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Doctoral Thesis

Disability following traumatic brain injury: Considering the wider context

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Word Count

The word count of this document conforms to the permitted maximum length for the Lancaster University Doctorate in Clinical Psychology thesis.

	Main text	Appendices (inc. tables, references, abstracts, footnotes and title pages)	Total
Thesis Abstract	0	290	290
Literature Review	8083	11549	19632
Research Paper	8259	7193	15452
Critical Appraisal	3520	501	4021
Ethics Section	3380	3414	6794
Total	23242	22947	46189

Thesis Abstract

This doctoral thesis documents a qualitative exploration of some of the wider contextual issues relating to disability following traumatic brain injury (TBI).

There is a relatively high prevalence of long term disability following TBI. Family members often provide informal care and can experience negative psychological outcomes as a result. The systematic literature review in section one presents a metasynthesis of 15 qualitative papers exploring the experience of caregiving following TBI. Negative emotional reactions were experienced, due to changes to their injured relative and to their own lives. Caregivers were more able to cope if they could develop a good understanding of the person with TBI. Importantly, this review noted that families experienced a sense of wider supports crumbling beneath them following discharge form hospital. Lack of material, social, and professional supports intensified experiences of distress, as caregivers had fewer options. The findings support the need to address wider issues alongside any individual intervention.

Many people with TBI need to claim state financial benefits due to disability. The Work Capability Assessment (WCA) was introduced in the UK to assess ability to work and decide upon benefits received. The WCA process has been associated with increased mental health difficulties and has been criticised for neglecting contextual factors. The assessment may not be suited to the complexity of impairment following TBI. The research paper in section two explores the experiences of nine adults with TBI regarding the WCA. The data was analysed using critical narrative analysis. Participants experienced the assessment as distressing and saw the WCA as neglecting important functional difficulties. They experienced multiple barriers to the process. There is a need for the WCA to adopt a biopsychosocial approach to assessment of disability, and to make reasonable adjustments for people with TBI.

Declaration

This thesis documents research undertaken between September 2016 and August 2017, in partial fulfilment of the Lancaster University Doctorate in Clinical Psychology. The work presented here is my own, except where due reference has been made. This thesis has not been submitted for the award of a higher degree elsewhere.

Signature:

Print name:

Date:

Acknowledgements

I would like to thank the people who shared their experiences with me as part of this research; it was a pleasure to meet them and a privilege to hear their stories. I would like to thank Bill Sellwood and Stephen Weatherhead for their invaluable supervision and support throughout this process. I would also like to thank Andy Tyerman for his support with the research paper, in particular.

Finally, I would like to extend personal thanks to my parents, Colin and Lynne, for everything they have done that has helped me reach this point. I would also like to thank Gareth for his constant encouragement and belief in me when I doubted myself.

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Section One: Literature Review

Experiences of caregiving following traumatic brain injury: A metasynthesis

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Abstract[1]

Objective: Traumatic brain injury (TBI) can result in enduring physical, cognitive, behavioural, and emotional problems, and caregiving responsibilities may have a negative impact on relatives. This review aimed to identify and synthesise qualitative research regarding the experience of providing informal care following TBI. ***Method:*** A systematic literature search identified 15 relevant qualitative papers which were analysed using a framework for metasynthesis. ***Results:*** Three themes were drawn from the findings: (1) A new path with an unknown person; (2) Navigating the new terrain; (3) Strong supports or crumbling foundations. Some caregivers experienced negative emotions resulting from changes to their injured relatives and to their own role. When caregivers were able to develop a good understanding of their relative, this resulted in more successful coping strategies. However, material, social, and professional supports were often experienced as falling away, particularly following discharge from hospital. ***Implications:*** There may be a benefit to providing individual intervention for caregivers, focused on: managing emotional responses to the caregiving role; developing problem solving skills; and increasing understanding of TBI. However, these interventions need to be carefully considered in relation to the wider context, as many caregivers did not have sufficient social support, financial security, or access to services. Individual intervention may be unsuccessful if these wider issues are not also addressed.

Keywords: caregivers, carers, traumatic brain injury, qualitative metasynthesis

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[1] Section one is written in accordance with journal guidelines for Rehabilitation Psychology (Appendix 1-D). Where the paper deviates from these guidelines, it is in favour of instructions for Lancaster University Doctorate in Clinical Psychology Theses.

Traumatic brain injury (TBI) constitutes a significant health problem worldwide, leading to hospitalisation or mortality for an estimated 10 million people on an annual basis (Hyder, Wunderlich, Puvanachandra, Gururaj, & Kobusingye, 2007). TBI can result in a range of enduring physical, cognitive, behavioural, and emotional problems which affect daily activities and returning to work (Langlois, Rutland-Brown, & Wald, 2006). While less common than other conditions such as arthritis and back pain, TBI results in very high direct and indirect costs per individual; this is largely due to the young age of those affected and the severe disability that may follow (Ma, Chan, & Carruthers, 2014). For example, the prevalence of long-term disability as a result of TBI has been calculated at 500,000 in the UK (Headway, 2011) and 3.32 million to 5.3 million in the USA (Ma et al., 2014).

Informal or unpaid care refers to “care that is provided by family and friends to support people of all ages who are restricted in their activities of daily living through disability” (Baker, Barker, Sampson, & Martin, 2017, p.45). The provision of this informal adult care in the UK almost tripled in 15 years, reaching a value of £61.7 billion in 2010 (Office for National Statistics, 2013). It is often relatives who take on the caregiving role. In contrast to chronic health conditions, which may develop slowly over an extended period of time, TBI occurs suddenly and the transition to becoming a caregiver is abrupt (Chronister et al., 2016). Relatives are therefore more likely to be unprepared for the change in role.

Caregiving responsibilities can have a deleterious effect on relatives over time (Mazlan, Ghani, Tan, & Subramanian, 2016). The concept of ‘burden’ has been utilised in measuring some of the general negative experiences associated with caregiving (Chwalisz, 1992), levels of which tend to be elevated and increase over time when caring for a relative with TBI (Degeneffe, Chan, Dunlap, Man, & Sung, 2011; Minnes, Graffi, Nolte, Carlson, & Harrick, 2000). Another use of the term is the construct ‘objective burden’, which refers observable changes in the injured patient and environmental changes affecting the caregiver; this in turn can lead to ‘subjective burden’ which refers to the negative emotional reaction of the caregiver (Chwalisz, 1992).

