinding of researchers, confounding variables, statistical analyses, data collection methods and drop-outs. The tool consists of 14 questions, for which the rater responds with "yes," "no," "CD" (cannot determine), "NA" (not applicable) or "NR" (not reported). The QATOCCS also has additional guidance for the assessment of the quality of studies. An overall quality rating determines whether the study is of good, fair or poor quality. Of the selected studies, no studies were excluded based on quality. The ratings and issues of quality are discussed in relation to the interpretation of data.

Data Analysis

The first stage of analysis was tabulation; relevant data from full papers were extracted and presented to include descriptive summaries of the studies included in the review (Centre for Reviews and Dissemination, 2008). Summaries included the study aims, design, inclusion and exclusion criteria, outcome measures used and the study findings in relation to the review question. The second stage included quality consideration of the studies using the QATOCCS, and the completion of a second table. In order to improve rigour of the quality ratings, a random selection of papers was independently reviewed. Once both independent reviewers completed their ratings, they compared ratings and resolved any differences through discussion. Given the focus of

all of the studies, it was not possible to blind the assessors to the exposure. Therefore, this criterion did not apply to all of the studies in the review. The final stage of analysis was developing the narrative synthesis, by weighing the study descriptions, findings and methodological quality in order to reach some overarching conclusions.

Results

Study Characteristics

The review of the literature identified a sample of ten peer reviewed articles which were included in the current review. Only three of the studies were published prior to 2000 and seven studies were published between 2000 and 2016. The main characteristics of each study are presented in table 1. This includes the aims, sample characteristics, the measures used and the main findings in relation to the review. The overall quality ratings are presented in table 2, in accordance with the QATOCCS quality guidance. Due to the heterogeneity of the methodology of the studies, a narrative synthesis was utilised instead of a meta-analysis.

Design.

The review included seven cross-sectional survey designs (Curtiss et al., 2000; Knight et al., 1998; Blankfeld & Holaham, 1999; Chronister et al., 2016; Hanks et al., 2007; Calvete & de Arroyabe, 2012 and Kosciulek, 1997). Other studies included two comparison survey design studies with matched controls (Pelletier & Alfano, 2000; Boyle & Haines, 2002). One cohort correlational study was also included in the review (Davis et al., 2009).

From the review studies, two studies focused on family coping, depression and social support following TBI (Pelletier & Alfano, 2000) in addition to grief (Calvete &

de Arroyabe, 2012). One study investigated the effects of TBI on family structure and coping resources (Curtiss et al., 2000). Two studies focused on the effects of TBI on coping, social support and psychological adjustment of carers (Blankfeld & Holahan, 1999; Hanks et al., 2007). One study investigated perceived burden and quality of life of caregivers of individuals with TBI (Chronister et al., 2016) and two studies investigated the effects of TBI on family carers (Boyle & Haines, 2002; Knight et al., 1998). One study identified the dimensions of family coping following TBI (Kosciulek, 1997). It is important to note that Davis et al. (2009) investigated medical and psychosocial predictors of caregivers' distress and perceived burden following TBI. Many of the studies used measures of distress and burden as part of their investigations.

Participants.

A total of 866 caregivers were included in the studies across all papers. The inclusion criteria for the studies varied. One study only included family caregivers of severe TBI survivors (Boyle & Haines, 2002), the remaining nine studies included family caregivers of survivors of moderate to severe TBI. Two studies defined and referred to TBI as 'head injuries,' referring to enduring difficulties (Calvete & de Arroyabe, 2012; Kosciulek, 1997), which suggested they experienced moderate-severe TBIs.

Only three of the studies used Glasgow Coma Scores as a measure of TBI severity (Hanks et al., 2007; Curtiss et al., 2000; Davis et al., 2009). Three studies recorded the duration of coma (Calvete & de Arroyabe, 2012; Chronister et al., 2016; Knight et al., 1998). The remaining four studies did not indicate TBI severity using measures (Boyle & Haines, 2002; Blankfeld & Holahan, 1999; Pelletier & Alfano, 2000; Kosciulek, 1997).

The time since injury varied across studies; Kosciulek (1997) recruited caregivers at least one year following injury but did not offer further details; Curtiss et al. (2000) recruited family caregivers on average 10 weeks post injury, and Blankfeld and Holahan (1999) recruited caregivers on average 6 months since injury. Hanks et al. (2007) recruited family caregivers between 6 months – 15 years post injury; with an average of 4 years post injury. Pelletier & Alfano (2000) recruited families on average 4.3 years post injury. Knight et al. (1998) included carers who were on average 6 years post injury and Chronister (2016) recruited caregivers on average 8.6 years post injury. Calvete & de Arroyabe (2012) included caregivers on average 8.15 years post injury; Boyle and Haines (2002) recruited caregivers on average 9.8 years post TBI. Davis et al. (2009) recruited caregivers within two weeks following the TBI and completed follow up measures at this time point and approximately 12 months post injury.

A range of measures was used with family caregivers focusing on different aspects of coping following a family member sustaining a TBI. Two studies used the Coping Response Inventory (Blankfeld et al., 1999; Curtiss et al., 2000), whereas three other studies used versions of the Caregiver Appraisal Scale (Chronister, 2016; Hanks et al., 2007; Davis, 2009). The Ways of Coping questionnaire was used by two studies (Blankfeld, et al., 1999; Davis, 2009). One study used the Responses to Stress Questionnaire (Calvete & de Arroyabe, 2012) as a way to measure coping strategies of caregivers. The Family Coping Behaviours was used by one study (Kosciulek, 1997). One study did not state the measures used (Pelletier & Alfano, 2000).

The studies also focused on family functioning; Boyle and Haines (1998) used the Family Environment Scale. Chronister (2016) and Calvete & de Arroyabe (2012) both utilised the Family Needs Questionnaire; Hanks et al. (2007) used the Family Assessment Device. Blankfeld et al., (1999) used the Family Support Scale, which was derived from two subscales of the Family Environment Scale: cohesion and conflict.

Table 1

Study Characteristics.

Author	Aim of the study	Study design	Study inclusion and exclusion criteria	Characteristics of participants	Type of measures used	Findings in relation to SR Question
Blankfeld & Holahan 1999	Test a mediational model of risk and protective factors associated with the psychological adjustment of caregivers with head injured pts.	Cross sectional survey design	TBI patients' caregivers	45 caregivers	Self- report survey: The family support scale The friend support scale Social Resources Inventory Percentage approach coping Health and Daily Living Form- depressive symptoms scale State-Trait Personality Inventory- state anxiety scale.	Female caregivers reported significantly more psychological maladjustment than males Female caregivers experienced more burden than males Percent approach coping associated with lower levels of psychological maladjustment Caregiver burden showed direct relationship to psychological adjustment, social support indirect relationship to adjustment mediated by percent approach coping.
Boyle & Haines 2002	Investigated effect of TBI on family members and functioning	Cross sectional survey comparing BI family with matched controls	Respondents were primary caregiver for person who had experienced a severe TBI Excluded- if prior head trauma, psychiatric illness, or substance abuse	24 family members Comparison group- 32 Matched for SES status	The family environment scale Profile of mood states	Significant differences between TBI non TBI families TBI caregivers had lower levels of expressiveness, active-recreational orientation than the control group but greater levels on the control subscales. Depression- dejection subscales were significantly higher in the TBI caregiver group compared to controls in Profile of mood states

Calvete & de Arroyabe, 2012	Examined the associations between social support, coping responses, depression and grief symptoms in caregivers of TBI family members	Cross sectional survey design	Most responsible caregivers of TBI patients 18+ years Able to read Spanish	223 Spanish caregivers	Family Needs Questionnaire Texas Revised Inventory of Grief Centre for Epidemiological Studies Depression Scale Responses to Stress Questionnaire	Structural equation model suggests primary coping strategies (problem solving, emotional expression + disengagement) associated with more grief and depressive symptoms. Secondary coping strategies (acceptance, positive thinking) associated with less grief/ depressive symptoms.
Chronister et al. 2016	Does personal (caregiving mastery and problem-solving coping) and environmental (social support, and professional and community support) caregiver resources mediate the relationship between caregiver perceived burden and quality of life	Cross sectional correlational survey design	At least 18 years old Able to read English Consider themselves a primary caregiver Not paid Care recipient TBI aged 18+ Injury 12m+ prior Care recipient not living in residential care	108 caregivers	Patient Competency Rating Scale–Relative Version Interpersonal Support Evaluation List, The COPE, Family Needs Questionnaire Modified Caregiving Appraisal Scale World Health Organization Quality of Life–Brief Version	Significant association between functional disability and QOL, functional disability significantly related to burden. Mediator-burden sig related to QOL. Significant association between perceived burden and problem coping: greater burden is associated with greater levels of problem solving coping.

Curtiss et al. 2000	Investigate familial change and response to TBI using Olson's Circumplex model	Retrospective pre- and post TBI survey design	Spouses of TBI survivors Non-penetrating severe TBI active military duty or military veterans enrolled in the Defence and Veterans Head Injury Program (DVHIP)	21 caregivers	FACES II Coping responses Inventory	Significant effects for focus of coping and coping strategy- family type, focus of coping and coping strategy pre- vs post TBI significant. Balanced families post TBI had lower emotion focused behavioural coping compared with pre TBI scores
Davis et al 2009	To determine whether caregivers' medical and psychiatric histories, coping style and social support predicts distress and perceived burden	Correlational cohort survey study	Caregivers of patients with moderate to severe TBI, 1-2 years post injury	114 caregivers	Ratings of caregivers medical psychiatric History Disability Rating Scale Ways of Coping Questionnaire Multidimensional Scale of Perceived Social Support Brief Symptom Inventory Modified caregiver appraisal Scale	Increased use of escape- avoidance as a coping strategy related to increased distress.

Hanks et al. 2007	Positive and negative appraisals of caregiving in four main areas: perceived burden, caregiving relationship satisfaction, beliefs about caregiving, and mastery with caregiving.	Cross sectional Correlational survey design	16 years minimum Received acute care from service Able to give consent Excluded Mild TBI that were discharged from A&E and did not receive acute care	60 primary caregivers	Glasgow Coma Scale Disability Rating Scale Functional Independence Measure Social Provision Measure Coping Inventory for Stressful Situations Family Assessment Device Caregiver Appraisal Scale	Caregivers who reported substantially higher scores with respect to Perceived social support showed strong positive association with task-oriented coping and inverse associations with emotion-oriented coping and the General Functioning scale of the FAD FAD's significant predictors: emotional oriented coping, behavioural control and social support.
Knight, Devereux & Godfrey 1998	Examine constructs of social support, appraisal of coping resources and perception of severity of TBI symptoms	Cross sectional survey design	Primary caregiver of person who had TBI for 12 months minimum	52 caregivers	Care Burden Scale 4 items based on social support questionnaire -3 items asked ppt's perception of abilities to cope with caring and 2 items embedded in CBS Centre for Epidemiologic Studies Depression-symptom distress questionnaire Demographic questionnaire	Symptom severity predicts carer burden Social support, demographics and injury severity not related to caregiver satisfaction Coping satisfaction scores predicted by depression scores Symptom distress and coping satisfaction had significant beta weights in the stepwise analysis

| Kosciulek, 1997 | Identify the dimensions of family coping with head injury by replacing and extending previous study | Cross sectional survey design | Primary caregivers of head injured pts

English speaking

Injured pt 18+ years

12 months post injury | 82 primary caregivers | Frequency of Family Coping Behaviours

Family Information Sheet | Cluster analyses indicated 2 dimensions of clusters associated with coping following head injury:
Using social support vs cognitive coping
Head injury focused coping vs family tension management |
|---|---|---|---|---|---|---|
| Pelletier & Alfano 2000 | Investigated the relationship between family coping (and perceived stress) and the patient's psychological functioning following TBI | Correlational cross-sectional survey design- comparison group | Moderate to severe TBI | 13 matched pairs of TBI patients and their family members (recruited from a larger study) | Questionnaires not named | Confrontive Coping, Accepting Responsibility, and Problem Solving. Patients' level of depression was significantly and negatively correlated with family members' perceived stress attributed to the physical limitations of the patient.

Patients' perceived stress positively and significantly associated with family members use of confrontative coping. |

Methodological Quality

Nine of the ten studies were rated as methodologically 'poor.' Only one study was rated as 'fair' (Davis et al., 2009). A strength of all of the studies reviewed was that they defined the research objective and the study characteristics clearly. All studies with the exception of one study (Pelletier & Alfano, 2000) described the types of outcome measures used. Additionally, of these nine studies, the majority of measures they employed were valid and reliable. The exception was the Knight et al. (1998) study that embedded two additional questions into the Care Burden Scale regarding their ability to cope with the caring role. Blankfeld and Holahan (1999) developed their own Care Burden Scale for the purposes of their study.

Seven of the studies utilised cross-sectional survey designs (Blankfeld & Holahan, 1999; Knight et al., 1998; Chronister et al., 2016; Hanks et al., 2007; Pelletier & Alfano, 2000; Calvete & de Arroyabe., 2012; Kosciulek, 1997). The outcome measures were only completed at one time-point. In addition, a weakness of these studies is that they cannot determine causality, instead only commenting on the association.

The Davis et al. (2009) study utilised a cross-sectional cohort design which strengthened the methodology. They repeated the outcome measures at 12 months. Curtiss et al. (2000) compared outcome measures of caregivers pre- and post TBI. However, they asked spouses to retrospectively respond to questions for the pre- TBI measures, which increased the risk of bias. Boyle and Haines' (2002) study compared families with a survivor of TBI with matched controls with the same social economic status, which added greater methodological rigour. Although the research objectives, study population, and outcome measures were clearly defined, this study did not justify the sample size or complete power analyses.

However, all of the studies included risks of bias, which meant that all of the studies were rated as either 'poor' or 'fair' using the QATOCCS. All studies, with the exception of Davis et al. (2009), did not complete sample size calculations, so it is unclear whether these samples are large enough to power the analyses undertaken. This could result in a risk of these studies not detecting a genuine effect. Other weaknesses across the studies included not including the participation rate of eligible participants (Boyle & Haines, 2002; Blankfeld & Holahan, 1999; Davis et al., 2009).

Study Findings

Coping and emotional responses of TBI family caregivers.

Pelletier & Alfano's (2000) study included a small sample size, of 13 matched pairs of TBI patients and family members. This adds risk of bias in terms of limiting the study's ability to draw definite conclusions from the results, which Pelletier and Alfano (2000) acknowledge. They did not state the outcome measures used; therefore, it was not possible to determine the validity of these measures or how their conclusions were reached. As this study was rated as having 'poor' methodology, the study findings should be taken with caution. They reported patients' perceived stress was significantly and positively correlated with family members' use of confrontative coping. They also reported TBI survivor's levels of depression to be significantly and negatively correlated with perceived support from family. Due to the small sample size, no further analyses were conducted to control for confounding variables.

Blankfeld and Holahan's (1999) study was also rated as methodologically 'poor'. They recruited a relatively small size (n=45) and did not report on statistical power. The outcome measures were valid, with the exception of using a Care Burden Scale (CBS) which they developed for the purposes of this study, which is therefore

unknown. The CBS was found to have high internal consistency. They included a variable of 'caregiver' (including BI caregivers and non-caregivers/controls) and a variable of 'coping,' which were significantly associated. They reported female caregivers indicated to experience significantly more psychological maladjustment than male caregivers, when burden was controlled for. Neither caregiver relationship nor age related to psychological maladjustment. Blankfeld and Holahan (1999) reported social support significantly related to greater percentage coping; and percentage approach coping was significantly associated with lower levels of reported psychological maladjustment amongst TBI caregivers.

Kosciulek's (1997) study investigated the coping dimensions of families following TBI. They replicated a previous study (Kosciulek, 1994) in order to produce generalisable findings; however, their findings should be taken with caution as the study was also rated as methodologically 'poor'. They obtained a 37% response rate from the questionnaires sent out, introducing a risk of bias in terms of unknown data. Kosciulek (1997) used a measure developed in previous studies: the Frequency of Family Coping Behaviours (FCB; Kosciulek, 1994), which had good internal consistency. Although weak, the study identified two dimensions of family coping following TBI; the meaning of the TBI versus family situation. This dimension refers to the way in which families use positive appraisals and cognitive reframing. The second dimension was the head injury focused coping versus family tension management, defined as the extent to which families attempt to seek support for the TBI survivor, and the extent to which families attempt not to attribute their difficulties towards the brain injury itself.

Finally, Boyle and Haines' (2002) study investigated the effects of TBI on family caregivers. They employed a comparison control group, which improved

methodological quality. There were significant differences between TBI non-TBI family caregivers. Within the Family Environment Scale, caregivers of survivors of TBI scored significantly lower on the expressiveness, active-recreational orientation subscales than the control group. Caregivers of TBI survivors also scored significantly higher on the control subscale. For the Profile of Mood States, the depression- dejection subscale was significantly higher amongst caregivers of TBI survivors compared to the control group.

Mediators of TBI caregivers and psychosocial or coping outcomes.

Chronister (2016) utilised a cross-sectional correlational survey design, which meant that follow up measures were not completed. Although effect sizes calculations were not completed, a moderately sized sample was included (n=108). Burden was a mediator which was significantly related to quality of life and functional disability. The results also indicated significant associations between perceived burden and coping. Furthermore, perceived burden was significantly and negatively associated with problem-solving coping. Mediation analysis indicated perceived burden and social support mediate the relationship between burden and quality of life.

Blankfeld and Holahan (1999) tested a mediational model of risk and protective factors associated with the psychological adjustment of TBI caregivers. They found support for their proposed model, which included exogenous variables for caregiver burden, social support and endogenous variables for percentage approach coping as a mediator between social support and psychological maladjustment, and endogenous variable for psychological maladjustment as the outcome variable. They reported that burden and social support impact upon psychological maladjustment, via the effect of the percentage approach coping style.

Calvete and de Arroyabe's (2012) study investigated the association between social support, coping responses, depression symptoms and grief symptoms of TBI family caregivers. They had a low response rate (27.5%) which introduces a risk of bias. They found that overall caring for a TBI survivor was associated with depression and grief. They also found that the type of coping styles acted as a mediator between social support and distress perceived by caregivers. A structural equation model suggested that primary coping strategies such as disengagement (i.e. avoidance and denial) were associated with more depression and grief. Furthermore, secondary coping strategies, such as acceptance, cognitive restructuring and distraction techniques were associated with less depression and grief. Perceived social support was negatively associated with depression. This was the only study to only include Spanish caregivers, however, did not employ a control groups with non-Spanish cultures.

Factors associated with/ that predict psychosocial outcomes.

Of the studies that found significant associations between aspects of family coping and TBI, Davis et al. (2009) was the only study that was rated as 'fair' according to the QATOCCS in this review. This was because the study was the only correlational cohort study and followed up caregivers and completed outcome measures after 12 months post injury. This is the most valid way to test predictive models. Other studies attempting to do this using cross-sectional designs can only identify associations, and possibly infer indirect effects, but cannot assess prediction. One weakness of the study was that of n=217 caregivers, n=103 were lost to follow up. However, the power analyses indicated the effect size remained moderate to large despite the loss to follow-up. Davis et al. (2009) found that using escape and avoidance coping techniques was associated with elevated caregivers' levels of

distress. The study reported that after 12 months, caregivers' increased use of escape and avoidance coping strategies were also associated with increased levels of perceived burden.

Knight et al. (1998) completed a cross sectional correlational survey. They had a modest sample size (n=52) of caregivers, however did not conduct any statistical analyses of effect size or power calculations. They reported positive and negative emotions related to caregiving and reported a significant difference between spouses and parents' distress- in terms of their pessimism and worry. This was the only study in the review to investigate differences in the types of familial relationships. They compared spouse and parents but were not matched well as parent groups were significantly older than the spouse groups. Hierarchical regression analysis indicated symptom distress and coping satisfaction had significant weights. Burden was found to be more severe in caregivers of male survivors of TBI than female TBI survivors. The majority of the primary caregivers were female (n=43) compared to male (n=9) caregivers.

Coping styles associated with better or worse outcomes.

Of the studies indicating significant associations between caregivers coping following TBI, Hanks et al. (2007) was rated as methodologically 'poor.' As this utilised a cross sectional correlational survey design, the outcome measures were not repeated. Hanks et al. (2007) also did not state the eligibility rate of participants, therefore it was difficult to determine whether this posed as an additional risk of bias. The study found that levels of caregiver burden and coping were significantly associated with family functioning and coping. In particular, satisfaction with the

caregiving relationship was better amongst those who relied upon task-oriented coping and minimised emotion-focused coping.

Curtiss et al. (2000) conducted pre- and post TBI family type and pre- and post- injury coping comparisons amongst veteran families. However, they asked spouses to recall a stressful event that had occurred six months prior to their veteran spouse sustaining a TBI, creating a risk of response bias. The outcome measures were completed at the same time point, and the sample size was small (n=20). They found the interaction between family type, focus of coping, coping strategy and pre- versus post- TBI was significant. They reported balanced families experienced the most dramatic change. Balanced and moderately balanced families reported lower emotion- focused behavioural coping scores post TBI compared with pre-TBI. In addition, moderately balanced families scored lower on emotion- focused cognitive coping post TBI. Extreme families reported higher problem-focused behavioural coping following TBI.

It is important to note that four of the studies recruited from brain injury support groups (Chronsiter et al., 2016; Boyle & Haines, 2002; Knight et al., 1998; Kosciulek, 1997). It cannot be assumed that these participants experienced challenges in coping. Despite the challenges of caregiving for individuals with TBIs, there are families that cope relatively well or even have positive experiences, and this population also require further research (Perlessz, Kinsella & Crowe, 1999, 2000).

Table 2.

Quality ratings using the QATOCCS.

Criteria	Boyle et al.	Blankfeld et al.	Calvete et al.	Chronister et al.	Curtiss et al.	Davis et al.	Hanks et al.	Kosciulek	Knight et al.	Pelletier et al.
Research question or objective clearly stated?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Study population clearly defined?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Participation rate at least 50%?	CD	CD	No	Yes	Yes	No	CD	No	Yes	Yes
Clear inclusion/ exclusion criteria?	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Sample size justification?	No	No	No	No	No	Yes	No	No	No	No
Exposures measured prior to outcomes?	No	No	Yes	No	No	Yes	No	CD	No	No
Sufficient timeframe between measures?	No	No	No	No	No	No	No	No	No	No
Different categories of exposure?	No	No	No	No	Yes	No	Yes	No	No	Yes
Exposure measures clearly defined?	Yes	No	No	Yes	Yes	Yes	Yes	No	Yes	CD
Exposure assessed more than once?	No	No	No	No	No	No	No	No	No	No
Outcome measures clearly defined?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Outcome assessors blinded?	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
Follow-up loss below 20%?	NA	NA	NA	NA	NA	Yes	NA	NA	NA	NA
Confounding variables measured?	No	Yes	Yes	Yes	No	Yes	Yes	No	Yes	No
Overall quality rating	Poor	Poor	Poor	Poor	Poor	Fair	Poor	Poor	Poor	Poor

Synthesis of Results

There are methodological limitations of the studies included in the review. The patterns of the findings indicate that psychological difficulties are more likely in carers of those with TBI than the general population. The degree of their distress is likely to be influenced by the coping style they use, as well as their feelings of burden. Some families may respond to TBIs by seeking external support or reframing the challenges of the situation, or they may try to avoid blaming the injury. There is also limited evidence to suggest that the types of coping styles act might mediate the relationship between perceived social support and distress following TBI. There is an indication that approach coping may be associated with better outcomes, whereas avoidance-coping may be associated with poorer outcomes. Although evidence was weak, the studies suggest that the type of relationship (for example spouse or sibling) and family structure (balanced or extreme) might also contribute to coping styles of caregivers.

Discussion

This is the first systematic review, to the author's knowledge, that has aimed to draw together current research to determine the coping styles of family caregivers following TBI. However, due to the variability of the studies reviewed, and the methodological quality of the studies rated fair and poor, it is difficult to answer the review question with certainty. The studies can offer general patterns about some of the ways families cope following their loved ones experiencing a TBI; mediating factors, and possible predictors of psychosocial outcomes.

The coping styles that families may experience following TBI include confrontative coping (Pelletier & Alfano, 2000), approach coping (Blankfeld & Holahan, 1999), escape- avoidance (Davis et al., 2009), task-oriented and emotion focused coping (Hanks et al., 2007). Other types of coping include primary, such as avoidance and denial, and secondary coping, such as acceptance, cognitive restructuring and distraction (Calevete & de Arroyabe, 2012). Other ways families might cope include seeking social support, or reframing the difficulties (Kosciulek, 1997). The studies reviewed included measures of a number of emotional or psychological outcomes including stress and depression (Pelletier & Alfano, 2000), grief and depression (Calvete & de Arroyabe, 2012), burden (Blankfeld & Holahan, 1999; Knight et al., 1998), distress (Davis et al., 2009), and pessimism and worry (Knight et al., 1998). In addition, TBI caregivers expressed elevated levels of depression and dejection compared to non TBI caregivers (Boyle & Haines, 2002).

One study associated escape and avoidance coping associated with elevated distress (Davis et al., 2009), whilst a further study showed primary coping styles such as avoidance and denial could contribute towards reported levels of depression and grief (Calevete & de Arroyabe, 2012). Another study suggested that approach coping was associated with lower psychological maladjustment (Blankfeld & Holahan, 1999). This indicates a possible significance of approach -avoidance dimension of coping style, a finding which has been found extensively in other clinical studies (Smith & Godfrey, 1995). The type of family functioning (Curtiss et al., 2000) or type of familial relationship (Knight et al., 1998) could contribute towards coping styles. Furthermore, the families of veterans in the Curtiss et al. (2000) study could have different attitudes towards coping or could be offered alternative support systems, which was not explored in depth.

As the methodology was generally poor amongst the studies, better quality research is needed to understand the complex ways in which families cope following TBI. Further research is needed to test hypotheses regarding the types of familial relationship, types of family functioning and the impact of coping styles.

A weakness of the study designs included investigating factors that might be influencing emotional outcomes of TBI family caregivers using cross sectional designs. None of the studies included blind raters. Another weakness was that many of the sample sizes were small. Only one study was a cohort study, and just over half of the participants were lost to follow up. Four of the studies recruited participants from brain injury support groups, which may have influenced the type of responses participants gave.

Limitations of this review

There are some limitations of the current review, as this review only included studies that were written in English, so it is possible additional studies might have been included if the criteria accepted other languages. The Calvete et al. (2012) study is the only study focusing on a non-western culture; and studies from other languages could also incorporate additional cultures. In the current review, although a second rater independently assessed quality ratings of a random selection of studies, they were not included in the selection of studies process and data extraction and any disagreements resolved (PLOS medicine, 2009; Centre for Reviews and Dissemination, 2009).

Implications for future research and clinical practice

Future research investigating the predictors of emotional outcomes of TBI caregivers and mediating roles of coping requires longitudinal or cohort studies. Alternatively, investigating TBI carer or family characteristic patterns of coping and mental health require suitable comparison groups. Additionally, blind raters may improve methodological quality of the research. It is possible that information regarding severity of the TBI could be collected and handled separately from assessors. Data collection could be completed via online or postal surveys. In order to maintain a good follow-up response rate, online surveys or postal surveys may provide participants with flexibility to minimise attrition rates. Finally, there appears to be different levels of familial relationships that might be explored in further detail. For instance, spouse and parent relationships appear to be predominant amongst these studies, and siblings are mentioned amongst the sample size in only three of the studies (Knight et al., 1998; Hanks et al., 2007; Calvete & de Arroyabe, 2012). It would be beneficial to also explore the relationships for siblings further and how this might influence how coping styles for families of TBI survivors as a whole.

Disclosure of interest

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Chapter 2.

Bridging Chapter

Bridging chapter

The systematic review focused on reviewing existing literature investigating coping styles of family TBI caregivers. The review found the research to be of generally poor quality, and given the broad question, the methodology and outcomes of the studies were diverse. The systematic review highlighted the need for better quality research amongst family caregivers of TBI. The review suggested some of the coping styles family caregivers used, such as avoidance-coping and approach coping. These coping styles could influence psychosocial and emotional outcomes for family caregivers. The type of family functioning or type of familial relationship can also contribute towards coping styles, and the types of support they seek. Furthermore, the extent of caregivers' distress is likely to be influenced by the coping style they use, as well as their feelings of burden. This review confirms the importance of addressing family needs in rehabilitation settings.

The evidence base for including wider systems in brain injury research is growing. In the last decade, studies have looked at a range of factors for family caregivers, including subjective burden, psychological distress, perspectives of the natures of the injury and quality of life and life satisfaction (Bowen, Yeates & Plamer, 2010). The relational context of brain injuries allows us to consider the systems around survivors of brain injury.

Rehabilitation settings provide support and rehabilitation for survivors of ABI, and their families. The World Health Organization's International Classification of Functioning (WHO-ICF) has been applied to rehabilitation of cognition (Wade, 2006). Rehabilitation specialists argue that 'participation' in society is the focus of interventions. By extension, the relational and social context can be applied to neurorehabilitation settings, and therefore, the healthcare

professionals working within these settings. There is limited information regarding healthcare professionals within in neurorehabilitation settings. For this reason, the empirical paper focuses on exploring the lived experiences of working with individuals with ABIs. To the author's knowledge, this is the first qualitative study exploring the experience of neurorehabilitation healthcare workers of survivors of brain injuries. This allows us to develop an in-depth understanding of the experiences for this group of healthcare workers, and in turn help us to consider ways in which they can be supported, so they can support survivors of brain injury and their families effectively.

Chapter 3.

Empirical paper prepared for submission to: Disability and Rehabilitation

Staff Experiences of Working with Individuals with Acquired Brain Injury:

A Qualitative Study

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Abstract

Purpose

The aim of this thesis is to explore qualitatively the experiences of healthcare workers within neurorehabilitation settings.

Method

An Interpretative Phenomenological Analysis (IPA) approach was used to understand the experiences of people working in ABI services. Interviews were conducted with nine individuals, across professions including psychologists (n=2), speech and language therapists (n=2), rehabilitation assistant (n=1), occupational therapists (n=3) and physiotherapists (n=1) within community neurorehabilitation NHS and non NHS settings.

Results

Three key themes emerged: personal emotional experience, impact of meanings in personal lives, and frustrations towards the organisation.

Conclusions

The findings suggest that lived experiences of working within neurorehabilitation can provoke strong emotional responses, which staff manage independently. This study emphasises the importance of conducting qualitative research and these insights can be used for future research. Understanding the humanisation of care can be applied to neurorehabilitation staff. Implications of the results are discussed.

Introduction

Acquired brain injury (ABI) includes all forms of brain injury which are sustained after a period of normal development, including traumatic brain injury, strokes, and hypoxic brain injury (The Brain Injury Association of America, 2012). In 2013-2014, there were 348,934 UK admissions to hospital with ABI including stroke, equating to 566 admissions per 100,000 of the population (Headway, 2017). The rates of ABI are rising, as admissions in the UK have increased by 9% since 2005-6 (Headway, 2017).

The effects of an ABI on an individual depend on a number of factors, such as the type, location and severity of the injury. Symptoms can be wide-ranging, including significant physical, cognitive, emotional and behavioural effects (British Society of Rehabilitation Medicine, 2003). The effects can also include a lack of self-awareness of deficits, attention difficulties, and disinhibited behaviour, including sexually inappropriate behaviour, aggression and irritability (Lezak, 1989; Zasler & Martelli, 2003; Khan, Baguley & Cameron, 2014). People who have experienced ABIs also face multiple potential challenges across a range of abilities and roles, including significant changes in self-concept and comparison of their current self with their pre-injury self (Ponsford, Kelly & Couchman, 2012).

Due to these complex symptoms, the care for survivors of brain injury often falls to family members (Carnes & Quinn, 2005), which can be especially difficult when families may still be adjusting to a new situation (Bowen, 2007). Support and rehabilitation requires skilled multidisciplinary input (Pagan et al., 2015). Neurorehabilitation aims to support survivors of ABI to achieve their maximum potential, participation in society and quality of life (Wade, 2009; British Society of

Rehabilitation Medicine, 2015). This includes identifying the deficits resulting from the brain injuries and achievable goals to work towards.

Therefore, healthcare staff have the responsibility of managing a multitude of needs, not only for service users but also their families, such as the expectations of family members. Professional caregivers in elderly nursing homes also commonly experience emotional situations which can be intense and sometimes challenging to manage (Abrahamson, Suitor & Pillemer, 2009).

Staff and ABI

The focus of the limited research to date has been based on quantitative studies investigating stress, burnout and therapeutic barriers. These studies provide some information regarding the experience of healthcare workers.

Working in neurorehabilitation and stress.

Gosseries et al. (2012) investigated burnout amongst a range of healthcare workers caring for patients with severe brain injuries and disorders of consciousness, working in neurorehabilitation centres or nursing homes. Of the staff that responded to questionnaires, they found 18% suffered from burnout, and 33% reported to have emotional exhaustion. There was a difference in the type of profession; nurses and nursing assistants experienced higher rates of burnout (23% and 24% respectively) compared to speech and language, occupational or physiotherapists (8-10%). This could be linked to the direct work involved in their roles, or the type of support they received. A comparison study between rehabilitation nurses in a general unit, an acute physical rehabilitation unit and a brain injury unit, (McLaughlin & Erdman, 1992) found greater levels of distress in nurses in the brain injury unit. However, reported levels of distress did not reach similar levels as a normative psychiatric

outpatient group. Contrastingly, a comparison study of nurses working within general rehabilitation and those working with patients who had sustained head injuries (Van den Broek & Lye, 1995) showed no significant differences in overall measures of stress and job satisfaction. The research into stress and burnout amongst brain injury staff has not investigated sources of stress, which could be explored further.

Therapeutic barriers.

Possible insights into this could be gained from the literature focusing on commonly occurring challenges in neurorehabilitation. Judd and Wilson (2005) investigated the clinical challenges of forming a therapeutic alliance with survivors of ABI. They found the main barriers included difficulties in self-awareness, memory difficulties, poor concentration, language difficulties, emotional ability and disinhibited behaviour amongst the client group. A survey study found that multidisciplinary clinicians perceived barriers towards rehabilitation, including the duration of their experience, their confidence ratings as well as their clients' functional status (Pagan et al., 2015).

This literature can be used to assist in developing some inferences regarding the experience of staff working with ABI. However, questionnaires and survey studies do not provide in-depth information regarding the phenomenon of working professionally in brain injury rehabilitation. Furthermore, much of the research focuses on the challenges and negative experiences, such as burnout and emotional exhaustion. It is important to conduct in-depth research in order to gain a fuller sense and range of the experiences of this professional working group working within community settings, which may provide the direction of future research.

The experiences of professionals working in physical healthcare.

Due to the unexpected nature of ABIs and the relational effect of health issues, there may be similarities between health care professionals working within oncology or palliative care units. Research into these areas might offer some insight into working with conditions that are unexpected and have a "ripple effect" on family members as well as the patient. Healthcare professionals are exposed to many factors, such as increased work-loads and pressure, and focusing on the emotional and physical needs of their patients (Haynes et al., 1999). Healthcare professionals working in this field utilised their interpersonal strengths enabling them to draw on their resilience moderating the stressful effects of working in palliative care (Ablett & Jones 2007). An oncology staff study found resilience to be negatively correlated with distress, but not empathy (McFarland & Ross, 2017). Psychosocial skill training and supervision may improve job satisfaction and reduce burnout amongst oncology nurses (Mcmillan et al., 2016). Therefore, it is important to understand the experience of healthcare workers to better understand their support and supervision needs.