Elevated scores for anxiety and depression are found amongst caregivers (Claude Blais & Boisvert, 2005; Degeneffe et al., 2011; Ennis, Rosenbloom, Canzian, & Topolovec-Vranic, 2013; Gan, Gargaro, Brandys, Gerber, & Boschen, 2010). Negative outcomes on measures of life satisfaction, quality of life (Dijkers, 2004), and marital breakdown (Wood & Yurdakul, 1997) have also been identified, as well as instrumental difficulties including financial problems and loss of employment (Kreutzer, Serio, & Bergquist, 1994; Ponsford, Olver, Ponsford, & Nelms, 2003).

The constructs explored in regards to caregivers of people with TBI, such as that of ‘burden’, are not always clearly defined. In addition, many caregiver outcomes, such as those relating to psychological distress, are inherently subjective (Sander, Maestas, Clark, & Havins, 2013). Research on negative outcomes in particular has been criticised, due to the relative neglect of positive outcomes for caregivers (Baker et al., 2017). Indeed, satisfaction has been shown to remain high for some caregivers, even where burden and distress are present (Wells, Dywan, & Dumas, 2005), and TBI can lead to their psychological growth (Cohen, Colantonio, & Vernich, 2002).

Studies focusing on caregiver outcomes can be limited by the heterogeneity of the samples (Claude Blais & Boisvert, 2005) and it is important to consider factors which might predict outcome. Severity of injury does not always accurately predict caregiver outcomes, when compared with neuro-behavioural sequalae (Claude Blais & Boisvert, 2005; Kreutzer, Gervasio, & Camplair, 1994). The presence of cognitive and behavioural problems has been found to increase caregiver stress (Simpson & Jones, 2013), strain (Mazlan et al., 2016), burden (Machamer, Temkin, & Dikmen, 2002) and emotional distress (Sander et al., 2013).

The level of functioning or level of support required by the person with TBI has also been related to caregiver outcomes (Kreutzer, Gervasio et al., 1994; Sander et al., 2013).

Caregiver characteristics may influence caregiver distress. There is only weak evidence for caregiver age and pre-injury emotional distress as predictors of post-injury emotional distress (Sander et al., 2013) and there are minimal differences between spouses and parents in terms of anxiety and depression (Ennis et al., 2013). However, there is the potential for ceiling effects where high levels of distress have been reported, meaning that subtle differences may be hard to detect (Ennis et al., 2013). The experiences of spouses and parents are likely to be qualitatively different to one another, due to their very different relationships with the injured person (Florian & Katz, 1991; Lezak, 1988; Serio, Kreutzer, & Gervasio, 1995).

More recently, research has been directed at establishing variables which mediate relationships between the characteristics of the caregiver or care recipient and the level of stress experienced by the caregiver. This has involved consideration of the ways in which caregivers understand and cope with the situation they are in. The concept of perceived stress involves an appraisal of the caregiving situation; it has been suggested as a “common factor” which underlies various measures that have been used to quantify subjective burden as an outcome (Chwalisz, 1992, p.194). Perceived stress has not only been found to predict outcome (Chronister & Chan, 2006; Chwalisz, 1996), but also to mediate the relationship between functional disability and outcome (Chronister et al., 2016).

In regards to coping skills, problem-focused coping[2] has been shown to result in improved caregiver outcomes, in contrast to emotion-focused coping which may constitute a

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[2] Lazarus and Folkman (1984) identified two categories of coping strategies: emotion-focused, where the aim is to reduce negative emotions; and problem-focused, where the source of distress is targeted objectively. Emotion-focused coping can be used positively (e.g. positive reappraisal) or negatively (e.g.avoidance or wishful thinking).

barrier to positive adjustment (Claude Blais & Boisvert, 2005; Rivera, Elliott, Berry, & Grant, 2008; Sander, High Jr, Hannay, & Sherer, 1997). A related concept of caregiving mastery refers to the sense of control caregivers feel they have over the caring situation (Struchen, Atchison, Roebuck, Caroselli, & Sander, 2002) and this can influence quality of life (Chronister & Chan, 2006). Other studies have employed the construct of resilience, which is multidimensional in nature and includes a range of helpful thoughts, feelings and behaviours (White, Driver, & Warren, 2008). Simpson and Jones (2013) found resilience to be independent of functional impairment and associated with lower levels of caregiver burden.

One example of a theoretical framework that has been developed in consideration of the strategies caregivers use to cope and the appraisals they make regarding their situation is the perceived stress model of caregiver burden (Chwalisz, 1992; Chwalisz, 1996). This framework utilises Lazarus and Folkman’s (1984) transaction theory, which suggests that individuals experience stress when they perceive that the demands they are faced with exceed their resources. A primary appraisal of threat takes place followed by a secondary appraisal of available resources and a coping response; this process is bidirectional, with coping impacting on subsequent appraisals of threat. Chwalisz (1992) therefore proposes that it is necessary to define burden as perceived stress, in order to organise varying and often conflicting research findings. Caregiver’s appraisals of both the effects of TBI and the resources they have available to cope with the situation are what lead to negative or positive outcomes.

However, social support has been found to reduce adverse stress reactions of caregivers (Hanks, Rapport, & Vangel, 2007), perhaps by preventing stress appraisal in the first place or acting to calm a stress reaction (Chwalisz, 1992). This raises the question as to whether caregivers with increased social support are in a better place to use positive coping strategies, or whether it is the use of positive coping strategies that allows caregivers to seek out support. Indeed, Chronister et al. (2016) found that caregiving mastery only emerged as a significant mediator between perceived burden and quality of life after support needs were removed from the model. This suggests that interventions at the environmental level may in fact be more effective than those aimed at developing personal coping skills.

The literature outlined above gives a certain degree of direction when working with families coping with the after effects of TBI. However, being largely cross-sectional in nature and limited to the theoretical constructs investigated, the studies may not necessarily reflect the full range of relatives’ experiences or discover key issues in terms of the longitudinal nature of the career as a caregiver. Qualitative studies drawing on first-hand accounts of caregivers can provide professionals and researchers with additional insight into the experience, thereby informing meaningful intervention. In turn, systematic reviews of this literature increase the likelihood that qualitative evidence will be drawn upon in designing interventions, services and policy.

Martin (2012) conducted a qualitative synthesis of the caregiving experience following TBI. Studies were identified and synthesised using meta-aggregation techniques, producing four themes: Concerns about the future; balance and independence; support for expert carers; and impact on occupational choices. Recommendations were made regarding the provision of information, inter-professional education, and the need to address caregivers’ occupational balance and engagement. Limitations of this review include the fact that only five studies contributed to the synthesis. Furthermore, the method involved only an aggregation of the available findings, with no further interpretation which might lead to a more developed understanding of caregiver experiences.

The evidence base reporting on the experience of caregiving in TBI is expanding and a scoping review of the literature indicated that that an updated qualitative synthesis was timely. Given that further levels of interpretation integrate individual sets of findings to produce a more substantive whole (Finfgeld, 2003), it is beneficial to utilise qualitative synthesis methods which involve third order interpretations of data (e.g. metasynthesis), in addition to aggregating and describing the findings (Sandelowski & Barroso, 2007). The current paper therefore presents an extension of the previous (Martin, 2012) review of caregiver experiences following TBI, with the aim of informing the ongoing development of appropriate support.

Method

Metasynthesis is an approach to new knowledge development based on analysis of qualitative research findings (Thorne, Jenson, Kearney, Noblit, & Sandelowski, 2004). The present review utilises Sandelowski and Barroso’s (2007) guide to synthesising qualitative research, selected due to its focus on a comprehensive literature search and in depth advice on how classification of findings can inform the methodology of the synthesis. The framework can be roughly summarised in six steps: (1) conceiving the synthesis; (2) searching and retrieving literature; (3) appraising findings; (4) classifying findings; (5) synthesising findings into metasummaries; and (6) synthesising findings into a metasynthesis (Ludvigsen et al., 2016). In line with step one, the research question was defined as: “What is the lived experience of caregivers providing support to a relative or partner with TBI?”

Search Strategy

A high-recall[3] systematic search of the literature was carried out; recall was emphasised over precision in order to ensure that potentially relevant papers were not neglected (Sandelowski & Barroso, 2007). Five electronic databases (PsychInfo; MEDLINE; CINAHL; PubMed; and Web of Science) were searched in March 2017. The qualitative PICO tool (Fineout-Overholt & Johnston, 2005) was used to support identification of key terms and synonyms relating to the topic, by considering Population, Issue, Context and Outcome. A final set of key words was combined and entered into each of the databases. Where available, official subject headings or controlled vocabulary terms were browsed and database-specific terms were added to the strategy. No restrictions were placed on the date of publication. A subject librarian was consulted in the development of the strategy; the final set of search terms, Boolean operators, and restrictions utilised for each database can be seen in Appendix 1-A. The initial search produced 4226 papers (including duplicates) that were potentially relevant.

Selecting Studies

The inclusion criteria were: (1) Research articles published in a peer-reviewed academic journal; (2) Significant focus on the experience of adult (aged 18 years and over) informal caregivers or family members; (3) Caring for adults (aged 18 years and over) with a TBI; (4) In a community (ie. not inpatient or residential care) setting; (5) Qualitative research methods grounded in participant quotes. The exclusion criteria were: (1) Primary focus on development/evaluation of measures/services; (2) Primary focus on outcomes of people with TBI or beliefs about TBI; (3) Research involving individuals with disorders of consciousness;

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[3] A search in which most, or all, of the documents on a topic are retrieved, in contrast to high-precision searches in which a smaller number of mostly relevant documents are retrieved.

(4) Research involving a mixed sample where findings related to caregivers are not presented separately; (5) Research involving veterans with TBI; (6) Articles not published in English.

Large samples in qualitative reviews can create difficulties in carrying out an appropriate depth of analysis, thereby impacting the validity of the findings (Sandelowski, Docherty, & Emden, 1997). Consequently, it was important to ensure a specific focus on the research question when selecting studies and to maintain a suitable level of homogeneity across that selection. Criteria relating to the target population were set where groups were not sufficiently similar, for example, children as caregivers, adults caring for disabled children, families caring for veterans, and families caring for people with disorders of consciousness. These groups tend to be researched as distinct populations (see Brown, Whittingham, Sofronoff, & Boyd, 2013; Buera-Prinzi & Perlesz, 2004; Carlozzi et al., 2016; Giovannetti, Černiauskaitė, Leonardi, Sattin, & Covelli, 2015, for recent examples) and are likely to require dedicated systematic review. Similarly, the experience of caring for a relative in the community was considered to be qualitatively different to the experience of supporting a relative on an acute ward or during transition home; these have also been researched as separate samples (e.g. Keenan & Joseph, 2010; Nalder, Fleming, Cornwell, & Foster, 2012).

During screening it became apparent that a number of studies used qualitative methods to inform the development of measures or services. These studies were excluded as they tended to shift the focus away from the lived experience of being a caregiver and often entailed superficial analysis. Studies which explored the outcomes of people with TBI, through the reports of their caregivers, or focused on general beliefs about TBI were excluded for the same reasons.

The process of identifying papers can be seen in Figure 1 and a full breakdown of reasons for exclusion in Appendix 1-B. A number of papers were duplicated and these were removed before screening the titles and abstracts of the remaining papers in accordance with the inclusion and exclusion criteria; papers were excluded where sufficient information was available to support a decision. Full texts of the remaining papers (n=68) were obtained and reviewed in order to establish those appropriate for inclusion. The reference lists of the selected papers were searched by hand and no further eligible papers were located. A total of 15 papers were identified for inclusion.

[INSERT FIGURE 1 HERE]

Appraisal and Characteristics of Selected Studies

The 15 selected papers were appraised individually and comparatively in order to establish the quality (Table 1) and characteristics (Table 2) of the research. Quality of the papers was assessed using the Critical Appraisal Skills Programme (CASP, 2013), which provides a framework for reviewing qualitative research across eight areas. Studies were not excluded based on the outcome of the quality appraisal, as it is acknowledged that only the written account of the study can be appraised as opposed to the research itself (Sandelowski & Barroso, 2007).