The Rationale for this Study

Existing research highlights the impact on emotional wellbeing for staff working within settings such as learning disability, dementia care, oncology and palliative care. In particular, aspects of these roles, such as managing challenging behaviour and emotional distress have been shown to have an impact on the emotional wellbeing of staff. Many of these factors, such as burnout, facing barriers in therapeutic rapport, and stress are prevalent for those working with survivors of ABI. As Smith et al. (2009) describe physical illness as being seen as having

relational and social contexts, it is also important to explore carers' personal experiences. Similarly, this could be applied to professionals that care for survivors of ABI. There is a lack of literature that considers the individual experiences of staff that are supporting survivors of ABI and, by extension, their families. It is important to understand this group of healthcare professionals working in neurorehabilitation to better understand their lived experiences within this particular context, the emotional impact of the role, and to consider ways in which they might be supported in terms of well-being, supervision and support needs.

The primary question of this project is therefore: what is the experience of staff working with survivors of ABI in neurorehabilitation? In order to explore this, the current study will consider important areas for staff experience of their roles, how their role impacts on their emotions, and nature of the complex and unique experiences of their role within brain injury rehabilitation.

Methodology

IPA Methodology

The primary aim of IPA is to collect rich, detailed and first-person accounts of their experiences of the phenomena- in other words- to understand participants' lifeworld (Larkin, Watts & Clifton, 2006). The secondary aim is to interpret the experience in relation to a social, cultural and theoretical context. This interpretative analysis focuses on how people understand and make sense of their experiences, the meaning of the experience, and how they engage with a particular context (Larkin, Watts & Clifton, 2008). The process of analysis means that the researcher must

engage with and interpret these experiences. Smith (2011) described this process as a double hermeneutic process; in which the researcher attempts to make sense of the participants' sense-making. The overall outcome of which should offer the researcher a renewed insight into the interested phenomenon.

Therefore, IPA was the chosen methodology as it fits well with this study's aims. The interview questions were developed using IPA principles to enable the participants to be as open and flexible as possible (Smith, Flowers & Larkin, 2009). This perspective fits with the principles of IPA as meaning is constructed through the context of the interview.

Interview schedule.

Can you tell me about what it is like to work with individuals with acquired brain injury?

- How does it feel?

Prompt: What is the experience like? Can you tell me more about it?

How do you manage these emotions?

Prompt: how does it feel for you?

Can you tell me about an experience that has been challenging?

Prompt: What was that like for you?

Can you tell me more about it?

Can you tell me about an experience that has been rewarding?

Prompt: What was that like for you?

Can you tell me more about it?

Method

Individual semi-structured interviews were carried out with participants using a flexible topic guide (see Appendix D). Interviews were conducted at participants' place of work, lasted between 39-75 minutes and were audio-recorded.

Participants and Recruitment

Inclusion criteria:

- Qualified clinical staff working directly with those who have suffered an ABI, inclusive of those who have completed training qualifying them to perform their roles.

- A minimum of 12 months of experience

- They spend the majority of their time working clinically (at least 75% of their time, split posts are accepted).

- English must be the first language of participants.

Nine participants were recruited from ABI neurorehabilitation services; within NHS and non NHS services across three largely rural counties in the United Kingdom. Participants included a range of qualified health care professionals (see table 3 for further demographic information).

Table 3:

Demographics of participants.

Job title	Age bracket	Years working in neurorehabilitation
Senior Occupational Therapist	30-39	4
Clinical Psychologist	50-59	20
Head Speech and language therapist	50-59	18
Rehabilitation assistant	40-49	19
Specialist Clinical Psychologist	30-39	2
Occupational Therapist	40-49	11
Lead Speech and Language therapist	50-59	14
Head Physiotherapist	60+	40
Occupational Therapist	40-49	10

Ethical Considerations.

Approvals were sought from Faculty of Medicine at the University of East Anglia ethics committee (Appendix E) and Health Research Authority Ethics (Appendix F) to conduct research across brain injury rehabilitation services across three counties, with Research and Development approval from the relevant NHS Trusts (see Appendix G, Appendix H) and local protocols for the relevant non NHS services.

Results

The analysis resulted in three overall superordinate themes: Personal Emotional Experience, Impact of Meanings in Personal Lives and Frustrations Towards the Organisation. These superordinate themes comprised between two to five subordinate themes each, which were drawn from the emergent themes in individual transcripts and then across transcripts. The structure of these themes is presented in figure 2. The details of the analysis, including emergent themes, superordinate themes for participants, and superordinate and subordinate themes across participants is presented in the appendix (Appendix I). In order to maintain confidentiality[1], job titles have been removed. Hesitant utterances such as "um" and "er" have been replaced with "…" for ease of readability.

Figure 2. Diagrammatic Representation of Emergent Themes.
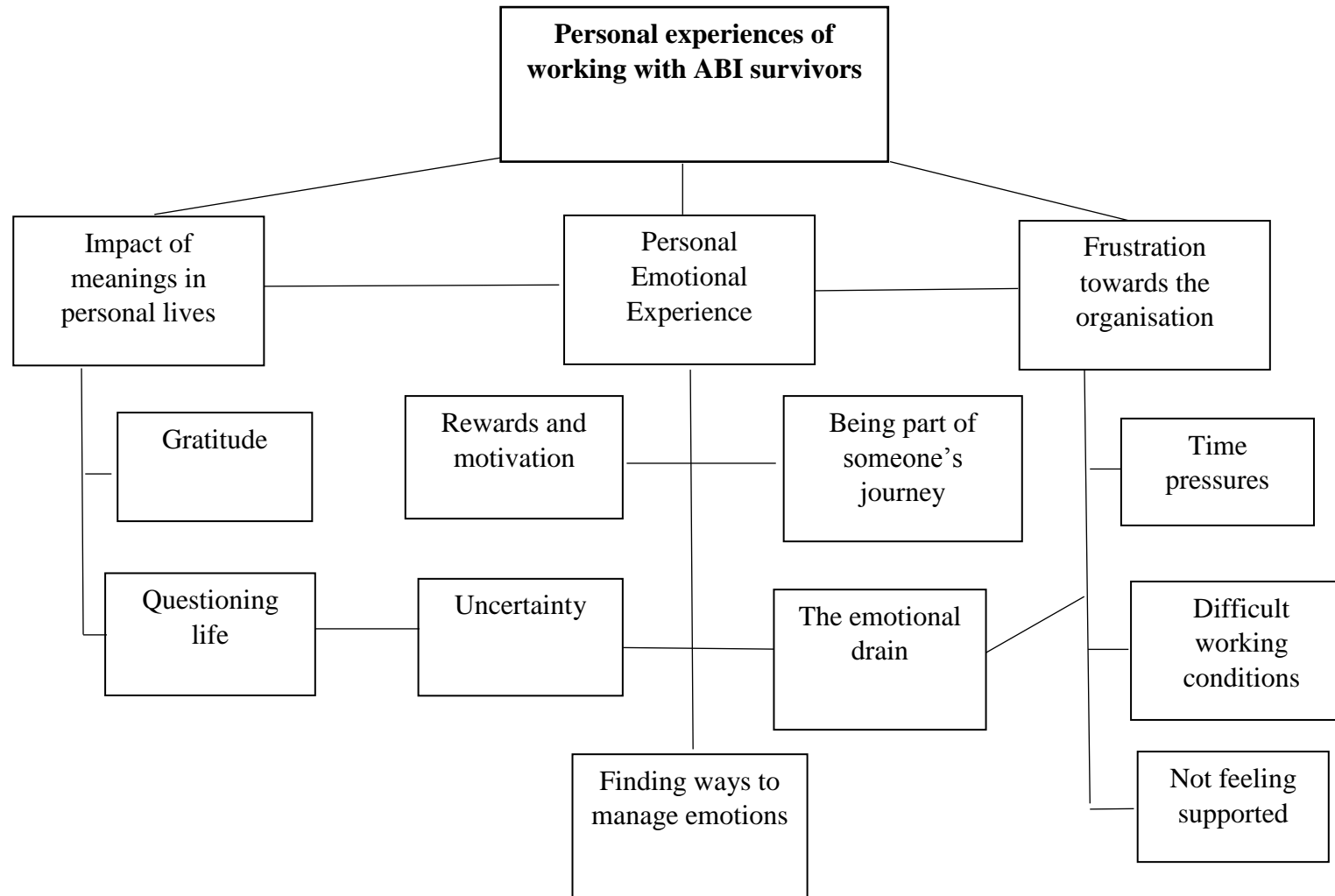
There is a link between the Personal Emotional Experience and Impact of Meanings in Personal Lives themes, which are both personal emotional responses to staff members experience of working in neurorehabilitation. The Personal Emotional Experience theme relates to the myriad of emotions that may be experienced through participants' roles on a daily basis; and reflects on the challenges as well as the rewards of the role, despite the difficult emotions that working with survivors of ABI brings. The Impact on Meaning in Personal Lives theme involves a deeper emotional, spiritual response which caused participants to question the meaning of life.

Personal Emotional Experience

Rewards and Motivation.

For many of the participants, their individual personal motivations for choosing to work clinically in neurorehabilitation with survivors of ABI were significant. Emily described her emotions being a driving motivation to work within this area, and extends her role to being very much part of who she is as a person:

Emily: "…I think it becomes part of our identity…I think a job is not just a job. I think, you know…I've had friends who have had… more office based jobs, or things like that where a job is a means of getting money. I think that… there has to be a greater motivator than money to do this job. Because it takes so much more…than just time and energy. It takes emotion and…I want to say dedication, but that, you know, that sounds really… modest to say that."

> *Sara: "I was always going to do this. I mean I've turned down better paying jobs to carry on doing this. It's not so important to me how much I'm being paid as being happy doing what I'm doing."*

For Kayte, the experience of her role allows her to feel younger and she has a love and passion that came across throughout the duration of her interview.

> *Kayte: "Actually I think that because I love my job so much…and I do like those kinds of challenges I think it keeps me very young. It keeps me going very much. So… you know, I'm at that age of…I could have retired… I have no intention of retiring at this point in time. I like it too much, you know, to keep go-- You know, so I will be keep going and I think that does keep me very young."*

Sara's experience goes deeper than being happy in her day to day work; she learns a lot from the clients she has worked with as a result of this close working relationship.

> *Sara: "And I also think it's a privilege to be given the chance to work with somebody with an ABI, personally…because you can learn from that person enough a lot."*

For Sam and Harriet, their roles provided a sense that they had 'made a difference' to those with ABI, and their families.

> *Sam: "I think… the fact that we can make a difference".*

Harriet: "Through, you know, major life changes that, you know, yeah you-you -- They will remember for the rest of their lives. They'll probably remember those people…"

Being a part of someone's journey.

For many professionals, this role involves working very closely with those who have experienced an ABI as well as their families. This experience appeared to be unique to their role because of the nature of supporting those with ABIs to recover from their injuries, which was experienced as becoming part of someone's life for an intense period of time.

Sara: "It's a very very powerful thing in ABI to happen to a person or to happen to a family. And we work very closely with the clients… And work with them very closely and I think that's what one of the things that I most enjoy."

Sara also described this with the use of a metaphor:

Sara: "You become a part of that person's life…It's like I'm an author. I'm added fiction too. … and it's like you become a part a character in that person's story -for a chapter or two."

Emily: "And I've gotten involved in kind of weird situations... with things like marriage- marriages, where...somebody can't communicate... at all and they're unable to say to somebody that they love them and then the

partner will be in the room and say, "Well, they don't say 'I love you', anymore," and you kind of have to say, "Well, they can't say 'I love you'," and, and be in a situation where you've said to the patient, "Well, do you love your wife? You know, she is saying you don't say it," and he- and the patient indicates kind of, "Of course, of course," you know...So-so it's... these things are very personal and very... you get to know people very intimately."

Timothy: "I guess I kind of feel protective in a way for the client..."

The closeness of the working relationship with their clients may invoke mixed feelings when they have been discharged or no longer attend services. Harriet discussed the nature of letting go feeling similar to losing someone who is part of her life, like a friend:

Harriet: "And-and actually I say, 'cause you work with them so intensely for six months, and then you just don't hear something, you feel like you've lost a friend. And you know- it's really hard and... like you kinda have to professionally do wonder kinda go, "I wonder what happened to them.""

The emotional drain of the role.

Six participants discussed their experiences of the emotional aspects of the role. The first of these aspects was the emotional drain of supporting survivors of ABI. Harriet particularly found this to be a struggle between wanting to help her

clients, but this caused her to feel emotionally drained during the process. Harriet

repeatedly used the word "drained" throughout her interview.

>
> *Harriet: "I've been here four years but does feel a bit like a lifetime."*

>
> *Harriet: "They can't get to that acceptance point. So they kind of keep*
>
> *coming to us and asking us to deal with their life. And help us help them --*
>
> *Help them to live. …. They always come to us and looking for those answers.*
>
> *And we can't always provide it."*

The experience of feeling these emotions are protective and support self-

reflection, and Timothy shared feeling emotions is an essential part of his role:

>
> *Timothy: "But yeah, I think if we didn't- if it didn't impact us in some*
>
> *way, some level, you know, I don't think maybe we should be doing the job."*

Uncertainty.

Two of the participants experienced feelings of uncertainty within their role,

which could be a result in working with clients who are chaotic and uncertain

themselves. Sandy questioned whether she was providing the "right" care and

support within her role to clients who had experienced acquired brain injuries.

>
> *Sandy: "But I think, the thing with ABI is because it's so complex. I*
>
> *can have someone who I'm thinking, "Oh, am I quite doing the right thing*

with you? Am I quite using the right approach?" You have to go with it. Then

invariably, it's fine when I talk it through with a supervision after you're okay

but could have done with that support at that time."

Alex summarised how incredibly complex the impact of acquired brain injuries can have on survivors, and this can impact each person in a unique way, thus impacting on developing individualised treatment plans.

Alex: "...yeah, and-and with the brain injury, even though

anatomically, they might have the same experience as somebody else, in

terms of the trauma up to the brain...we know that everybody presents

different need, you know. And, yeah. I'm much more interested in what

they're experiencing, their impairments, and how they feel about that..."

Finding ways to manage emotions.

In order to manage the emotional aspects of their role, three of the participants had specific ways to cope with these emotions. Harriet and Timothy found communicating and sharing with the teams they work with to be helpful, as the team have a shared understanding of the complexities of the role. Whereas, Harriet found humour as a way to manage the more difficult clients:

Harriet: "It can be quite draining. And, so yes, we do bring a lot of

humour about funny things that people say and...it's not...seen in a negative

way. It's a way of us processing and dealing with it."

Timothy: "I guess because of the environment where we've working has a very close team. So it's great having the support the others to, you know, talk to them about it. It's great, it's kind of invaluable really."

Whereas Kayte had a personal way to cope and share her emotions, not only with family, colleagues but the clients she might be working with:

Kayte: "I'm a person who talks about my feelings and…and I cry… and I find that that makes a big difference… I acknowledge that, that one is, that particular thing is really hard for me….And I think by just acknowledging that, it allows me to continue to move- move forward with that you know."

Sam developed her way of coping over the years of working within neurorehabilitation services.

Sam: "I mean I think the more, I think it's in getting older, as well, is...I really think it's important to…you work and then you go home."

Impact of meanings in personal lives

Five of the participants reflected that their clinical roles of working with survivors of ABI made them appreciate their personal lives more.

Gratitude.

Participants found meaning in their personal lives, particularly when working daily with the occurrences of ABIs in other people's lives. In response to seeing the destruction and "tragedy" (Emily), participants seem to value the appreciation of life more.

Sam was able to have found a way to navigate through the difficulties that ABI brings which essentially challenges 'meaning' in life and over time she was able find meaning and not only appreciate her day to day work, but wider meaning and connection to the world through nature.

> *Sam: "And I think I'm very lucky, I have good friends. I've started running and I enjoy that. So there are things that, again, it's a positive. We were saying this morning, wasn't the sky beautiful? I think it's nice that you can just stop and go, "wow.""*

> *Katye: "It makes me so appreciative and full of gratitude for my life, for my state of health ...for those around me… I do think that I have a different outlook on life because of that… I think I take things in stride much differently because of that…I also know that when things happen, it's not the end, you know, when things change, if things don't go the way you think they're going to be going in your life, it doesn't mean that your life ends, it just means it's going in a different route".*

For Kayte this was not only a result of her role working with survivors of ABI, but almost a way that she had grown as a person and experienced life:

"Well, again, it goes back to that gratitude aspect of it. It makes me stop and think when I get my pants in a bunch about something or when, "Oh woe is me," anything like that, I just stop short and I say, "Actually, I don't have anything to complain about here." You know, my life is very easy and…, so I reflect in that way and it keeps me very positive in my overall life."

Questioning Life.

Contrastingly, two of the participants had an even deeper response to their role which led them to question why these events, such as ABI happens to people and, in turn, questioned their faith and spritualty:

Timothy: "You can guarantee if something's gonna go wrong then there will be like a chain of things for some people, it's just like why. Why? You know, why does that happen to them you know. Things come in a cluster."

Emily struggled to make sense of her experience of "coming into work and dealing with the tragedy," whilst dealing with her own personal challenges. Emily referred back to her own purpose in life and her own reasons for working in brain injury rehabilitation.

Emily: "It's interesting for me. I'm not sure, so I, you know, the make a difference thing, came from being a teenager from youth groups from wanting… to make a difference in this world and it was from a religious point of view and a purpose… but in recent years things have felt more

futile...that…they haven't felt as hopeful. They've felt a lot more unfair. And

that has brought into question... my belief system."

Emily struggled to understand why, despite her religion, that such losses such as ABI could happen to people. She described this as a ripple effect of her role, not only impacting the lives of survivors but her life and her own beliefs.