[INSERT TABLE 1 HERE]

[INSERT TABLE 2 HERE]

Comparative appraisal of papers involved ascertaining the range and prevalence of topics and enabled the identification of multiple reports presenting findings from a common sample (Sandelowski & Barroso, 2007). Three papers published by Wongvatunyu and Porter (2005, 2008, 2008b) analysed the same set of data; these were all included in the review as each paper presented additional participant quotes and author interpretations. Despite the increased amount of findings from one sample, a degree of triangulation is likely due to the inclusion of 12 other papers in the synthesis (Finfgeld-Connett, 2010).

The selected papers were published between 1996 and 2017, originating from the USA (n=8), Australia (n=2), Sweden (n=2), Botswana (n=1), Canada (n=1), and the UK (n=1). The total sample of caregivers included 458 participants (336 female, 113 male, 9 unknown, with gender inferred from relationship where possible). This is consistent with a greater number of working age females becoming caregivers in the population as a whole (Dahlberg, Demack, & Bambra, 2007). The age of caregivers, where reported, ranged from 18-78 years. The age of individuals with TBI, where reported, ranged from 18-75 years. Injury severity was most often reported as moderate-severe, with one study including people with complex mild TBI (Hammond, Davis, Whiteside, Philbrick, & Hirsch, 2011). The time since TBI was up to 26 years, where papers reported on this. The relationship between the caregiver and person with TBI was sibling for the majority of participants (n=292), due to one very large study which collected data from 280 siblings (Degeneffe & Olney, 2008). Other relationships were spouses (n=72), partners (n=45), parents (n=39), children (n=3), friends (n=2) and ex-spouse (n=1), with some relationships not reported (n=4).

The aims of the studies generally focused on the experience or long term impact of caring for a relative with TBI, sometimes with specific focus on caregiver burden. Two studies aimed to explore the impact on relationships and family life (Hammond et al., 2011; Wongvatunyu & Porter, 2008) and three studies focused on specific aspects of caregiving, such as supporting decision making or managing challenging behaviour (Bodley-Scott & Riley, 2015; Knox, Douglas, & Bigby, 2015; Tam, McKay, Sloan, & Ponsford, 2015). Data collection involved interviews (n=9), focus groups (n=2) and essay data from written surveys (n=2). Methods of data-analysis were reported to be various phenomenological methods of interpretation (n=5), thematic analysis (n=4), grounded theory (n=3), content analysis (n=1), descriptive analysis and intersubjective dialogue (n=1), and unspecified qualitative interpretive method (n=1).

In contrast to methods requiring that studies report a similar philosophical position (e.g. Noblit & Hare, 1988), Sandelowski and Barroso (2007) advocate classification of findings on a spectrum ranging from topographical surveys to interpretive explanation. The findings from papers in the present review were classified as either conceptual/thematic descriptions or interpretive explanations, which are considered amenable to metasynthesis. Implicit in the act of conducting a metasynthesis is the acknowledgement that "'results' exist and are subject to synthesis through an empirical view" (Ludvigsen et al., 2016, p.322). However, the above classification of findings justifies incorporating papers that report a constructivist stance in a metasynthesis. This allows a pragmatic approach and means that a suitably wide range of qualitative literature can be synthesised.

Analysis and Synthesis

Sandelowski and Barroso (2007) recommend preceding an interpretative synthesis with a "quantitatively oriented aggregation of qualitative findings" (p.151); a metasummary of the findings was therefore completed based on topical similarities. Manifest frequency effect sizes were calculated to ascertain the frequency of occurrence of findings. The number of papers containing a particular finding (minus any duplicate papers reporting the same finding) was divided by the total number of included papers (minus duplicates reporting the same finding). Intensity effect sizes were calculated by dividing the number of findings reported in a single paper by the total number of findings, thereby showing the relative contribution of each paper.

Completion of the metasummary involved the researcher immersing themselves in the data and becoming familiar with aspects of the caregiver experience which were most frequently reported, or carried the most weight. It also allowed early conceptualisation of how these salient aspects may be related to one another. In this sense, the metasummary acted as a “bridge” (Sandelowski & Barroso, 2007, p.151) to subsequent metasynthesis; while the metasummary focused on individual findings retrieved from reports, the metasynthesis aimed to provide a sense of the caregiving experience as a whole. During this second stage of analysis, a process of reciprocal translation and synthesis of concepts was carried out. Authors’ second order interpretations were re-conceptualised and presented as a set of third order interpretations, which can be seen as greater than the sum of its parts (Finfgeld, 2003).

Results

Metasummary

A total of 72 abstracted findings were identified on the basis of surface-level similarities within the papers. Findings were grouped according to six topics: (1) Perceived changes in the person with TBI; (2) Negative impact of care giving; (3) Positive aspects of care giving; (4) Coping and adaptation; (5) Relationships and roles; (6) Professionals and services. Abstracted findings with frequency effect sizes >25% are displayed in Table 3 and a full set of abstracted findings can be seen in Appendix 1-C. The contribution of each paper to the metasummary findings, assessed through the calculation of intensity effect sizes, ranged from 6% to 51% (Appendix 1-C). Papers with more restricted word counts contributed less to the metasummary, along with papers that presented caregiver’s experiences as only a portion of the overall findings.

[INSERT TABLE 3 HERE]

Metasynthesis

The metasynthesis findings are presented below as three themes: (1) A new path with an unknown person; (2) Navigating the new terrain; (3) Strong supports or crumbling foundations. The reciprocal translation of themes is summarised in Table 4. A model of caregiving incorporating findings from both the metasummary and the metasynthesis stages of analysis can be seen in Figure 2.

[INSERT TABLE 4 HERE]

[INSERT FIGURE 2 HERE]

A new path with an unknown person.

This theme encapsulates caregivers' experience of changes following TBI, resulting in a feeling that their injured relative had become a 'different' person. These changes directly impacted upon caregivers' roles and responsibilities, creating a new life path. Caregivers variably made a conscious commitment to the journey ahead or felt swept up in the changes.

Changed identity of the injured relative.

TBI occurred suddenly (Jumisko, Lexell, & Söderberg, 2007) and caregivers found themselves with a different person as a relative: "I am still confused, however, as to who is this man I live with, and where is the other one, I unconsciously wait for him to return" (Chwalisz & Stark-Wroblewski, 1996, p.33). Changes in personality and behaviour most contributed to the sense that the person was no longer the same. Some caregivers received verbal and physical abuse, due to increased irritability and aggression in the person with TBI (Bodley-Scott & Riley, 2015; Kratz, Sander, Brickell, Lange, & Carlozzi, 2017; Tam et al., 2015). Injured relatives were perceived to have cognitive losses (Chwalisz & Stark-Wroblewski, 1996) and became more rigid and egocentric. Spouses, in particular, experienced a lack of warmth and affection from their injured partner and missed their sense of humour (Bodley-Scott & Riley, 2015).