Emily: "And that's been interesting and difficult. But I don't know

whether that's maturity. I don't know whether as people mature they are less

accepting of what they've been told or question things more... but it does have

an impact. And it's had an impact on my family as well because I think the

questions that I've raised from the things that I have seen. So, for example,

seeing... patients where things just seem totally unfair and why would God

allow that to happen."

Feeling frustrated with the organisation

All participants found the organisational context for which they worked challenging and frustrating, which impacted upon how they experienced their roles within brain injury rehabilitation.

Time pressures.

Three participants discussed the time constraints of the role having a direct impact on how they experienced their role. Alex spoke of being busy and repeated "more and more," suggesting she felt overwhelmed by her workload as well as

always feeling that she could do more for clients, which may have induced feelings of guilt.

> Alex: "...and even if I've got a quiet day today, in terms of the number of patients I'm seeing, there just always needs to be more and more and more! And then you know, you can never stop. But also, there are the restraints of the number of hours that you have in terms of what funding we have..."

The majority of Sandy's interview revolved around time restraints and always feeling pressured to feel that she should be working late, and feeling overwhelmed by how much she had to do:

> Sandy: "I've done enough years working in the NHS. So now that you could multiply each individual by ten and not have enough of you."

Not Feeling Supported.

Sara had experienced some of the challenges of working for the NHS, and had considered the importance of staff well-being. She felt very strongly about the responsibility of not only individual staff members working in the organisation, but the responsibility of the organisation itself to ensure well-being of all workforce employees.

> Sara: "If we're gonna talk about how common mental health problems are and how much pressure people are under, how much stress people are under in the general population, we have to realize that it's also the same in the NHS population, and the teaching would be very similar. It would probably be very, very similar. And when I was working in the place

and then half the staff were on anti-depressants, which is probably higher

than the general population."

Sara: "I think on how I look after myself is up to me. It's my

responsibility but I think when I'm in a work place, there's a responsibility

for the work place and the team is held to look after each other, which we're

not doing."

Difficult Working Conditions.

Two of the participants felt that the conditions they worked in were difficult:

Emily: "Well, when I feel sometimes that we do this job with our

hands tied".

Jamie felt very strongly about this and came back to the difficulties she found

with working within the organisation throughout her interview, without prompting:

Jamie: "Completely demoralized, completely despairing and pretty

much without hope for anything to improve…yeah. I think, seeing, looking at

the bigger picture is always been a bit of a…I wouldn't say fault but it doesn't

help me sometimes because… yeah. I don't see much hope… in the NHS's

future and that does make it difficult to do the work sometimes."

Discussion

The main aim of this research project was to qualitatively explore the experiences of staff working with survivors of ABI. This research question was developed in response to the limited literature regarding the lived experiences of those employed within neurorehabilitation settings, and was as open as possible, without any presumptions of the findings. The data was analysed following the guidance of Smith's (2011) IPA.

Three themes emerged from the data: Personal Emotional Experience, Impact of Meanings in Personal Beliefs, and Frustrations Towards the Organisation. The results provide an in-depth account of the experiences of a cross section of healthcare workers in neurorehabilitation services. The Personal Emotional Experience theme covers a wide range of positive as well as challenging emotional, relational responses as a result of working with survivors of ABI. This includes feelings of the rewards and motivations that they require to be able perform within their role. These motivations often went beyond their daily duties choosing to work in an area that brings feelings of happiness and that they are making a difference to other people's lives. Due to the nature of ABI and the wider social context of survivors, their families and beyond, participants experienced a sense of working very closely to survivor's lives, which emerged as the Being Part of Someone's Journey subtheme. This close relationship was valued highly, and necessary, with feelings of loss when the journey came to an end.

These roles brought participants challenging emotions, such as the Emotional Drain of the role and Feelings of Uncertainty subthemes. By supporting survivors of ABI, some participants questioned their own knowledge and skills as a result of the many challenges that survivors of ABI were facing, including their need for

individualised treatment and support plans. These emotions all came with participants' Finding Ways to Cope subtheme. Many drew on support from their clinical teams, and others felt more drawn towards finding personal ways to express their emotions as a way of processing them.

The Impact of Meanings in Personal Lives theme goes somewhat deeper into participants' sense making experience, and relates to participants' existential, and personal responses to the phenomenon of working with survivors of ABI; and essentially questioning the meaning of life.

Finally, the Frustrations Towards the Organisation theme suggests that the context in which participants' work has implications for and influences the way they work with both survivors and teams. This context inevitably has an impact upon participants' experiences of working within neurorehabilitation.

These results contrast with previous research, indicating many differences. Previous quantitative research with healthcare workers in neurorehabilitation found a number of participants experiencing burnout and emotional exhaustion (Gosseries et al., 2012). Other research found greater levels of distress amongst nurses within a brain injury unit compared to nurses on general and acute physical rehabilitation units (McLaughlin & Erdman, 1992). With regards to the literature focusing on therapeutic barriers of neurorehabilitation, the participants in the current study experiences did not reflect on the cognitive, behavioural and emotional sequalae to interfere with therapeutic alliance (Judd & Wilson, 2005). Similar to the findings of Pagan et al. (2012), participants had worked in neurorehabilitation for a number of years. Despite this experience, many still found the complexity of this client group challenging.

Previous research suggests high levels of distress, anxiety, grief, quality of life and emotional health issues are experienced amongst family caregivers (Volger et al., 2014; Marwitt & Kaye, 2006). The current study found a strong emotional impact of the role amongst participants. This offers a new insight and differences between family caregivers and healthcare professionals.

The existing research has been predominantly quantitative, measuring specific constructs such as burnout, distress with the use of standardised measures. Whereas this study did not reveal similar constructs as significant themes for this group of participants.. The phenomenological experiences and meanings of these developed by individuals is very much lost in quantitative measures. This is highlighted by Hunt and Smith's (1994) study which showed the importance of recent survivors of stroke carers experiences; and highlighted the relational and social context of health issues.

Interestingly, an IPA study investigating the experiences of palliative care staff drew similarities with the current study's findings (Ablett & Jones, 2006). This set of results indicate a range of personal emotional experiences that participants experience whilst working within neurorehabilitation. Ablett and Jones (2006) found themes such as aspects of job satisfaction, personal attitudes towards life and death, awareness of own spirituality and ways of coping. These themes draw similarities with the Personal Emotional Experience and Impacts of Meaning of Personal Lives (specifically rewards and motivation, finding ways to manage emotions, gratitude, and questioning life) themes. Through IPA methodology, these studies essentially raise existential questions about the meaning of life, given both staff working within palliative care and neurorehabilitation. Ablett and Jones (2006) went on to draw

similarities between theoretical models of personality constructs that explain hardiness and sense of coherence.

IPA research allows researchers to explore phenomenological perspectives and provides insights into the lived experiences of people. Quantitative research will not be able to provide this perspective through standardised questionnaires, focusing on narrowly defined variables, such as depression, stress and burnout. This qualitative study investigates the 'insider's perspective' (Conrad, 1987) whilst keeping in mind the view of the person within their context (Husserl, 1929/1977) about the complexity and the challenges that people experience, and the meanings for which people attribute their experiences (Shinebourne, 2011). These individual perspectives are then drawn together to generate general statements, maintaining the essence of their experiences (Shinebourne, 2001; Smith at al., 2009). This study endeavours to maintain the standard of IPA research, which really draws together the lived experiences of healthcare workers within a neurorehabilitation context.

It is possible that there are links between other areas of research, such as humanisation within healthcare. Todres, Galvin and Holloway (2009) developed a conceptual framework for the humanizing of healthcare, focusing on qualitative research to offer support to a humanizing emphasis for care. This framework has influences from existential, phenomenological and sociological approaches, focusing on *'what it means to be human.'* This can be a valuable base for guiding care, and is, therefore, of relevance to this study.

The subordinate theme Being Part of Someone's Journey relates to the 'togetherness-isolation' domain, in which individuals experience both feelings of aloneness and intimacy. Todres et al. (2009) describe the dimension as a possibility of experiencing empathy of 'the other.' This can also be understood in the current

study as walking alongside with an ABI survivor's journey, and experiencing

empathy and support for them whilst they are experiencing struggles following the

ABI, which is an unexpected and challenging event that has life-long consequences.

The Impact on Meaning of Personal Lives theme (specifically subthemes of

gratitude and questioning life) draws parallels with the sense- making and loss of

meaning dimension. Todres et al. (2009) describe the context of this dimension: "to

be human is to care for the meaning of things, events and experiences for personal

life." (pp. 5, Todres et al., 2009). They go on to further discuss the sense making as a

meaningful experience to search for the narrative truth, and in doing so we can

experience a sense of dislocation and meaningless-ness. This resonates particularly

with the theme of 'questioning life', whereby participants find themselves

questioning their belief systems, and experiencing life to be more futile as a result of

seeing tragedy daily, but also within the constraints of the organisations that they

work in. Their experiences, therefore, move towards the 'loss of meaning' side of the

dimension.

Contrastingly, other participants found grounding and meaning of their lives

in the subordinate theme entitled 'gratitude.' It is possible that within this context,

participants attempt to make sense of their own personal lives within the context of

loss of meaning when faced with the profound effect of ABIs on survivors' lives.

They were able to find a way of moving past the difficulties they faced daily, by

making connections within their larger lifeworld context by making connections to

their family, nature and their lives as a result of the work they do.

The Frustrations Towards the Organisation theme links with another

dimension described by Todres et al. (2009). This theme describes the way in which

participants' organisations for which they work create limitations and feelings of

pressure, hopelessness and struggles. This could link to a limitation and loss of sense-making due to the wider system of care. Todres et al. (2009) also describe how the context of human beings being forced into standardised practices as systems of care. This supports the notion that there is insufficient appreciation of how different systems of care, and the agencies within them contribute to the fragmentation of sense-making by the organisations, and therefore lead staff to feelings of disconnectedness and losing meaning.

Todres et al. (2009) also describe how the eight domains within their conceptual framework to be part of a spectrum, and individuals are able to move along the dimensions depending on their internal experience at particular stages of their own context. For example, Sam moved from a time of feeling inexperienced to experienced, during her career. She also moved from a position of loss of sense to one of sense making, by developing her own way of coping over many years of working with survivors of ABI.

The results from this study could be understood in a way which mirrors the survivors of ABIs narrative. There are studies that suggest individuals with ABIs experience changes in the way in which they view life, and what is important in life (Grace, Kinsella, Muldoon & Fortune, 2015). Experiences such as distress and post-traumatic growth were related to meaning in life and life satisfaction (Triplett, Tedeschi, Cann, Calhoun & Reeve, 2012). This process of finding a way of making sense and asking existential questions came across in the Impact of Meaning of Personal Lives theme, and some of the subthemes of the Personal Emotional Experience theme. Over time, as healthcare workers become more experienced within this role, they are able to make sense of their own personal lives within this context and find a greater meaning in their lives.

Limitations of Study

Although this study provides research with a richness of data, we have only heard from a self-selected group of participants. There may be other staff members who would have wanted to take part but were unable to within the timeframe of recruitment, or staff members who did not wish to take part in this study, who may have had very different or diverse lived experiences of their role within neurorehabilitation.

Within the sample, there were differences between individual interviews, with hesitations and reflection in-vivo, whereas other interviews flowed more and it was clear to the lead researcher that some participants had spent time reflecting on their experiences, and others were open to being reflective during the course of the interview.

This study only focuses on the perspective from a community neurorehabilitation setting. There is a possibility that other staff working within acute or inpatient settings for survivors of ABI might have different experiences.

The lead researcher's interpretation of the data is offered; however, other research may include the interpretation of a group of researchers (Rodham, Fox & Doran, 2013). This type of shared analysis and reaching a consensus may offer alternative interpretations. Additionally, the lead researcher's position as a trainee clinical psychologist, at the start of their career is vastly different to many of the participants who had been in their roles for many years. The lead researcher endeavoured to maintain a high level of validity and quality, as outlined by Elliot et al. (1999) Yardley (2000) and Stiles (1993). However, it not possible to ensure testimonial validity via participant feedback, to ensure whether they agreed, due to

practical reasons. Future research could also implement this stage to ensure further methodological rigour.

Clinical Implications

All participants found spontaneous ways to manage their emotions and sought support of the staff teams to be invaluable (as described in the Finding Ways to Cope theme), through a shared understanding of each other's experiences, through use of team support or humour or personal ways to cope with the emotions that their roles bring. The organisational parameters within such services have impacted upon the time available for staff and have developed barriers to enabling support from the teams and time to reflect. A national longitudinal evaluation of the provision of dedicated time to enable the sharing of emotional, social or ethical challenges of their roles found health professionals to experience less psychological distress, improved teamwork and increased empathy for their patients as well as their colleagues (Maben, Shuldham, Taylor, Foot & Dawson, In Press). They have recommended that staff well-being is prioritised within neurorehabilitation services, and by enabling more structured time to provide reflective spaces, which can have implications for staff burn-out and emotional exhaustion.

Staff training and supervision for specialised neurorehabilitation roles, maintaining staff well-being and developing a work-life balance from an early start in professional careers could be beneficial as a way to ensure that staff are continuously maintaining their well-being. The unexpected and disruptive nature of ABIs on survivors' lives is extremely challenging, and the majority of participants within this study were more emotionally affected by survivors of ABI who were of a similar age to them. Providing healthcare workers with structured time to reflect with

their teams could have a beneficial impact upon well- being and provide peer supervision.

The National Guidelines for Stroke Rehabilitation (Royal College of Physicians, 2016) and the National Guidelines for Specialist Neurorehabilitation services (British Society of Rehabilitation Medicine, 2015) describe rehabilitation needs for survivors of stroke and brain injuries, and refer to staffing ratios. Over the past decade, stroke guidelines have increasingly noted the importance of the psychological sequalae for stroke survivors, and this has developed service provision for this client group. However, these guidelines do not provide guidance for the psychological and emotional well-being of staff working within neurorehabilitation services, such as supervision or training needs. It is essential that staff well-being is prioritised within national guidelines.

Recommendations for Future Research

Further research should investigate humanizing care principles (Todres et al., 2009) and use this as a basis for the development of further research. This notion of 'what it means to be human' fits well not only with qualitative research, but can apply to caring roles within healthcare, such as ABI services. Further research using this framework could bring a new perspective to research amongst staff and as well phenomenological experiences, bringing together the 'human' side of caring towards health care.

Through IPA methodology, the study exposes existential questions that healthcare professionals might ask regarding the meaning of life, highlighting the importance qualitative research. Finally, there is scope to conduct longitudinal

research exploring the lived experiences of healthcare professionals continuing to do this type of work over an extended period of time.

Disclosure of interest

There is no conflict of interest. This research was supported by the University of East Anglia as fulfilment of the Doctoral Programme in Clinical Psychology.

Endnotes

[1]Pseudonyms have been used throughout when referring to participants, to protect their confidentiality.

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Chapter 4.

Extended Methodology of Empirical Paper

The extended methodology chapter includes a discussion of ontology and epistemology, and an elaboration of the rationale for using IPA methodology over alternatives, including grounded theory, thematic analysis and narrative analysis. The researcher's reflective stance, and research procedures conducted as part of this research study are also presented. The procedure for IPA is outlined, and consideration of quality and rigour are also explained.

Ontology and Epistemology

Ontology is the philosophical study of being, which is concerned with reality and whether this exists entirely separately from human practises and understandings (Braun & Clarke, 2013). There are different ontological positions that can be placed upon a continuum between realism and relativism. From a perspective of realism, "'reality' is entirely independent of human ways of knowing about it" (pp. 27, Braun & Clarke, 2013). In other words, reality is seen as the absolute truth, which is understood by conducting research. Contrasting to this view is relativism, where reality is dependent on the interpretation and knowledge of humans (Braun & Clarke, 2013). From a relativist perspective, it can be argued that there are numerous realities that are constructed; what we know reflects 'how' and 'where' knowledge is generated. In the middle of this continuum is critical realist position. This position assumes that there is a 'real world' that exists, however, we cannot 'know' this with complete certainty; which means that our understandings are tentative (Cook & Campbell, 1979). Different ontological positions are important in research, as they provide the basis of research methodologies; for instance, realist

positions generally inform many quantitative methodologies, whereas relativist positions might inform some qualitative methodologies (Braun & Clarke, 2013).

Epistemology is a branch of philosophy which is concerned with the theory of knowledge and considers the nature of what and how we generate this knowledge (Braun & Clarke, 2013). Similar to ontological positions, epistemological positions reside on a continuum. At one end of the spectrum is positivism, which assumes that it is possible to obtain valid knowledge via established scientific methods. At the other end of the spectrum is constructionism; which states that knowledge is an objective reflection of reality; but our ways of knowing the world is tied to the social context that the research occurs within (Madill & Gough, 2008). In the middle of the spectrum is contextualism; which does not assume a single reality. From this perspective, knowledge is understood to emerge from contexts whilst reflecting the researchers' positions (Madill et al., 2000; Tebes, 2005). Therefore, ontology and epistemology are not independent of each other, they interconnect and underpin particular methodologies for researchers, together composing the appropriate method for the research question (Braun & Clarke, 2013).

Researcher's Theoretical Framework

Having considered different philosophical positions regarding ontology and epistemology, the philosophical underpinnings of this project will now be discussed, along with my theoretical framework. The essential component of qualitative research is that the data are words, whereas quantitative data requires numbers and statistics (Braun and Clarke, 2013). Qualitative research focuses on how individuals make sense of events and what the meanings of events might be for them (Larkin, in

Smith, 2007). Given that there are different perspectives of researchers, which influence the methodology as well as the types of knowledge produced from the research. Larkin (in Smith, 2007) describes the process of finding an approach that may match a researcher's project, their relationship to it, or one that is consistent with one's view of the world. He also describes how the researcher's approaches could be influenced from a generally qualitative stance, and therefore influences the epistemology and methodological decisions of that researcher. This means that one needs to have some ownership of their epistemological perspective, as this may risk the reflective processes (Larkin, in Smith, 2009), which is essential for data analysis. This can also be understood as having an awareness of what we might bring as researchers in advance but being open to further pre-conceptions may arise during the process of new information being presented (Smith et al., 2009). The essential components of being a qualitative researcher can also be understood as ensuring one's own personal perspectives are identified and they have the ability to reflect on one's investment in the research (Elliot et al., 2008).

In order to be transparent, and open to any preconceptions I may have, I will describe my background in relation to this research study (Elliot el al., 2008). My experience is one through clinical psychology training, working within several multi-disciplinary teams on placement and a previous role within a residential home for adult survivors of ABI. These experiences have given me an awareness of the complexities of such roles, which have been described in narrowly defined terms in previous literature, and I feel that it is important to give those "a voice" to those working in these settings.

To my knowledge, the experiences of healthcare workers working within neurorehabilitation settings have not yet been explored openly and I feel that is of

importance to open this dialogue. It is important to explore these experiences, as there might be a range of rich and subtle aspects of various emotions that might arise from working in this field. The aims of this study were to not only explore the lived experiences of healthcare workers working with survivors of ABI, but to develop an in-depth, rich and detailed understanding of their individual and unique experiences. I therefore hope to provide a basis for future research in terms of well-being needs, supervision, staff motivations, support or training needs of those working within neurorehabilitation settings.

My ontological stance lies towards a critical realist perspective (Cook & Campbell, 1979), in the middle of the ontological continuum. From a critical realist stance, the world is real and identifiable, which is located behind the subjective and socially placed knowledge that we are able to access through research (Madill et al., 2000). This perspective also views knowledge as socially influenced, reflecting a separate reality that we can only partially access. Furthermore, from this position of an external reality (i.e. one's feelings or experiences), provides a basis for knowledge (Braun & Clarke, 2013). My position as a critical realist also means the replicability of research is of importance. Therefore, the processes of data collection, and how the conclusions are drawn need to be explicit for other researchers to replicate the study and develop similar findings (Barker, Pistrang & Elliot, 2005). This position has shaped the research questions and the types of knowledge produced from this thesis portfolio (i.e. both quantitative in the systematic review and qualitative in the empirical paper).

At present, the literature around the experience of healthcare workers in neurorehabilitation settings is limited, so it is important to explore how those working with survivors of ABI experience their roles; how they make sense of this

experience and not to impose any predefined constructs or labels- thus remaining open to the diverse and unique participants' experiences. The philosophical position of this study is rooted in phenomenology. The philosopher, Edmund Husserl, developed phenomenology and is concerned with how unique subjective experiences are and how exploring these experiences can identify common and unique ways of experiencing the world. The study aims to gather an in-depth understanding how healthcare workers make sense or working within neurorehabilitation and of their unique, individual lived experiences of their role. The philosophy of phenomenology and it's theoretical underpinning are explored further in the following paragraphs.

Rationale for IPA methodology

IPA was used as the epistemology of IPA aligns with the epistemology of this study. IPA is an experiential and inductive approach, centred in psychology (Smith, 2011). The theoretical underpinnings of IPA fit in with the study aims, by studying the phenomenon, looking at the meanings of these experiences, and the unique experiences of each individual perspective. Larkin and Thompson (2012) outline the main epistemological assumptions of IPA including; an understanding of the world requires an understanding of experience, engagement with personal accounts of individuals, therefore drawing on an idiographic approach. Larkin and Thompson (2012) also state there is a process of intersubjective "meaning making" (pp. 103), an element of reflexivity is required from the researcher, and finally, we can reflect upon our role in producing these interpretations, whilst maintaining a commitment to being grounded in the participants' views.

IPA draws on three main areas of the philosophy of knowledge: phenomenology, hermeneutics, and ideography (Smith et al., 2009). These areas will

be explored and considered in relation to this study. As the focus of IPA questions are typically experiential and exploratory (Larkin & Thompson, 2012), this study's aims are focusing on the experiences of healthcare workers, working specifically in community neurorehabilitation settings, and giving voice to their unique experiences.

Phenomenology.

IPA draws on key concepts from phenomenology, which is a philosophical approach concerning the study of experience. Phenomenology was developed by the philosopher, Edmund Husserl (1929/1977). He described the process of examining experiences and necessitating taking a step back from our 'natural attitude,' to go beyond language and move towards the 'phenomenological attitude,' whereby we shift to "turning one's gaze towards how the object appears to consciousness" (pp. 17, Shinebourne, 2011). In other words, modifying the way in which we engage with others' lived experiences (Giorgi, 1997; Smith et al., 2009), whilst maintaining a 'phenomenological attitude' (Shinebourne, 2011), which goes deeper and focuses into the unfiltered, raw experience itself.

In contrast, Heideigger, Husserl's student, argued against Husserl, and introduced the notion of not being able to separate oneself from the subject being studied; our observations are always created through our personal experiences, contexts and meaning (Shinebourne, 2011). Heidegger developed the phenomenological concept of intersubjectivity, which is "the shared, overlapping and relational nature of our engagement in the world" (pp 17, Smith et al., 2009). He also asserted the view of "the person in context," which is central to hermeneutics. Hermeneutics is derived from the Greek word "to make clear" or "to interpret," and

within the context of qualitative analysis, is concerned with the subjective experience of individuals. IPA is rooted in the philosophy of phenomenology and within the context of psychological research is a specific approach to qualitative research, drawing upon the phenomenological tradition. IPA applies hermeneutics to qualitative analysis of unique human experiences and the meaning for which people attribute their experiences (Shinebourne, 2011).

This epistemology of phenomenology connects with the philosophical underpinnings and aims of this research study, which also connect with the framework and epistemology of IPA. The study explores how those have made sense of their experiences of working within neurorehabilitation settings. From a critical realist ontology and phenomenological epistemology, experience cannot be understood in isolation. This experience can be understood through the researcher's interpretation of participants experiences; the next section explores this notion further.

Hermeneutics.

Hermeutics is the second main philosophical underpinning of IPA, which is the theory of interpretation. Heidegger argued that what only be offered is an interpretation of experience. Smith and Osborn (2003) state that IPA involves a double hermeneutic. The 'interpretative' component of IPA can be understood as the participant making sense of and interpreting their own experiences, and then the researcher interprets what the participant has shared with them (Smith et al., 2009).

This is where reflexivity is important (Smith et al., 2009), and described in further detail in the following paragraphs.

Smith et al., (2009) suggest that researchers are using their everyday phenomenological skills, which they describe as a "natural attitude" (pp. 191) are refined during analysis. From their perspective, it is important to give priority to the nature of study, rather than to one's pre-conceptions, which Heidegger described as 'fore- structures.' They state that Heidegger's conceptualisation of phenomenology as an explicitly interpretative, and which links to hermeneutics. Furthermore, Heidegger's complex and dynamic concept of fore-understanding is one that allows us (researchers) to understand bracketing as something that cannot be fully achieved and a cyclical process. Successful IPA combines both stances, by being an empathic and questioning researcher, one is essentially trying to gain an understanding of what this experience is like for someone, in the sense of making sense of something (Smith et al., 2009). This hermeneutic approach also underpins the current study, as it focuses on how participants make sense of their experiences which is central to developing an understanding of their experiences.

Idiography.

Finally, IPA is concerned with a particular person's experience at a particular time, therefore can be considered an idiographic approach. Idiograpy refers to an in-depth analysis of individual cases and perspectives prior to generating general statements (Shinbourne, 2011; Smith et al., 2009). This can be understood in terms of IPA's commitment to the sense of detail, which also means the depth of analysis (Smith et al., 1999). Further, understanding individuals within their context is of importance in IPA (Smith et al., 2009). Idiography can refer to individual cases in their own right or can move to more cautiously to seek more general ideas, whilst

maintaining the individual and unique ideas. This is a complex notion, see Gergen (1991) for more detailed information. In terms of this research study, idiography is also a central underpinning of this study. Through the process of IPA analysis, the study aims to uncover each individual participant's experience of working professionally with survivors of ABI, which may uncover some common and discrete themes amongst the data.

Successful IPA is a balance of these three theoretical and philosophical underpinnings of IPA, which are all central to the research question. There is also a clear methodological framework, guidelines for analysis and a range of literature to support quality and rigour.

Qualitative methodologies

Having discussed the philosophical underpinnings of this study, I will now go on to discuss how different ontological and epistemological positions apply across different qualitative analytic approaches. Qualitative approaches have similar aims which are to identify the diverse experiences of individuals, and giving individuals a 'voice,' through their methodologies (Ashworth, 2003). In other words, qualitative research aims to understand how we make sense of their world and how they experience events (Willig, 2001). Whereas other methodologies seek to derive a theoretical explanation, or to cause a social or political change through revealing a marginalised voice. Qualitative methodologies such as Thematic Analysis (TA) and Grounded Theory (GT) all include unpacking the data, searching for richness, and transparency of the analysis. These methodologies have distinct approaches to produce high quality research (Yardley, 2000) and will be explored individually for their methodologies and philosophical approaches.

Thematic Analysis.

Thematic Analysis (TA) was first developed in the 1970's by a physicist and historian of science (Merton, 1975). However, TA has more recently been used as a qualitative methodology with a set of procedures amongst social scientists (Braun & Clarke, 2006). This method can be used to identify, analyse and report themes within data, by organising and describing the data set in depth (Braun & Clarke, 2006).

TA only provides a method of data analysis, rather than providing a philosophical underpinning, and epistemological framework (Braun & Clarke, 2013). However, there are many variations of TA; meaning that it can be used as a realist method, reporting experiences, meaning and participants' reality (Braun & Clarke, 2006). Alternatively, TA can a be used as a constructionist method, which focuses on the ways in which events, meanings and experiences. Finally, TA can also be used as a contextualist method, such as critical realism (Willig, 2001); by acknowledging the ways individuals make sense of their experience, and the ways the broader social context are maintained (Braun & Clarke, 2006).

Whilst TA can be used for a variety of research questions, and themes can be identified flexibly (i.e. bottom-up or top-down), there are limitations of TA that make this methodology unsuitable for this particular study. Firstly, despite some variations of TA as described above, it can be argued that there is a lack of theoretical framework underpinning the methodology of TA (Braun & Clarke, 2013). Secondly, the 'voices' of participants may at risk of becoming lost due to lack of continuity of the focus of the data (Braun & Clarke, 2013). This might impose a risk of not capturing the unique, individual experiences of the healthcare workers within neurorehabilitation settings and potentially move away from the idiographic and phenomenological rooting of this study.

Grounded theory.

Grounded theory (GT) was developed in the 1960's by sociologists, Glaser and Strauss. This method allowed researchers to use an 'approach' of grounded theory that is concerned with developing theory of the phenomena that is 'grounded' in the data (McLeod, 2001; Braun & Clarke, 2013). This means that GT provides researchers with a framework and a set of principles, guidelines and strategies that enable researchers to understand the phenomenon under investigation (Charmaz, 2014). The methodology provides researchers with guidelines on the identification of categories, establishing relationships and between these categories (Willig, 2008). There are different versions of GT, which suit different theoretical and epistemological frameworks. Whilst GT shares features of phenomenological research, focusing on social processes takes a more contextualised and dynamic approach (Willig, 2008).

Earlier versions of GT had been criticised due to the lack of acknowledgement of the researcher's reflexivity, by adopting an objective, positivist ontological (realist) position that deemed the data as (Charmaz, 2014). one of the challenges of completing GT research is that it does not take into account the researcher's perspective and role, by assuming that the data 'speaks for itself.' (Willig, 2009). For certain GT approaches, this framework does not address reflexivity; and researchers suggest that the categories do not "emerge" from the data- the researcher constructs these processes as part of the methodology (Dey, 1999). However, later versions incorporated a constructivist GT, assuming that social reality is multiple, processual and constructed, therefore hast to take the researcher's position, alongside their perspective and interactions into account as part of the research reality (Charmaz, 2014). This also means that from this

perspective, the researcher must explore and examine how their preconceptions shape the research (Charmaz, 2014).

As GT is concerned with how a phenomenon develops, with a focus on social processes, thus developing a theory from the data, this would not be an appropriate methodology for this study. This study aims to explore how healthcare workers make sense of their experiences of working with survivors of ABI.

Narrative analysis.

Narrative Analysis (NA) can be described as an exploration of an individual's narrative within the context of life chapters, significant people, key events, future script, stresses and problems, personal ideology or life themes (Crossley, 2000). NA is not limited to, but is often used as a way to explore social and political constructs (Stephens & Breheny 2012). This qualitative methodology is underpinned by both phenomenology and social constructionism (Smith, in Braun & Clarke, 2013). The ontology of NA may be seen by some researchers as being grounded in realism; which suggests that there is a reality in the stories of one's life. However, opposing this stance, some narrative analysts adopt a relativist ontology, or constructivist epistemology; suggesting knowledge is socially constructed through analysis through researcher, and their perspective of participants' stories (Smith & Sparkes, 2012).

Smith and Sparkes (2006) identify many tensions of narrative analysis; including the ontology or nature of narrative, as outlined above. They also discuss the challenge of the relation between narrative and self or identities; which might be seen by some researchers as identical and others as inseparable. Another factor of NA is the consideration of cultural influences, which can provoke challenges for researchers, particularly those from different cultural backgrounds (Reissman, 1993).

Generally, the focus of NA is to explore social and political constructs, underpinned through social constructionism and phenomenology. Whilst there are some philosophical underpinnings that might be suitable for this study, the overall aims of NA are opposed to the aims of this study therefore would not be appropriate for the aims of this study.

Reflexivity

In line with standard IPA practice, reflection regarding the lead researcher's own perceptions, conceptions and processes were recorded throughout the process using a reflective journal (Smith, 2004). The reflective commentary was also used to record the lead researcher's initial impressions of each data collection session, patterns appearing to emerge in the data collected and theories generated. In line with transparency, extracts of the lead researcher's reflections diary can be found within the extended methodology chapter. This commentary was important in monitoring the lead researcher's own developing constructions, which is considered to be critical in establishing credibility (Shenton, 2004).

This chapter explores different ontological and epistemological philosophies and discusses the epistemological underpinning of this study, which is rooted in phenomenology. Whilst alternative qualitative methodologies are explored (such as TA, GT and NA), IPA was deemed the most appropriate in terms of my ontological position as a critical realist, and in terms of the research question which aims to explore the experiences of healthcare workers working with survivors of ABI. The philosophical underpinnings of the study and IPA both are grounded in phenomenology, which take into account the individual, rich and unique experiences of healthcare workers. The philosophical underpinnings of IPA also acknowledge the researcher's context as the interpretative element of IPA is through the researcher's

interpretation of how people have made sense of their experiences. The 'double hermeneutic' (Smith & Osborn, 2003) concept of IPA further strengthened the rationale for choosing an IPA methodology. The following sections will explain the research procedures of the study.

Research Procedures

Recruitment Procedure

The lead researcher obtained approval from relevant gatekeepers (i.e. service managers of NHS and non NHS services) before meeting the teams for recruitment (see Appendix J). Gatekeeper approval was recorded prior to the study opening recruitment at the relevant sites. The lead researcher then presented the study to the teams formally with participant information sheets (Appendix K) and a flyer promoting the study and the presentation to the team meeting was sent to the managers to disseminate to the team members (Appendix L). Demographics forms were emailed to staff members interested in taking part in the study (Appendix M). The lead researcher had intended to visit all teams, however due to time pressures of teams, service managers suggested they facilitate the study by passing information to the teams, including participant information sheets and the contact details of the lead researcher. Any interested staff members contacted the lead researcher directly to discuss the study. Upon reading the information sheet potential participants contacted the lead researcher to arrange a suitable time and date for an interview, and answer any questions regarding the study. Since the maximum number of participants was reached and there was further interest in the study, a prepared letter was sent to participants explaining that their involvement was no longer required (Appendix N).

The interview.

During the interview, the lead researcher ensured the participant was reassured there were no wrong or right answers and it was their experience that the lead researcher was interested in. The topic guide was placed so the interviewee could read this. Participants were reminded that they were able to stop the interview if they wished to. They were also informed they could gain support outside the interview from staff support provided by the NHS (the Psychology head of services) Participants were offered breaks as required and at the end of the interview, participants were thanked for their input.

Ethical Considerations

Ethical Approval.

The lead researcher obtained a peer review from the Patient and Public Involvement (PPI) input from Inspire at Norfolk and Suffolk Foundation Trust group (Appendix O). The lead researcher gained sponsorship and indemnity insurance from the University of East Anglia (UEA). The lead researcher obtained ethical approval from the Faculty of Medicine and Health Sciences at the University in East Anglia, preceding a review from the NHS Health Research Authority. The lead researcher also sought relevant approvals at the local NHS Trusts for the study to begin recruitment.

Informed Consent.

The lead researcher obtained written informed consent before the start of each interview (Appendix P). Participants were reminded of their right to withdraw at any stage until the point of data analysis. A copy of the completed participant information sheet and consent form were given to the participants for their own

records. Participants were given contact details of the lead researcher and the

Primary Research Supervisor should they require them.

Risks and benefits of taking part.

At the start of all interviews, all participants were informed that the content

of the interview would remain confidential unless there was any disclosure of risk to

themselves or others, or if it became apparent that a staff member had breached their

duty of care. If this occurred, the NHS Code of Conduct would be followed.

It was not anticipated that harm would come to participants. However, there

was a chance that some emotional distress may have been experienced whilst

discussing personal experiences during the interview process. In the case that this

might happen, participants were informed at the start of the interview that they were

able to take as much time as they needed; they were also reminded of their right to

withdraw from the study, or pause the interview. The lead researcher ensured that

clinical and empathic skills were used throughout each interview. Participants were

reminded they may speak to the lead researcher's supervisors, and can contact

Patient Advice and Liaison Service (PALS).

Researcher's safety.