Caregivers felt a sense of loss for the ‘old’ person and sometimes reacted with anger and frustration due to having to adjust to this ‘new’ person (Bodley-Scott & Riley, 2015; Kratz et al., 2017). Changes in behaviour could be experienced as embarrassing (Jumisko et al., 2007) or perceived as immature: “It’s like a childish 2 or 3 year old that will have a tantrum on the floor” (Tam et al., 2015, p.815). Nonetheless, some caregivers identified enduring personality traits or viewed the changes positively (Bodley-Scott & Riley, 2015; Wongvatunyu & Porter, 2008b).

Committing to the journey.

Changes in the person with TBI translated into reduced independent participation in the home and community (Degeneffe & Olney, 2008; Tam et al., 2015). Caregivers’ lives were thrown onto a new path as they experienced physical, emotional and life situation changes along with a sense of constant responsibility (Chwalisz & Stark-Wroblewski, 1996; Engström & Söderberg, 2011; Jumisko et al., 2007; Mbakile-Mahlanza, Manderson, Downing, & Ponsford, 2016). Caregivers often experienced changes in their own occupation, either giving up work to provide care or alternatively having to take on employment responsibilities (Hammond et al., 2011; Tam et al., 2015). There was an overall sense of losing the life that was once theirs: “I had to give up my job, and my life, and my home, and all excitement... you kind of put your whole life on hold” (Wongvatunyu & Porter, 2008b, p.1067).

The nature of relationships could change, with some caregivers likening the relationship with their injured relative with one of ‘parent and child’ (Hammond et al., 2011; Jumisko et al., 2007). This change was experienced more negatively within a marriage or partnership. Hammond et al. (2011) noted gender differences in that wives resented their new role: “He doesn’t have the motivation. He can literally sit in a chair all weekend... And I think, ‘is this what my life is supposed to be like?’ And I’m angry...” (p.74). Husbands, on the other hand, seemed to view caregiving as a natural extension of the spouse role and accepted it with more ease. Mothers of adult children had an ongoing commitment to parenting: “She was wearing diapers when she came home from the hospital, just like a baby... It was just like starting over” (Wongvatunyu & Porter, 2008b, p.1066). There was a sense of returning to a previously familiar role, as opposed to the fundamental change experienced by spouses.

Emotional connections were also affected. Some spouses were unable to love their injured partner in the same way and struggled to face the path ahead: “I don’t love the person he is now. I don’t even like him – he’s so horrible to us” (Bodley-Scott & Riley, 2015, p.213). Caregivers’ commitment to the journey was sometimes pragmatic, for example, to provide a stable home for the children. For others, there were thoughts of separation and divorce (Chwalisz & Stark-Wroblewski, 1996). Conversely, feelings of love could transcend the injury (Knox et al., 2015).

Navigating the new terrain.

Caregivers needed to make sense of the new layout of their lives to find direction. They developed coping strategies which varied depending on how they understood and felt about their situation; these strategies subsequently impacted further upon wellbeing.

Establishing direction.

Caregivers invested their resources into making sense of the changes in the person with TBI. Through ongoing interaction, they reflected on behaviour and communication (Knox et al., 2015). Triggers for behaviours were identified and linked to what the caregiver knew about brain injury: “At the end of the day, we all have bad days and we [family] think it’s his way of lashing out a bit... His way of communicating is through his banging and you know trying to grab” (Tam et al., 2015, p.818).

An in-depth understanding provided caregivers with direction in terms of developing proactive strategies to support their injured relative; these strategies were continued when they worked well and refined as needed (Knox et al., 2015). Challenging behaviour was addressed by setting limits and prompting time outs (Tam et al., 2015; Wongvatunyu & Porter, 2008b) and approaches to communication were altered as caregivers “[learned] a different language... a different way of speaking” (Knox et al., 2015, p.750). Routines and lists were developed, constituting a support for the injured person to lean on, while minimising the weight placed on the caregiver (Kao & Stuifbergen, 2004; Wongvatunyu & Porter, 2005). Caregivers promoted the independence of the person with TBI by giving them control over their lives, to the extent that they could manage this. Overall, increased understanding of changes resulted in more successful management (Bodley-Scott & Riley, 2015).

Failed attempts at making sense of changes resulted in caregivers feeling stranded without a way forward. Equally, significant levels of negative emotion and perceived lack of control resulted in fear and hopelessness: “Scary really, actually. He says that he- he said when he’s in the moods that he feels that he can’t stop” (Bodley-Scott & Riley, 2015, p.211). These caregivers did not have the energy or inclination to adapt their communication approach and gave up on conversation. They opted out of decisions or went along with the injured person’s controlling behaviour through fear of the consequences (Bodley-Scott & Riley, 2015; Knox et al., 2015). Escape felt like the only option: “Staying out of the house, avoiding him, because I don’t know how to deal with him anymore...” (Hammond et al., 2011, p.73).

Finding a way to keep going.

Some caregivers found a route forward through hope and acceptance, seeking out positives to focus on: “I try to be philosophical and just you know, enjoy life...” (Tam et al., 2015, p.818). They looked for signs of improvement and this fuelled feelings of hope, pride, and happiness (Engström & Söderberg, 2011; Wongvatunyu & Porter, 2008b). Caring was a priority and the new role was wholeheartedly embraced: “In my heart I knew I had to look after him. I put my heart and soul into caring for him...” (Mbakile-Mahlanza et al., 2016, p.563). However, recurrent disappointments regarding recovery could diminish hope (Kao & Stuifbergen, 2004). For some, hope was a defence mechanism to deal with the unacceptable reality of the injury; hope for a miracle was intertwined with despair and longing for the past (Hammond et al., 2011).

Caregivers drew on personal resources, such as personality traits and organisational skills, where they had confidence to do so (Chwalisz & Stark-Wroblewski, 1996). Parent caregivers developed contingency plans for the future and siblings felt more able to assume care giving responsibilities when these plans were in place (Degeneffe & Olney, 2008; Wongvatunyu & Porter, 2005). Advocacy ensured the best possible resources for the path forward: “I write letters to every single person who tells me no. I stay up all night and I write letters and complaints...” (Kratz et al., 2017, p.24).