Although potential risks to the lead researcher were minimal, the lead

researcher ensured the local NHS Trust's and the UEA's lone working policies were

followed.

Data Collection

The Interview Process

Smith et al. (2009) suggest the elicitation of qualitative interview data is supported by quiet, safe environments of convenience for participants, as well as a place of familiarity. For these reasons, in the current study, interviews took place in a quiet interview room on the premises of neurorehabilitation centres, and one was conducted at the participants' home. The CI was able to arrange with reception staff for rooms to be booked for the duration of the interview. Interviews ranged between 39 minutes and 75 minutes duration. The average length of interviews were 55 minutes long.

Personal reflection of interviewing.

I had an awareness of wanting to separate out my own experiences of working within this field many years ago, and during the interviews. I was genuinely curious to hear about each person's individual experiences. I was aware this cannot be completely bracketed this experience off but one is able to be present, 'in the moment' during the interviews. I feel that the way participants expressed their experiences varied and were unique to their personal reasons for choosing to work with survivors of ABI. I found the interviews to be a continuous balance of not want to lead the interviews too much through my own curiosity and wanting to know more as a researcher, and allowing participants to discuss what they felt were important experiences in their role. Some interviews were incredibly powerful and will stay with me, through the duration of my clinical training and beyond as a qualified clinician.

Transcribing.

Smith et al. (2009) advise researchers to personally transcribe interviews to help them to become immersed in the data. However, for practical reasons this was not possible for the current study. The lead researcher listened to each of the recordings again once they had been transcribed in order to remain close to the data, and read the transcripts for accuracy and familiarity with the data.

All interviews were transcribed via a confidential transcribing company (Go Transcript), to ensure that all interviews were transcribed efficiently. A non-disclosure agreement was signed to ensure confidentiality of participants interview content remained confidential (Appendix Q). Transcripts were transcribed in full verbatim, including all repetitions and pauses within interviews.

Analysis

Analysis followed guidance from Smith, Flowers and Larkin's (2009) guide (pp. 79-107) and Pietkiewicz, and Smith (2012). The lead researcher took the following steps to ensure good quality IPA analysis was conducted. Smith et al. (2009) offer an established guide of 'steps' which have been useful for novice IPA researchers to follow. These steps offer practical focus and strategies to help organise and focus the analytic process.

1. Reading and re-reading the transcript in order to become familiar with the participant's interview.

2. Initial noting of descriptive comments regarding the content, linguistic comments regarding how it was said, and conceptual comments at a more interpretative level.

3.   Searching for connections across emergent themes for individual cases (see example of transcript in Appendix I).

4.   Moving to the next transcript and repeating the process

5.   Searching for connections across participant interviews

6.   Looking for patterns across participants transcripts (Appendix S).

The lead researcher completed the analysis independently, with support from the primary and secondary supervisors through supervision. The process of analysis was an iterative process rather following the steps in a linear order.

Personal Reflection of Analysis

I found the process of analysing data and being 'immersed' in the data to be all-consuming. This process required dedication, patience, time and concentration. I found myself moving slowly through an iterative process before fully completing the hermeneutic cycle. I was keen to get to the stage of having clear superordinate themes and subordinate themes for all of the participants. However, I needed to ensure I spent enough time on each individual transcript, being clear of what these individual superordinate themes were first.

I found the process to be akin to being lost, and then finding my way to safety, whereby the start of the process I was unclear and uncertain what I might find, at the end of the process I had gained clarity and understanding. I enjoyed the process of being immersed in the participants experience, I was careful to stay close to the data, staying close to the phenomenology and their words. I wanted to ensure that I maintained their individual voices throughout analysis and in the results section.

Some of the reflections and experiences of the healthcare professionals I interviewed were resonated with my own, in finding meaning in their lives and personal motivations for wanting to make a difference to people's lives through pursuing clinical psychology training. It was only after I had completed analysis and reflected on this process I became aware of these similarities of experience. I wondered how these might apply to other healthcare professionals in other settings.

Validity and Rigour

Stiles (1993) organised good practice in qualitative research under two main headings: firstly, to ensure standards of trustworthiness of the data, including disclosure of the researcher's orientation, preconceptions and descriptions. Secondly, the validity of the data (trustworthiness of conclusions that can be drawn from the data) via triangulation, coherence, testimonial validity. Guba and Lincoln (1989) state that qualitative studies are credible if the descriptions presented are recognisable and all conclusions are grounded in the data, and any differences are explained by the researcher's interpretative scheme.

In 1999, Elliot, Fischer and Rennie provided a set of evolving guidelines in order to encourage good quality qualitative research in psychology. This checklist covers aspects relating to quantitative research and qualitative research, included: explicit scientific context and purpose, appropriateness and specification of methods, and clarity of presentation. There are also guidelines pertinent to qualitative research: owning one's perspective, situating the sample, grounding in examples, credibility checks, coherence of the data, accomplishing general research tasks and resonating with the readers. Sandelwoski (1986) describes the process of dependability as clear

audit trail so that another researcher is able to follow the decisions of the investigator in the study, and drawing similar conclusions.

The lead researcher attempted to ensure trustworthiness and credibility of the data using these principles described (Guba & Lincoln, 1989; Elliot et al., 1999). In order to maintain transparency, the lead researcher followed the principles of transparency so that a clear audit trail was left for other researchers (Sandelwoski, 1986).

Following the first interview, the lead researcher ensured the transcription and analysis processes were conducted accurately with the support of the Research Supervisors' guidance and peer support. The lead researcher met with the Primary and Secondary Research Supervisor in order to reflect on the interview and the appropriateness of the topic guide. The transcript and coding was shared with both Research Supervisors in order to assess the plausibility of interpretation of the analysis. Both of the research supervisors have experience of working in ABI services, and thus enhancing credibility of the analysis. This ensured that the lead researcher's analysis process followed the correct structure so that the themes matched closely to the transcriptions.

Furthermore, reflections were shared with peer clinical psychology trainees, who also conducting separate doctoral level qualitative research project through a qualitative research forum. Consultation with these individuals and the research supervisors ensured that the rigour and standards of IPA were met. The research supervisors and peers had no access to personally identifiable information. Together, the lead researcher and peers were able to check the quality of analysis for each stage described above during a 'double coding session'. The aim of this was not to ensure

inter-rater reliability, but to ensure the steps by Smith et al. (2009) were followed

providing a clear process of analysis; and different interpretations were discussed.

Chapter 5.

Overall Discussion

Overall thesis portfolio discussion

This chapter provides an overall discussion for the thesis portfolio. The chapter begins with reflections from the lead researcher on the process of the research study. The chapter will then synthesise the findings from the systematic review and empirical paper, and link to previous research in the wider literature. Finally, clinical implications, strengths and weaknesses of the project are discussed, with suggestions for future research.

Final reflections

During my time undertaking clinical training, I have experienced personally and professionally challenging times. In many ways, the reflections from the professionals I interviewed in this study resonate with my own experience of working in psychological settings for several years. Whilst I was able to empathise with participants at the time of interviewing, I focused on ensuring the steps for IPA were followed and that I had completed a thorough project to a good standard. I feel that I have developed my research skills and have learnt the process by which themes were developed from interviews.

Now that I have come to the end of the project, I have noticed that I am considering the well-being of healthcare professionals more and more. I too, have always wanted to make a difference, and gain meaning in my own life. I too, have learnt the importance of self-care, and maintaining a balance, which is not always possible during clinical training. I too, feel strongly about supporting the physical and emotional well- being of healthcare professionals. I have also experienced the pressures from the organisations that we work within.

What struck me, was how powerful the interviews were. Many participants had spent the majority of their lives working in neurorehabilitation settings. Despite the challenges, participants had so much love and passion for their work, which is something I aspire towards. I feel that I have been privileged to be able to complete an incredibly valuable piece of work that will stay with me throughout my career.

Overview of results

The thesis portfolio aimed to explore the social and relational context of brain injuries. Firstly, the systematic review aimed to scope existing literature regarding the coping styles of family caregivers of TBI. Secondly, an empirical research project was conducted that qualitatively explored the lived experiences of healthcare workers within community neurorehabilitation settings.

Systematic review

The review identified methodological limitations of the studies reviewed. The findings indicate that psychological difficulties are more likely in family caregivers of those with TBI compared to the general population. These difficulties include distress, feelings of burden, worry and pessimism. The extent of caregivers' distress is likely to be influenced by their coping styles, as well as their feelings of burden. There is an indication that approach coping may be associated with better outcomes, whereas avoidance-coping may be associated with poorer outcomes. Although evidence was weak, the studies suggest that the type of relationship (for example spouse or sibling) and family structure (balanced or extreme) might also contribute to coping styles of caregivers. These results contribute to the importance of conducting research into family caregivers of TBI survivors.

Empirical Paper

The research paper in this portfolio aimed to explore the lived experiences of healthcare professionals within neurorehabilitation settings. Three main themes emerged from the data: Personal Emotional Experience, Impact of Meanings in Personal Lives, and Frustrations Towards the Organisation. The results provide an in-depth account of the experiences of a cross section of healthcare workers in neurorehabilitation services.

The empirical paper's findings offer new insights into research of working within neurorehabilitation settlings. These results contrast with previous research, indicating many differences. Previous quantitative research with healthcare workers in neurorehabilitation found a number of participants experienced burnout and emotional exhaustion (Gosseries et al., 2012), and distress (McLaughlin & Erdman, 1992). Therapeutic barriers such as therapeutic alliance (Judd & Wilson, 2005) were not supported by the study findings. Despite several years of experience, many participants still found the complexity of this client group challenging, which supported some previous findings (Pagan et al., 2012).

Previous research suggests high levels of distress, anxiety, grief, quality of life and emotional health issues are experienced amongst family caregivers (Volger et al., 2014; Marwitt & Kaye, 2006). The systematic review confirms these findings and the current study found a strong emotional impact amongst participants.

The current study offers new insights into the experiences of healthcare workers. These experiences include the emotional impact of the role, and trigger existential questions. The organisational contexts of neurorehabilitation settings inevitably influenced the lived experiences of healthcare workers. This research portfolio provides further evidence to support the relational approach to

rehabilitation. The research findings can also be associated with the humanisation of health care. This conceptual framework for the humanising of health care (Todres, Galvin, & Holloway, 2009) lends itself to frame qualitative research. The framework draws on influences from existential, phenomenological and sociological approaches, focusing on 'what it means to be human.' The emergent themes lend themselves to this framework, and can be a valuable base for guiding care.

Strengths and Limitations of Thesis Portfolio

The research study was valued by participants; if the recruitment sample size could accommodate a larger sample, more staff would have participated in the study. Unfortunately, one potential participant was ineligible due to their role, one had time constraints as part of their role, which meant they were unable to participate within the recruitment window. An additional three eligible participants were not able to take part as the maximum sample size had been reached, thus would have impacted on the quality of analysis. Through IPA methodology, this research study gave participants a "voice," who may not have had the opportunity to do so, as well as for their colleagues working in neurorehabilitation. All participants wanted to be informed of the results of the study.

This is an original study- no previous studies have qualitatively explored the experiences of those working with survivors of ABI. This will provide a platform for future research, which will be discussed in the following paragraphs. The study interviewed a range of disciplines and working groups, representing members of inter-disciplinary teams, in the UK.

The lead researcher's own experience as a trainee clinical psychologist was shared with interviewees and having previous experience as a health care assistant in

a residential rehabilitation home for survivors of ABI meant that the lead researcher was able to take more of a 'insider' researchers approach, with sensitivity to their needs (Conrad, 1990; Yardley, 2000). The lead researcher was able to use their clinical skills to enable interviews to be as comfortable, and genuine as possible.

However, there are also limitations to the research study. The findings are based on this particular group of self-selected healthcare workers. There may be other staff members who would have wanted to take part but were unable to within the timeframe of recruitment, or staff members who did not wish to take part in this study, who may have had very different or diverse lived experiences of their role within neurorehabilitation. There were differences between interviews, with hesitations and reflection in-vivo. Other interviews flowed more, suggesting that these participants had spent time reflecting on their experiences.

This study only focuses on the perspective from a community neurorehabilitation setting. There is a possibility that other staff groups working within acute or inpatient settings for survivors of ABI might have different experiences, within a slightly different context.

The lead researcher's interpretation of the data is offered; however, other research may include the interpretation of a group of researchers (Rodham, Fox & Doran, 2013). This type of shared analysis, and reaching a consensus may offer alternative interpretations. Additionally, the lead researcher's position and social context as a trainee clinical psychologist, at the start of their career is vastly different to many of the participants who had been in their roles for many years. The lead researcher endeavoured to maintain a high level of validity and quality, as outlined by Elliot et al., (1999) Yardley (2000) and Stiles (1993). However, it not possible to ensure testimonial validity via participant feedback, to ensure whether they agreed,

due to practical reasons. Future research could also implement this stage to ensure further methodological rigour.

Clinical Implications and Recommendations for Future Research

This thesis portfolio also emphasises the importance of quantitative and qualitative research. Through these research methodologies, the caring roles of survivors of brain injury are recognised to be complex, challenging, rewarding and emotional. This portfolio particularly highlights the need for better quality research amongst family caregivers and healthcare workers for survivors of brain injury.

Given the emotional outcomes for family caregivers can influence successful rehabilitation of brain injury survivors, it is important for services to provide appropriate support. The importance of supporting family caregivers is confirmed. Future research needs to be of good quality, possibly employing longitudinal groups, and comparisons to health controls.

Humanising health care principles (Todres, Galvin and Holloway, 2009) might offer a value- based framework to consider future research. Their notion of "what it means to be human" is applicable to both paid and unpaid caring roles. Further research using this framework could bring a new perspective to research amongst staff and as well phenomenological experiences, bringing together the 'human' side of caring towards health care.

The empirical study highlights the importance of a shift from a phenomenological perspective could develop the evidence base and support needs of professionals. The project exposes existential questions that healthcare professionals might ask regarding the meaning of life. There is a need for national guidelines to recognise the need to provide support for healthcare workers.

Overall Conclusion

This wider perspective of neurorehabilitation is important as the long-term implications of brain injuries are considered for family caregivers and healthcare workers. Often brain injuries are complex and there is a high prevalence of co-morbidity with other difficulties, for example depression or epilepsy (Bowen et al., 2010). The shift in perspective to a relational and social approach is important in neurorehabilitation.

The review findings emphasise the need for further quality studies in both quantitative and qualitative research. The study shows that neurorehabilitation professionals experience significant existential and phenomenological questioning and emotional responses as a result of the work they do with survivors of ABIs. This group of staff have spontaneously found ways to manage these emotional experiences. It may be important to consider the ways humanisation of healthcare is present within rehabilitation settings. We are, after all are humans caring for other humans.

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Appendix B

Quality Assessment Tool: Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies

Criteria	Yes	No	Other (CD, NR, NA)*
1. Was the research question or objective in this paper clearly stated?			
2. Was the study population clearly specified and defined?			
3. Was the participation rate of eligible persons at least 50%?			
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?			
5. Was a sample size justification, power description, or variance and effect estimates provided?			
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?			
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?			
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure			

Criteria	Yes	No	Other (CD, NR, NA)*
measured as continuous variable)?			
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?			
10. Was the exposure(s) assessed more than once over time?			
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?			
12. Were the outcome assessors blinded to the exposure status of participants?			
13. Was loss to follow-up after baseline 20% or less?			
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?			

Quality Rating (Good, Fair, or Poor)
Rater #1 initials:

Quality Rating (Good, Fair, or Poor)
Rater #2 initials:
Additional Comments (If POOR, please state why):

*CD, cannot determine; NA, not applicable; NR, not reported

Appendix C

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We also refer authors to the community standards explicit in the American Psychological Association's (APA) Ethical Principles of Psychologists and Code of Conduct.

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Case reports - CARE

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Observational studies - STROBE

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Systematic reviews, meta-analyses - PRISMA

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Structure

Your paper should be compiled in the following order: title page; abstract; keywords; main text, introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s); figures; figure captions (as a list).

In the main text, an introductory section should state the purpose of the paper and give a brief account of previous work. New techniques and modifications should be described concisely but in sufficient detail to permit their evaluation. Standard methods should simply be referenced. Experimental results should be presented in the most appropriate form, with sufficient explanation to assist their interpretation; their discussion should form a distinct section.

Tables and figures should be referred to in text as follows: figure 1, table 1, i.e. lower case. The place at which a table or figure is to be inserted in the printed text should be indicated clearly on a manuscript. Each table and/or figure must have a title that explains its purpose without reference to the text.

The title page should include the full names and affiliations of all authors involved in the preparation of the manuscript. The corresponding author should be clearly designated, with full contact information provided for this person.

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For tables and figures, the usual statistical conventions should be used.

Drugs should be referred to by generic names. Trade names of substances, their sources, and details of manufacturers of scientific instruments should be given only if the information is important to the evaluation of the experimental data.

Formatting and templates

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A structured **abstract** of no more than 200 words. A structured abstract should cover (in the following order): the *purpose* of the article, its *materials and methods* (the design and methodological procedures used), the *results*and conclusions (including their relevance to the study of disability and rehabilitation). Read tips on writing your abstract.

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5-8 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.

A feature of this journal is a boxed insert on **Implications for Rehabilitation**. This should include between two to four main bullet points drawing out the implications for rehabilitation for your paper. This should be uploaded as a separate document. Below are examples:
Example 1: Leprosy

Leprosy is a disabling disease which not only impacts physically but restricts quality of life often through stigmatisation.

Reconstructive surgery is a technique available to this group.

In a relatively small sample this study shows participation and social functioning improved after surgery.

Example 2: Multiple Sclerosis

Exercise is an effective means of improving health and well-being experienced by people with multiple sclerosis (MS).

People with MS have complex reasons for choosing to exercise or not.

Individual structured programmes are most likely to be successful in encouraging exercise in this cohort.