Caregivers acknowledged the importance of maintaining their own mental and physical energy levels, taking opportunities for rest when possible (Tam et al., 2015; Wongvatunyu & Porter, 2005). Some drew upon religion for strength (Chwalisz & Stark-Wroblewski, 1996; Mbakile-Mahlanza et al., 2016; Tam et al., 2015) and others incorporated activities which helped them maintain their identity: “I find the best thing for me is the painting. When I go in my space... I’m something other than a carer” (Tam et al., 2015, p.818).

Strong supports or crumbling foundations.

Wider context intensified or relieved any negative emotional impact of providing care. Where strong supports were present, caregivers leaned on these to feel safe and empowered. However, there was more often a sense that existing foundations were crumbling, leaving caregivers increasingly isolated and hopeless.

Having a wider team.

Family relationships could become closer following TBI, particularly where family members appreciated caregivers' efforts and did not let the injury define their relationship with the person with TBI (Jumisko et al., 2007; Wongvatunyu & Porter, 2008). Alternatively, formerly close relationships could suffer (Chwalisz & Stark-Wroblewski, 1996; Tam et al., 2015). It was especially disappointing when relatives were involved soon after the injury before drifting away (Jumisko et al., 2007). Caregivers felt guilty for neglecting other family members due to their new responsibilities; they found themselves investing energy into maintaining or rebuilding relationships, rather than being able to draw on them for support (Engström & Söderberg, 2011; Jumisko et al., 2007).

Similarly, wider social support networks began to collapse (Chwalisz & Stark-Wroblewski, 1996) as friends didn't always recognise what the caregiver was dealing with (Jumisko et al., 2007; Kratz et al., 2017; Mbakile-Mahlanza et al., 2016). There was a sense of being judged or criticised by others (Kratz et al., 2017; Mbakile-Mahlanza et al., 2016) which left caregivers feeling alone and misunderstood: "...the heartbreak of head injury is that we caregivers are voices crying in the wilderness – 'but you just don't understand'" (Chwalisz & Stark-Wroblewski, 1996, p.34). The social isolation of the person with TBI encompassed the caregiver too (Engström & Söderberg, 2011; Lefebvre, Cloutier, & Josee Levert, 2008); they experienced sadness and loss as fewer people stopped to say 'hello' and previously shared friendships slipped away: “I don’t fit anymore. A lot of our friends were couples” (Kratz et al., 2017, p.30). Where friendships did endure and were a source of support, this was of enormous value to caregivers (Chwalisz & Stark-Wroblewski, 1996; Tam et al., 2015).

Positive relationships with professionals allowed caregivers to feel safe and supported in their roles; they were able to see things more clearly and this had a positive impact on everyday life (Chwalisz & Stark-Wroblewski, 1996; Jumisko et al., 2007; Tam et al., 2015; Wongvatunyu & Porter, 2008b). However, professionals were not always experienced as helpful and were regularly a source of frustration. They were perceived as lacking in knowledge and not investing sufficient time in supporting families (Chwalisz & Stark-Wroblewski, 1996; Wongvatunyu & Porter, 2008b). Relatives’ perspectives were not taken into account: “They don’t listen to us who are close to her and know what she needs...” (Jumisko et al., 2007, p.361). Caregivers were in a relatively weak position and had little sense of control over what was going to happen and why: “I knew there was a day when we were going home. I was scared that meant Dan wasn’t going to get any better” (Wongvatunyu & Porter, 2008b, p.1068). Enduring relationships with empathic and knowledgeable professionals were desired in order that caregivers had somewhere to turn (Kratz et al., 2017), particularly in emergency situations (Tam et al., 2015).

Availability of resources.

Financial security provided a strong support for caregivers and their injured relative. Options for accessing resources were increased when money was available (Chwalisz & Stark-Wroblewski, 1996). When income was interrupted, this could have immediate effects in terms of caregivers’ abilities to meet their families’ basic needs, especially when the person with TBI had previously filled this role (Mbakile-Mahlanza et al., 2016;

Wongvatunyu & Porter, 2008). Negative emotions were heightened in the absence of this security: “The burden of recovery is one thing – having to worry about the finances too is quite overwhelming” (Chwalisz & Stark-Wroblewski, 1996, p.33).

Caregivers experienced a lack of services and information. Where building of supports had begun in acute rehabilitation, this was often experienced as crumbling following the move back to the community (Kratz et al., 2017; Lefebvre et al., 2008; Wongvatunyu & Porter, 2008). Services did not continue or adapt according to the evolving needs of families; there were concerns that there would be nowhere to turn in difficult times (Chwalisz & Stark-Wroblewski, 1996). Availability of services varied depending on where the family lived and some families considered moving (Wongvatunyu & Porter, 2008). This resulted in further loss of important relationships and informal support. Caregivers identified a need for respite (Kratz et al., 2017) but perceived paid carers as undertrained and residential facilities as unsuitable for promoting their relatives’ independence (Tam et al., 2015).

Caregivers felt unprepared and regretted they were not given information sooner (Chwalisz & Stark-Wroblewski, 1996; Mbakile-Mahlanza et al., 2016). Services had not considered when information might be best received by families, who varied in terms of their ability to process information: some caregivers would have preferred to have information about long term financial aid soon after the injury, whereas others said it “would not register” during the acute phase (Wongvatunyu & Porter, 2008b, p.1068). Lack of information about available community services left caregivers with little stable ground to build upon when their relative was discharged from hospital (Jumisko et al., 2007; Mbakile-Mahlanza et al., 2016; Wongvatunyu & Porter, 2008b).

Discussion

Outcomes for caregivers following TBI are mixed. However, the synthesis presented above provides an overview of potential key aspects of the caregiving experience. The metasummary notably indicates that negative experiences were far more frequently reported by caregivers than positive ones. However, this may be a representation of who is more likely to take part in research. Indeed, a number of the studies focused specifically on challenging behaviour or personality changes, which have been linked with poorer outcomes for caregivers (Claude Blais & Boisvert, 2005; Kreutzer, Gervasio, & Camplair, 1994). Furthermore, personality and behaviour changes were most frequently reported across this sample, regardless of study focus. Negative outcomes most often included financial difficulties, feeling isolated and stuck, and feeling burdened, stressed and overwhelmed; these are all consistent with previous research (Degeneffe et al., 2011; Kreutzer, Gervasio, et al., 1994; Minnes et al., 2000; Ponsford et al., 2003).