Acknowledgement. Please supply all details required by your funding and grant-awarding bodies as follows: *For single agency grants*: This work was supported by the under Grant . *For multiple agency grants*: This work was supported by the under Grant ; under Grant ; and under Grant .

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Appendix D

Topic Guide

IRAS Project ID: 212544

UEA
University of East Anglia

Topic Guide
Version 2 (Date 24/02/17)

Semi structured interview schedule

Can you tell me about what it is like to work with individuals with acquired brain injury?

- How does it feel?
Prompt: What is the experience like?
Can you tell me more about it?

- How do you manage these emotions?
Prompt: How does it feel for you?

- Can you tell me about an experience that has been challenging?
Prompt: What was that like for you?
Can you tell me more about it?

- Can you tell me about an experience that has been rewarding?
Prompt: What was that like for you?
Can you tell me more about it?

Appendix E

University of East Anglia FMH Ethics Approval

Faculty of Medicine and Health Sciences Research Ethics Committee

UEA

University of East Anglia

Inderpal Panesar
MED

Research & Enterprise Services
REN West (SCI)
University of East Anglia
Norwich
NR4 7TJ

Email: fmh.ethics@uea.ac.uk
Telephone: +44 (0) 1603 59 1490

Web: http://www.uea.ac.uk

4th November 2016

Dear Inderpal,

Title: Understanding staff experiences of working with acquired brain injury: a qualitative study
Reference: 2016/2017 - 12

The submission of your research proposal was discussed at the Faculty Research Ethics Committee meeting on Thursday 27th October 2016.

The Committee were happy to approve your application in principle but have the following concerns which they would like you to address and amend accordingly:

Recruitment
1. This is a governance issue but is offered to support your study, but the committee feels the project would benefit from a recruitment flier to inform potential participants of the recruitment presentation that will happen at the team meeting.
2. Please clarify whether all staff will be captured at one team meeting or will there need to be a number of presentations at each site.

Sampling
3. This study would be more robust if you provided an expression of interest form which would allow purposive sampling to facilitate recruiting respondents with a variety of demographic information and also including level of experience and professional identity. Otherwise recruitment will be by first-come, first-served which would not reflect the phenomenological focus.
4. Page 4 of 17, clarify why the supervision procedures and reflective practices experienced by clinical psychologists prevents them from being suitable as possible respondents; the same could apply for OTs who also have supervision and reflective practice.
5. Protocol, page 10, justification of sample size says 10 – 12 participants will 'allow for attrition as IPA lends itself to a small sample size' – what does this mean?
6. P10 of protocol – talks about recruitment across Cambs and Norfolk – what about ICANHO in Suffolk?
7. Protocol, page 10, clarify from which Ethics Committees you are getting approval

Data Collection
8. Data collected at work can be very different to that collected away from work and the committee has asked that you explore this in your application with a methodological and epistemological justification of collecting the data this way.
9. The possibility of home interviews has been mentioned in the safety checklist but not on any of the participant information. This needs to be included in the participant information sheet and again you will need to explore the fact that different qualities of data will be collected in this different type of venue.
10. Provide a clear description of the duty of care procedures that will come into play should a participant become upset. Within this please also provide contact information for appropriate support services and a method to make participants aware of these services.

11. This is not an ethical issue but is offered to support your study, as the Committee feels it would be more in keeping with the phenomenological focus to ask participants to tell you about an experience that is challenging/rewarding et al. In this way participants will couch their experiences within a narrative structure which potentially elicits much richer data than the prompts in the current topic guide, which may just produce just a list of challenges.

Analysis

12. Clarify who will be transcribing the interviews. In the main application, it states the researcher will do this but Appendix F, page 15 of 17, there is £160 outlined for audio transcription services. If someone else is involved in transcribing a confidentiality agreement will have to be produced and please clarify how data transfer to that transcriber will be kept secure.

13. This is not an ethical issue but is offered to support your study, but the Committee would suggest that the project would be more robust, and more confident claims of the data could be made if other trustworthiness mechanisms were included, in particular respondent validation (where the emerging themes are shared with the participants to give them an opportunity to review the claims made of the data. Also, a fellow student acting in the role of researcher triangulation is only useful if the other person has some skill in qualitative analysis - is this the case? Otherwise it would be better if you worked with someone with an appropriate level of expertise.

Documentation

14. Letter to gatekeeper, page 9 of 17:
- Ensure that the information is sufficiently clear for the gatekeeper to understand that staff could be absent from duties for at least 2 hours to take part in this study (including settling in time as well as the interview).
- review the readability of this, in particular paragraph 2 which is complex
- outline the recruitment strategy
- explain how the absence of a member of staff could be 'flexibly scheduled around the service demands 'Change "Patient" to "Participant Information Sheet" and check to ensure you have used the correct name for this document throughout.
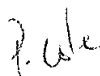- Provide contact information for the gatekeeper to send their response.

Participant Information Sheet, page 10 of 17:

15. please review the readability of this and ensure lay language is used throughout all of the information given to participants.
- State how many participants you are looking for and clarify the range of people you will be recruiting from.
- Clarify what you mean by "good level of spoken English", and how you will assess this.
- Duty of care is repeated in 2 places, please combine information.
- Include information for support services in case a participant becomes upset.
- Rephrase the section "What if I change my mind" as withdrawal is unlikely to ever pose medical or legal consequences. Also ensure that participants know that participation will not negatively impact on their job.
- The last sentence needs to be completed so the participants would understand the consequence of it being difficult to extract information.
- PALS is not appropriate for HPs involved in research, please change this to head of Clinical Psychology as the contact person in case of complaint.

16. Please provide gatekeeper consent prior to start of study.

17. Provide a thanks but no thanks letter in case there is over-recruitment.

18. Ensure all documentation has version numbers and dates.

Please write to me once you have resolved/clarified the above issues. I require documentation confirming that you have complied with the Committee's requirements. The Committee have requested that you detail the changes below the relevant point on the text in this letter and also include your amendments as a tracked change within your application/proposal. The revisions to your application can be considered by Chair's action rather than go to a committee meeting, which means that the above documentation can be resubmitted at any time. Please could you send your revisions to me as an attachment in an email as this will speed up the decision making process.

As your project does not have ethics approval until the above issues have been resolved, I want to remind you that you should not be undertaking your research project until you have ethical approval by the Faculty Research Ethics Committee. Planning on the project or literature based elements can still take place but not the research involving the above ethical issues. This is to ensure that you and your research are insured by the University and that your research is undertaken within the University's 'Guidelines on Good Practice in Research' approved by Senate in February 2012.

Yours sincerely

Dr Maggie McArthur
Deputy Chair
FMH Research Ethics Committee

CC Dr Paul Fisher

Faculty of Medicine and Health Sciences Research Ethics Committee

UEA

University of East Anglia

Inderpal Panesar
MED

14th December 2016

Dear Inderpal,

Project Title: Understanding staff experiences of working with acquired brain injury: a qualitative study.
Reference: 2016/2017 - 12

The amendments to your above proposal have been considered and I can confirm that your proposal has been approved on the basis that you review the use of the word 'running' on the poster as it is not grammatically correct and also include contact details (not just an email address).

Please could you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance and also that any adverse events which occur during your project are reported to the Committee. Please could you also arrange to send us a report once your project is completed.

Yours sincerely,

P. Cole

Dr Maggie McArthur
Deputy Chair
FMH Research Ethics Committee

CC Dr Paul Fisher

Appendix F

Letter of Approval from HRA Ethics

NHS
Health Research Authority

Miss Inderpal Panesar
Trainee Clinical Psychologist
University of East Anglia
Elizabeth Fry Building
University of East Anglia
Norwich
NR 4 7TJ

Email: hra.approval@nhs.net

26 June 2017

Dear Miss Panesar,

Letter of HRA Approval

Study title:	**Staff experiences of working with those with acquired brain injuries: A qualitative study**
IRAS project ID:	**212544**
Sponsor	**University of East Anglia**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. Please read *Appendix B* carefully, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

IRAS project ID	212544

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The attached document *"After HRA Approval – guidance for sponsors and investigators"* gives detailed guidance on reporting expectations for studies with HRA Approval, including:

- Working with organisations hosting the research
- Registration of Research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received 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/.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

Your IRAS project ID is **212544**. Please quote this on all correspondence.

IRAS project ID	212544

Yours sincerely

Steph Blacklock
Senior Assessor

Email: hra.approval@nhs.net

Copy to: *Ms Tracy Moulton, Sponsor Contact*
Ms Lesley Maloney, Norfolk Community Health & Care NHS Trust, Lead R&D Contact

IRAS project ID	212544

Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

Document	Version	Date
Confirmation of any other Regulatory Approvals (e.g. NIGB) and all correspondence [FMH approval from University of East Anglia]	1	14 December 2016
Confirmation of any other Regulatory Approvals (e.g. NIGB) and all correspondence [FMH approval for amendments from University of East Anglia]	1	28 April 2017
Copies of advertisement materials for research participants [Study Poster]	2	24 February 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance Letter]	1	22 May 2017
Interview schedules or topic guides for participants [Topic Guide]	2	24 February 2017
IRAS Application Form [IRAS_Form_24052017]		24 May 2017
Letter from sponsor [Letter from Sponsor]	1	22 May 2017
Letters of invitation to participant [Letters to service managers inviting staff]	2	31 March 2017
Non-validated questionnaire [Demographics Form]	1.1	10 November 2016
Other [SOA]	1	26 June 2017
Other [SOE]	1	26 June 2017
Participant consent form [Participant consent form]	2	07 April 2017
Participant information sheet (PIS) [Participant Information Sheet]	3	02 April 2017
Research protocol or project proposal [Research Proposal]	1.2	23 November 2016
Summary CV for Chief Investigator (CI) [Research CV chief investigator]		12 February 2017
Summary CV for student [CV for Chief Investigator]	1.0	15 April 2017
Summary CV for supervisor (student research) [Paul Fisher Supervisor CV]		20 May 2016
Summary CV for supervisor (student research) [Fergus Gracey Secondary Supervisor CV]		08 August 2016

IRAS project ID	212544

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability* **and** *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* **sections in this appendix.**

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Ms Tracey Moulton
Tel: 01603 597481
Email: t.moulton@uea.ac.uk

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	Applicant has provided a Statement of Activities and Schedule of Events for use with the participating NHS organisations.
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this

IRAS project ID	212544

Section	HRA Assessment Criteria	Compliant with Standards	Comments
			research study
4.3	Financial arrangements assessed	Yes	There is no external funding acquired for this study.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Not Applicable	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

This is a multisite, qualitative, staff only study with one site type.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for

IRAS project ID	212544

participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

Participating NHS organisations in England will be expected to formally confirm their capacity and capability to host this research.

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capacity will be confirmed is detailed in the *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* section of this appendix.
- The Assessing, Arranging, and Confirming document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

The Chief Investigator is responsible for all site activities as per the Statement of Activities.

GCP training is not a generic training expectation, in line with the HRA statement on training expectations.

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

Where arrangements are not already in place, network staff (or similar) undertaking any of the research activities listed in A18 of the IRAS form, would be expected to obtain a Letter of Access on the basis of a Research Passport (if university employed) or an NHS to NHS confirmation of pre-engagement checks letter (if NHS employed).

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.

- The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

175

Appendix G

Norfolk Community Health Trust Care NHS Trust Approval

IRAS 212544. Confirmation of Capacity and Capability at Norfolk Community Health and Care NHS Trust

SH

SUTHERLAND, Helen (NHS SOUTH NORFOLK CCG) <helen.sutherland6@nhs.net>

Reply|

Fri 7/14/2017, 1:54 PM

Inderpal Panesar (MED);
Maloney Lesley (Lesley.Maloney@nchc.nhs.uk);
Tracy Moulton (REN);
Woods Alison (Alison.Woods@nchc.nhs.uk);
'Tamara.Davidson@nchc.nhs.uk'

Inbox

You forwarded this message on 8/17/2017 11:41 AM

SOA_v1_26.6.17_212544 signed NCH&C.docx
94 KB

Show all 1 attachments (94 KB) Download
Save to OneDrive - University of East Anglia

Action Items

Dear Inderpal

Full Study Title: IRAS 212544. Staff experiences of working with acquired brain injury. Outcome of Application for HRA Approval.

This email confirms that Norfolk Community Health and Care NHS Trust has the capacity and capability to deliver the above referenced study. Please find attached our agreed Statement of Activities as confirmation.

We agree to start this study on a date to be agreed when you as sponsor give the green light to begin.
.
Please let us know which sites within NCH&C will be involved in the study for EDGE (research management) purposes.

If you wish to discuss further, please do not hesitate to contact the R&D Office snccg.RandDoffice@nhs.net.

Kind regards

Clare Symms

Research Management and Finance Lead, Norfolk & Suffolk Primary and Community Care Research Office on behalf of Norfolk Community Health and Care (NCH&C)

Cc: Lesley Maloney, Research Manager, NCH&C

Helen Sutherland
Research & Development Officer

Norfolk & Suffolk Primary & Community Care Research Office
Hosted by South Norfolk CCG
Lakeside 400, Old Chapel Way, Broadland Business Park, Thorpe St Andrew, Norwich, NR7 0WG
Switchboard - 01603 257000
Direct Dial - 01603 257083

E-mail: helen.sutherland6@nhs.net
Team email: snccg.RandDoffice@nhs.net
Website: http://nspccro.nihr.ac.uk

Appendix H

Local Trust Approval for Cambridgeshire Community Services

IRAS 212544. Outcome of Application for HRA Approval

PA

PHILLIPS, Alexander (NHS CAMBRIDGESHIRE AND PETERBOROUGH CCG) <alexander.phillips3@nhs.net>

Reply|

Mon 3/5, 10:45 AM

Inderpal Panesar (MED - Student)

Inbox

Blocked content will be shown while this message is open.

Dear Indi,

Thanks for sending documents across.

We have reviewed and discussed you study, no governance issues were found.

Please accept this email as formal notification of receipt of a retrospective submission. As you study has HRA approval and is completed, no further action is needed.

Best regards,
Alex

Alexander Phillips, Research Management & Governance Support Officer, NHS Cambridgeshire and Peterborough CCG, Lockton House, Clarendon Road, Cambridge, CB2 8FH, Tel: 01223 725469

Alexander.Phillips3@nhs.net

[www.crn.nihr.ac.uk/eastern]**www.crn.nihr.ac.uk/eastern**
https://sites.google.com/a/nihr.ac.uk/camstrad/

Primary and Community Care RMG Centre providing services on behalf of NHS Bedfordshire, Cambridgeshire Community Services, NHS Peterborough, and NHS Cambridgeshire

Appendix I

Example of Kayte's transcript: coding and development of superordinate
themes

Line No	Quote	Coding	Emergent themes	Superordinate themes
13-15	Because I love the-the-the challenges that it gives me because people with acquired brain injury umm vary, not only day-to-day, but moment-to-moment.	Love the challenges of the role- ppl with ABI vary, not only day-to-day, but moment to moment	Challenges are enjoyable- intellectual challenge?	
		Pts emotional stability, fatigue changes and movements change		
		Never knows what shes doing each day- changes		
19-20	I never know what dance I'm going to be doing that day. Umm. And I do see, umm, doing physio with people with, uhh, acquired brain injury, umm, as a dance.	Fluid like movement with role- Metaphor- doing a dance with a person with ABI	understand changes post ABI- change. Her role is fluid and flexible adapting to pts needs	(helping pts and their families) letting go of the fear of change
20-24	Umm, I'm guiding them through movement so that they can be as efficient with their movement as possible and have as many options of movement as possible. So that's how I've always-- That's how I've always-- viewed my role in, in working with people with stroke and brain injury. Umm, I'm guiding them through movement so that they can be as efficient with their movement as possible and have as many options of movement as possible. So that's how I've always-- That's how I've always-- viewed my role in, in working with people with stroke and brain injury.	Guiding them through movement so they can be efficient as possible	Guiding through movement	
25-28, 30	The other aspect that I, that I love about this, this job, is the resilience of humanity. You know, someone has, has a stroke, which I often, umm, talk with them that it's very similar to a tornado that went through my hometown. You know, no warning, boom, completely changed. Some of the things can be rebuilt-... and some of the things cannot.	tornado metaphor- some things can be rebuilt- some cannot The resilience of humanity- strength in ppl after having such a devatstating thing happen, rise above- privelidge to be a part of or help ppl adjust	Resilience of humanity- priveledge. Guiding pts/ families with new steps. Rebuilding lives following abi- change is needed	

32	And so something went in its place and that's kinda how I describe it.			
32-36	And so something went in its place and that's kinda how I describe it. And umm– And, and looking at th-the strength that people find after having such a devastating thing happen to them and their family, cause it never happens to just them, and how they, they rise above it, how they umm learn to, so to speak, take it in their stride, how they-- I mean, it takes a while to get to that point	A process that requires strength to help people to adjust following devastation in their lives, and their families	Devastating impact of ABI on pt and their families. Strength to overcome this	
36-39	I feel umm very privileged to be part of that to help people adjust to their umm way of living that's that's different than it was before, different than-- than how they thought it was going to be.	Some things go in it's place and people find a way to adjust- different than before and how they thought it would be	Adjustment to the ABI, a new way of being	
		People talk about changes and experiences people taking those changes and making something new with them		Feeling grateful for own life
			life, health, puts life into perspective	
		Treating many ppl younger than her		
51-57	Umm, it makes, uhh-- Makes me so appreciative and full of gratitude for my life, for uh my state of health um, for those around me. Umm-- I do think that I have a different outlook on life because of that. Umm, I think I take things in stride much differently because of that. Umm-- I also know that when things happen, it's not the end, you know, when things change, if things don't go the way you think they're going to be going in your life, it doesn't mean that your life ends, it just means it's going in a different route.	Appreciate and gratitude for own health, helps to take away shock, Changes in life are not the end, just life is taking a different route	Lifes changes are not the end.	Feeling humble/ grounded
64-69	Well, again, it goes back to that– to that gratitude aspect of it. It makes me stop and think-- when I get, uhh-- When I get my pants in a bunch about something or when I, "Oh woe is me," anything like that, I just stop short and I say, "Actually, I don't have anything to complain about here." You know, my life is very easy and, umm, so i-it, I-I reflect in that way and it keeps, umm, it keeps me very positive in my overall life.	Has a different outlook in life- takes things in stride more easily. Reflects- maintains perspective and keeps self positive in personal life	Positivite attitude (reflecting)	
			Life/ work experiences develop	
		Progress for a person is about them, some ppl can, some ppl cannot take it on board, not interviewee- keeps her centred	some people can take on board support	
		Input to everyone is the same		
102-107	Well I think that's-- like I said, that's the part I love. I-it allows me to be flexible, umm. In fact, I have to be flexible, because if I go in with a-- with a game plan of this is what I'm going to do today um, and they aren't able to, um, do that for whatever reason, um, then I have to come up with another game plan, I have to be on the ball, I have to know what I'm going to do so that I can make those changes right away. Um, and I just, I just find that, I like that part.	Love that role allows Flexibility- diff treatment options. Has to be on the ball- see how pt presents on day and what she can do so they make changes by end of session.	Working flexibly- depending on clients presentation that particular day	
		Professional approach os different		
		V Honest with pts but sensitive to their needs		
		Experience- in life and work makes an all round therapist- flows		

Appendix J

Letter to service managers

IRAS Project ID: 212544

UEA

University of East Anglia

<u>Letter to service managers</u>
<u>Version 2 (Date: 31.03.17)</u>

Postgraduate Research Service
Research and Enterprise Services
Elizabeth Fry Building 2.30,
University of East Anglia,
Norwich Research Park, Norwich,
NR4 7TJ

Dear (Service Managers Name),

I am writing with regards to my Doctorate in Clinical Psychology Thesis Research Project entitled 'Staff Experiences of working with Acquired Brain Injury: a qualitative study'. The study aims to recruit staff members from services across Cambridgeshire, Norfolk and Suffolk in order to find out staff experiences of working with this client group. There is a vast amount of research that looks into what acquired brain injury is like for the individuals and their families, but limited information regarding the experience of staff. Once this is better understood, there is a basis for future research which may also enable to support staff in their role.

Therefore, I ask permission to liaise with you and to assist in the recruitment of staff working at (insert site name) for this research project. This may mean that some staff members who would like to take part might need some time away from working hours to be interviewed (between 60-90 minutes for a one off interview, therefore a maximum of two hours in total). However any interview could be flexibly scheduled around the services demands, for example, on a day that there are fewer demands or a time that is appropriate for that staff member's schedule.

IRAS Project ID: 212544

As we have already discussed, recruitment will involve attending team meetings to present the study to clinical teams. This may require additional visits in order to capture all staff members. I also plan to send a research flyer and participant information sheets electronically for you to disseminate across the teams. The idea is that staff members can opt-in to take part, so they would contact myself if they would like to take part in the study. I also attach a summary of the study for your information.

The project has gained approval from the Doctorate in Clinical psychology and is currently going through the process of gaining ethical and research and development approval. I hope to begin recruitment in January 2017 so I look forward to hearing your thoughts and discussing the project further. I enclose a participant information sheet and consent form for your information. I am contactable on the above address, or via email, i.panesar@uea.ac.uk.

Yours sincerely,

Miss Inderpal Panesar

Trainee Clinical Psychologist

Appendix K

Participant Information Sheet

University of East Anglia

Participant Information Sheet (Version 3, Date: 02.04.17)

Understanding staff experiences of working with acquired brain injury: a qualitative study

Researchers: Inderpal Panesar (Trainee Clinical Psychologist, University of East Anglia (UEA)) and Dr Paul Fisher (Senior Clinical Tutor, UEA).

Introduction

We would like to invite you to take part in this qualitative research study. Before you decide if you are happy to take part, it is important for you to understand why the research is being done and what it involves. Please take the time to read this information sheet and discuss it with others if you wish. Thank you for reading this.

Why have I been invited to take part in this study?

There is a lot of information in research which informs us about the experiences of individuals who have acquired brain injuries (ABIs), and their families and carers. There is currently a gap with regards to researching staff working professionally with those with ABIs. Through your professional role, you may have several years of experience or few, but everyone will have their own

own unique and individual experiences. The researcher would like to find out about your experiences through an interview.

What is the aim of this research?

The aim of this research is to aid our understanding of working with acquired brain injury and may even provide information on the type of support staff might need. This is because there is currently not enough in depth information in this area. Through an interview, in-depth information about one's experiences can be gathered and each experience is individual and unique to that staff member and their role. This information can start to build a picture of what your experiences have been like and whether there might be specific areas for future research.

What does taking part involve?

You will be given at least 48 hours to decide whether you would like to take part in the study and there is no obligation to take part. If you do decide to take part, then you can contact the researcher directly to arrange a time and place at your convenience for an interview (such as your work place or your home). This will be a one- off meeting. During the meeting you will be asked to complete and sign a consent form (version 2, date 24.02.17). If you are happy to continue, there will be one face to face interview with the researcher, which

will take between 60-90 minutes. The semi-structured interview will be mainly about your experiences in your role, for example, how you have found your role and whether you have had any challenges. You will also be asked some basic demographic information, such as your current role and how many years you have worked with those with ABI.

What are the potential benefits of taking part?

Taking part will assist the wider research area of understanding of staff who work with ABI. You may also find it helpful to have some time to reflect on your experiences and share them with a researcher.

What are the potential risks or disadvantages of taking part?

It is unlikely that there will be any risks whilst taking part in the interview. Discussing your experiences may evoke some emotions that may be upsetting. You will be discussing your experiences with a trainee clinical psychologist who is trained to manage difficult situations. If you do become upset, you do not have to continue with the interview. Taking part will not negatively impact on your job.

Is the study safe?

Yes. This study has been reviewed and given a favourable opinion by a Research Ethics Committee.

Do I have to take part?

Your participation in this research is entirely voluntary. You are under no obligations to take part in this research and your job will not be affected. You have the right to withdraw your consent to taking part, without giving any reasons. If you change your mind once you have signed the consent form and have completed the interview, the recording on the dictaphone will be destroyed. You will have until analysis (48 hours after the interview), to withdraw from the research if you do change your mind.

Will my details remain confidential?

Only the researcher and Research supervisors will have access to your details. You will be given a unique identity number so that the researcher can identify each individual transcript. Only the researcher will know who has and has not taken part. The interview will be recorded on a dictaphone for analysis, and this will be uploaded onto an encrypted UEA computer and saved onto an encrypted memory stick. The recording will then be deleted from the dictaphone. The interview will be transcribed by either the researcher, or a professional transcribing service. The service works adheres to the Data Protection Act (1998), ensuring confidentiality of the data. Any identifiable information will be removed from the transcripts and store these on a password- protected document.

Any demographic or additional information will be stored securely in locked cabinets at the UEA with the research supervisor for 12 months and any personally identifiable information will be destroyed. Once the research study has finished, all the data will be stored securely at the UEA for 10 years.

You will be asked not to name any individuals you work with, for the confidentiality of their identity. If during the course of the interview, information regarding the safety and wellbeing of yourself and or others are compromised, confidentiality may need to be broken in order for the researcher to ensure a duty of care. Your safety and the safety of those you work with is paramount. Other professionals may need to be involved, such as your line manager or the local safeguarding team.

How do I make complaints?

If you would like to make a complaint, you may contact the Director of Psychological Services for Cambridgeshire and Peterborough NHS Trust, Dr Nick Oliver on 01223 219420 or email at: nick.oliver@cpft.nhs.uk. Alternatively, you can offer feedback by contacting Dr Ken Laidlaw, Head of Clinical Psychology at the UEA: 01603593600 or at K.Laidlaw@uea.ac.uk.

How do I get involved in the study?

If you work clinically with those with acquired brain injuries, or have further questions, please contact Inderpal Panesar either by email at I.Panesar@uea.ac.uk or by telephone on 07704912269.

Further Information and contact details

This study is part of a Doctorate in Clinical Psychology at the University of East Anglia.

If you would like to discuss the study further or have any questions, please contact Indi Panesar (Chief Investigator) via email at I.Panesar@uea.ac.uk or Dr Paul Fisher (Primary Research Supervisor) at P.Fisher@uea.ac.uk.

If you would like to speak to someone who is not directly involved in the study, you may contact Lesley Maloney (Research Manager, Community Services, Norfolk Community Health & Care NHS Trust) at Lesley.Maloney@nchc.nhs.uk.

Appendix L

Research Flyer

Are you interested in sharing your experiences of your role?

There is a research study that is coordinated by a trainee clinical psychologist at the UEA who would love to hear from you.

Who is eligible?

Anyone working clinically with people with acquired brain injury.

What is involved?

A one off 60-90 minute interview that will be recorded and analysed for a thesis study.

There will be a presentation at a team meeting shortly to find out more information.

Who do I contact to find out more information?

Indi Panesar, Trainee Clinical Psychologist on i.panesar@uea.ac.uk or telephone 07704912269.

Address: Elizabeth Fry Building, University of East Anglia, Norwich, NR47TJ.

Appendix M

Demographics form for interested staff members

UEA
University of East Anglia

Demographics form

Version 1.1 (Date: 10.11.16)

Understanding staff experiences of working with acquired brain injury

I am interested in taking part in the study 'Staff experiences of working with acquired brain injury: a qualitative study'. I understand this is NOT a consent form

1.   Please state your job role

………………………………………………………………………………………

2.   What is your age bracket? (please circle)

18-24   25-29   30-39   40-49   50-59   60+

3.   How many years have you been qualified in your profession? (please circle)

0 – 1 year   1 – 2 years   3 – 5 years   6 – 10 years   11 – 15 years
16 – 20 years   21+ years

4.   How many months/ years have you been working with individuals with acquired brain injury?

Appendix N

Over- Recruitment letter

IRAS Project ID: 212544

UEA
University of East Anglia

Over recruitment Letter
Version 1.0 (Date 10/11/16)

Staff experiences of working with acquired brain injury

Dear (insert name)

Thank you for your interest in the research study. Unfortunately the study has met the target number for recruitment so you will not be required to take part in the study. Due to the nature of this type of research, only a small number of participants are needed. I would like to take the opportunity to thank you for your interest and please continue to take part in research in the future.

With kind regards,

Inderpal Panesar

Trainee Clinical Psychologist

Appendix O

Feedback from Inspire

RE: Clinical Psychology Doctorate thesis proposal

I

Reply |
Mon 8/8/2016, 10:55 AM

Inbox
You replied on 8/8/2016 11:44 AM.

Show all 1 attachments (256 KB) Download

Action Items

Hi Indi,

Hope you're doing well.

Please find attached your comments for your summary, I hope that they are helpful to you.

Many thanks,

Tallulah

Tallulah Smith
Research Administration Apprentice

Norfolk and Suffolk NHS Foundation Trust
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From: Inderpal Panesar (MED) [mailto:I.Panesar@uea.ac.uk]
Sent: 22 July 2016 20:36
To: Inspire
Subject: Clinical Psychology Doctorate thesis proposal

Hi there,

I'm a first year clinical psychology trainee at the UEA. I wondered if you wouldn't mind having a look over a summary of my thesis proposal?

I'd appreciate you taking the time to have a look.

Kind regards

Indi

Inderpal Panesar
Trainee Clinical Psychologist

Reviewer comments for Inderpal Panesar:

REVIEWER 1:

I'm not sure that "going to find" is the correct phrase to use here. Maybe "This study will try to find out" or replace try with aims? Is the comma here necessary?)"There are many causes of brain injuries such as,.." I'd suggest editing this sentence as it doesn't read very well at the moment. Maybe "Brain injuries can cause problems with feelings, memory and emotions. They can also cause problems with walking, handling objects and talking". I think this sentence also needs editing as it reads like the project will actually be doing the research. "The researchers/student involved in the project will talk to staff members who work with patients who have suffered a brain injury. Talking to the staff members should help us find out how we can help and support these staff in their jobs".

REVIEWER 2:

I can easily see how knowledge gained from this project would be of benefit to both staff and patients. I think that, long-term, it would be useful to find out how the ways that care workers felt when working with acquired brain injury patients affects staff/patient relationships and the nature of resultant treatment. This project looks like it has the potential to make a positive contribution towards that goal.

It isn't clear from the summary if any specific methods have yet been chosen for this study and I am therefore unsure whether any input into this is being sought but, since the project appears to be exploratory in nature (due to the lack of existing research), I think that a qualitative design seems most appropriate. Since the research question is asking *what it is like* for staff members working with people with brain injuries, I would like to suggest a phenomenological approach as phenomenology deals very well with subjective experiences.

Because, as the summary points out, symptoms of brain injury can be extremely varied, I think that one of the main concerns in this project will be the extent that any findings can be generalised. Can we expect staff working with patients with one type of brain injury to have a comparable experience to those working with patients with another, and would it even be productive to attempt to? Also, there may be significant differences between staff in different jobs in different environments and different contexts during different stages of patient recovery. I suspect that seeking data or other knowledge of staff experience in working with brain injury patients in general may be less productive than looking at one specific situation and proposing that further research be conducted to look for differences and similarities. On the other hand, I can see how a wide-reaching and non-specific approach could be a good start to an under-researched area. Either way, I think a lot of thought should go into this.

One final point I would like to make is that, as a support worker, I feel that any effort made to understand thoughts and feelings of frontline workers can increase motivation and wellbeing and reduce the risk of staff burnout. I think that any research that focuses on what specific

circumstances are like for workers has the potential to have positive long-term consequences in terms of future research and recognition of this principle.

REVIEWER 3:

As there is no detail given in the summary, I guess the researcher is asking whether the summary is clear, and if the general idea is OK. The answer is yes to both.

As well as gaining an insight into experiences, there is a valuable opportunity to look at how the experiences are influenced by e.g. how long the member of staff has been working in their profession and/or how long working with this client group; whether any specialist training has been received in brain injury; perhaps even how much they are paid; volunteers might be included as well.

Appendix P

Participant Consent form

IRAS Project ID: 212544

University of East Anglia

Participant Consent Form version 2 (Date: 07.04.17)

Understanding staff experiences of working with acquired brain injury

Please initial the boxes to indicate you agree:

1. I confirm that I have read the Participant Information Sheet (Version 3,

Date: 02/04/17). I have had the opportunity to consider the information, ask

questions and have had these answered satisfactorily.

2.   I agree to have my demographic information recorded for the purposes

of the study including:

- My gender and age
- My job role
- How long I have been qualified in this role
- How long I have worked with those with acquired brain injury

3. I understand personally identifiable information will be destroyed after 12

months. I understand research data will be kept up to 10 years after the study

has finished.

4.   I agree to take part in the interview with the researcher about my

experiences within my job role.

5.   I agree to the interview being recorded for analysis purposes and any

names will be removed during transcription.

6. I understand the transcription process will require the researcher or

transcription services to transcribe the data, under the Data Protection Act

(1998), ensuring confidentiality of the data. Any identifiable information will be

removed from the transcripts and stored on a password- protected document.

7.   I understand that my participation is voluntary and that I am free to

withdraw until 48 hours after the interview, and without giving a reason. I

understand my role will not be affected.

8.   I consent to take part in the above study.

…………………………………… ……………………… .………………………..

Name of Participant   **Signature**   **Date**

………………………………….. ………………………. …………………………

Name of Researcher   **Signature**   **Date**

A copy of this form will be stored in a locked draw at the University of East Anglia, and you will keep a copy for your own records.

Appendix Q

*Co*nfidentiality agreement from transription company

07\11\2017

Confidentiality agreement between GoTranscript - Parker Corporation LP & the client Inderpal Panesar

1. I hereby undertake not to provide consultancy services to the client during the term of my agreement or after its termination for any reason unless expressly authorised by the client, or required by law to disclose information to any unauthorised person, nor use any of the confidential information related to or received from the client.

2. Such information includes but is not limited to financial information, client personal files and research data. Information is also confidential information if it is clearly marked as such or by its very nature is evidently confidential.

3. I understand that the use and disclosure of all information about identifiable living individuals is governed by the Data Protection Act. I will not use any personal data I acquire during my work for any purpose that is or may be incompatible with the purposes specified in this agreement.

4. I understand that I am required to keep all confidential and personal data securely.

5. I hereby undertake, during the term of my agreement to provide consultancy services to the client, to store all the records and materials related to the client in a safe, secure location as long as they are in my possession.

6. I hereby undertake to ensure that all records provided for the purposes of this agreement, including any back-up records, are deleted as directed, once I have received confirmation that the contract has been satisfactorily completed and all the required information has been provided in accordance with the client's wishes. I also confirm that the client will be able to personally remove the completed transcriptions from our database, and that the records and all the information and data related to them will be completely removed from the translators ' computers once the contract is satisfactorily completed.

7. I understand that the client reserves the right to take legal action against any breach of confidence, and will proceed with upmost speed to protect its interests in the event of any such breach.

Signed

Name: Peter Trebek

On behalf of GoTranscript

Address: 39 Duke Street, Edinburgh, EH6 8HH, United Kingdom
Phone number: +1 (347) 809-6761 **Email:** info@gotranscript.com **Website:**
www.gotranscript.com

Appendix R

Overarching superordinate themes across participants

	Sara	Emily	Jamie	Kayte	Sandy	Alex	Jamie	Timothy	Sam	Harriet	**Present in over half the sample?**
Managing professional role	Yes	No	No	No	No	Yes	No	No	Yes	Yes	**No**
Personal emotional experience	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	**Yes**
Frustrations towards the organisation	Yes	Yes	Yes	No	Yes	Yes	Yes	No	Yes	No	**Yes**
Impact of personal life	No	Yes	No	Yes	No	Yes	No	Yes	Yes	No	**Yes**