The theme ‘a new path with an unknown person’ highlights the experience of the injured relative’s identity being changed. Specific neuro-behavioural sequalae are linked with negative caregiver outcomes (Machamer et al., 2002; Mazlan et al., 2016; Sander et al., 2013; Simpson & Jones, 2013) and the current synthesis suggests this might be due to the significant impact upon the emotional connection within the relationship. This was particularly the case for spouses. There was a felt sense of loss which seemed more profound than the purely cognitive appraisals of deficits suggested by some of the previous research (Oddy, Humphrey, & Uttley, 1978). However, certain behavioural changes did appear to be appraised in light of societal norms, for example, perceiving behaviours as childish or embarrassing. Caregivers lives were thrown onto a new path and the fundamental nature of relationships changed. There was evidence that changes in role may be experienced differently for spouses as opposed to parents, with parents returning to a previously familiar role. The nature of the relationship between the caregiver and injured person should be taken into account in research and clinical practice (Florian & Katz, 1991; Lezak, 1988; Serio et al., 1995).

Caregivers needed to make sense of the new layout of their lives to find direction, which was encapsulated in the theme ‘navigating the new terrain’. Caregivers invested resources into making sense of the changes in their relative, in order to establish a direction for implementing proactive strategies. This could be seen as problem-focused coping (Lazarus & Folkman, 1984) and suggests that caregivers saw themselves as having the resources needed to cope with potentially stressful behaviours on the part of their injured relative. Indeed, there was a sense of increased confidence where caregivers viewed themselves as having relevant personal qualities, such as organisational and advocacy skills. On the other hand, failed attempts at making sense of the changes resulted in a perceived lack of control and a sense of hopelessness, perhaps indicative of a bidirectional relationship between experienced success of coping strategies and appraisal of subsequent threats (Chwalisz, 1992). An understanding of changes is, therefore, key for implementation of suitable strategies; this, in turn, is likely to result in improved sense of direction and perception of ability to cope in future.

Evidence of emotion-focused coping leading to negative outcomes (Claude Blais & Boisvert, 2005; Rivera et al., 2008; Sander et al., 1997) could be seen, with some relatives longing for the past and feeling despair. However, it is important to note that not all emotion-focused coping was unhelpful. Having a positive outlook and practicing acceptance resulted in caregivers feeling equipped to keep going. Some even experienced a degree of positive growth due to taking on the caregiving role (Cohen et al., 2002).

The final theme of 'strong supports or crumbling foundations' summarised the way in which the wider context could intensify or relieve any negative emotional impact of caregiving. There was an overall sense that there were few relationships that caregivers could draw up on for support, largely due to others not understanding what they were going through. Additionally, some caregivers felt that they needed to invest increased effort into maintaining family relationships This highlights the importance of not only considering the objective presence of a social network, but also the caregiver's subjective sense of whether these relationships are a potential source of support (Ergh, Hanks, Rapport, & Coleman, 2003). Caregivers reported concerns about the social isolation of their injured relative and also felt isolated themselves. The latter was partly due to the increased caregiving responsibilities resulting in a lack of time and energy to invest in maintaining relationships. However, there was also a sense that the loss of relationships experienced by the person with TBI could envelop the caregiver, suggesting a potential link between relatives' post-injury deficits in social skills and caregivers' loss of social support. This may partly explain the feeling in the current synthesis that the disintegration of social supports is outside of caregivers' control.

The availability of specialist services was generally reported to be insufficient which reflects previous research findings (Gan et al., 2010; Kolakowsky-Hayner, Miner, & Kreutzer, 2001). Given that caregivers frequently engaged in advocacy and information seeking behaviours, it seems that a lack of appropriate coping skills is unlikely to account for this experience. For example, some caregivers were prepared to move house to be closer to services. Information was reported to be similarly lacking and this is also consistent with previous research (Bond, Draeger, Mandleco, & Donnelly, 2003; Gan et al., 2010). Professionals play an important role in ensuring that information is shared with caregivers at appropriate times but were often experienced as unhelpful and lacking in knowledge. The way in which they related to families could perpetuate feelings of loss of control associated with the sudden onset of TBI (Chronister et al., 2016). It was important to families that relationships with professionals endured so that they had somewhere to turn in emergency situations, suggesting that simply knowing the option for support is there creates a feeling of safety.

Finally, the findings of this metasynthesis indicate a loss of material resources such as financial support (Kreutzer, Serio, et al., 1994; Ponsford et al., 2003). This was generally associated with the injured relative and/or the caregiver experiencing a loss of occupation following the injury. International research has explored relationships between social determinants and mental health (e.g. Friedli, 2009), and loss of finances may have a significant negative effect on families. Where financial resources were available, caregivers' options for accessing resources were increased, thereby improving their ability to make positive changes.

Clinical Implications

It was notable that the caregivers in these studies offered a number of solutions in regards to the difficulties they experienced. In particular, they wanted consistent support from services, which was adapted appropriately as rehabilitation progressed. Caregivers also expressed that professionals should have adequate knowledge of TBI, but also needed to listen to family members who knew the individual best. Communication and shared decision making should be a priority, in order that services do not inadvertently contribute to caregiver feelings of powerlessness. Caregivers felt that they lacked somewhere to turn in emergency situations, and would have appreciated having a pathway available to gain support.

Some caregivers experienced negative emotional impact, because of changes to their relative and to their own lives. This suggests the need for support regarding emotional responses to the caregiver role (Chronister et al., 2016). The experiences of these participants also provide evidence of the importance of caregiver appraisals and use of coping strategies, which does support the use of interventions targeted at increasing caregivers' problem solving skills (Powell, Fraser, Brockway, Temkin, & Bell, 2016) or understanding of TBI. However, the review has highlighted the experience of necessary supports falling away, even where caregivers demonstrate problem-focused coping behaviours; this affirms the importance of intervening at the environmental level by ensuring that strong supports are in place. Failure to cope may otherwise result in a sense of hopelessness. Group intervention involving caregiver peers may provide valuable social contact and support (Couchman, McMahon, Kelly, & Ponsford, 2014). In addition, links between health and social care are important; families were negatively impacted by financial difficulties and lacked suitable opportunities for respite.

Strengths and Limitations

Strengths of the current review include its high-recall search strategy and systematic approach to selecting studies. The process of synthesising the literature followed an established and detailed framework (Sandelowski & Barroso, 2007), which allows the reader to understand and potentially replicate the method. The included studies were conducted across a range of settings and utilised a variety of methods, meaning that findings are more likely to be robust across differing contexts (Lincoln & Guba, 1985). Papers were appraised as being good quality; although reflexivity was most often lacking in evidence, this can be due to limitations on publication length rather than lack of reflexivity in practice. A further strength is the completion of both a metasummary and metasynthesis when analysing the data. The metasummary provides a surface-level aggregation and description of currently available qualitative research, which allows the frequency of findings and the relative contribution of each paper to be established. The metasynthesis extends this by making third order interpretations to further the understanding of caregiver experiences.

Limitations include the inevitable presence of author assumptions at both the second and third order interpretation stages. Sandelowski and Barroso (2007) acknowledge that a reviewer can only synthesise the reports of studies in terms of the findings, rather than the original participant’s experience. However, quotes from participants were included so as to maintain at least some degree of connection with the first-order accounts; reflexivity was considered throughout the process. Qualitative research has been criticised for having a lower generalisability of findings when compared to quantitative designs (Finfgeld-Connett, 2010), which is certainly the case if the defined criteria for generalisability in quantitative research are considered. The present synthesis aims for idiographic generalisation, “drawn from and about informationally representative cases”, rather than applying generalisations from statistically representative samples to populations as a whole (Sandelowski & Barroso, 2007, p.2). Finally, due to the need for a manageable amount of data for synthesis, studies which primarily focused on the development or evaluation of measure and services were excluded from the review. It is acknowledged that these studies may have provided additional findings related to the caregiver experience and these may warrant separate review in future.

Future Research

Continued research on the association between environmental supports and caregiver coping following TBI would be beneficial. In addition, the qualitative literature in the present review reported more negative experiences than positive. Indeed, some studies focused on aspects of the caregiving situation that are inherently challenging to manage, such as behavioural problems following TBI. More quantitative research is emerging which focuses on positive outcomes for caregivers; there would be a benefit to carrying out qualitative research in this area to further improve understanding of the experience.

Conclusion

This systematic review identified 15 qualitative papers exploring the experience of caregiving following TBI. Findings were analysed using metasummary and metasynthesis approaches (Sandelowski and Barroso, 2007). Caregivers often experienced their injured relative as a ‘different person’ which resulted in feelings of loss; some made a conscious choice to commit to the journey ahead while others felt powerless and swept along by events. Resources were directed at attempting to form an understanding of the person with TBI, in order to establish coping strategies. Successful coping led to improved sense of direction, whereas failed attempts could result in hopelessness. Notably, caregivers often experienced wider supports as crumbling beneath them following discharge from acute care.

The findings suggest that although individual intervention may be beneficial, this should be accompanied by comprehensive assessment of wider supports. Without necessary foundations in place, individualised skills training may be unhelpful or detrimental. Social support networks should be assessed in terms of subjective perception, as caregivers were not always able to draw on support from the people around them. Group family interventions are likely to be beneficial in terms of expanding social support by connecting with others who understand, thereby reducing feelings of isolation. Caregivers need access to long-term support from services and knowledgeable professionals, with communication and shared decision making being a priority.

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Table 1. Quality appraisal[4]

Paper	Research design	Sampling	Data Collection	Reflexivity	Ethical Issues	Data analysis	Findings	Value
Bodley-Scott & Riley (2015)	Y	Y	Y	Y	Y	Y	Y	Y
Chwalisz & Stark-Wroblewski (1996)	Y	N	N	Y	N	Y	Y	Y
Degeneffe & Olney (2008)	Y	Y	Y	N	N	Y	Y	Y
Engström & Söderberg (2011)	Y	Y	Y	N	Y	N	Y	Y
Hammond et al. (2011)	Y	Y	Y	N	Y	Y	Y	Y
Jumisko et al. (2007)	Y	N	Y	N	Y	Y	Y	N
Kao & Stuifbergen (2004)	Y	Y	Y	Y	Y	Y	Y	Y
Knox et al. (2015)	Y	Y	Y	N	Y	Y	Y	Y
Kratz et al. (2017)	Y	Y	Y	N	Y	Y	Y	Y
Lefebvre et al. (2008)	N	Y	Y	N	Y	Y	Y	Y
Mbakile-Mahlanza et al. (2016)	Y	Y	Y	N	Y	N	Y	Y
Tam et al. (2015)	Y	Y	Y	N	Y	Y	Y	Y
Wongvatunyu & Porter (2005)	Y	Y	Y	N	N	Y	Y	Y
Wongvatunyu & Porter (2008a)	Y	Y	Y	N	Y	Y	Y	Y
Wongvatunyu & Porter (2008b)	N	Y	Y	N	Y	Y	Y	Y

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[4] Yes (Y) indicates that this aspect has been appraised as being sufficiently evident in the research paper, whereas No (N) indicates that there is a lack of evidence.

Table 2. Reported characteristics of selected studies

Paper	Research aim/question	Methodology and setting	Participant demographics
Bodley-Scott & Riley. (2015)	To explore how social, behavioural and emotional changes are experienced by partners of persons with TBI.	Data collection: Interviews on two separate occasions. Analysis: Interpretative Phenomenological Analysis. Setting: Recruitment through NHS outpatient brain injury service and head injury charity. UK.	Sample size: n= 5; Age range: 29-42 years; Gender: All female; Relationship to person with TBI: Partner. Age of person with TBI: 27-49 years; Severity of TBI: Not reported; Time since TBI: 9 months to 7 years.
Chwalisz & Stark-Wroblewski (1996)[5]	To add to the current body of research in the area of caregiver burden among spouses of brain injured persons by capturing the subjective experience of caregivers.	Data collection: Essay data provided as part of a larger quantitative study of caregiver burden. Analysis: Inductive typological content analysis. Setting: USA	Sample size: n=27; Age range: Not reported; Gender: Female (n=26), Male (n=1). Relationship to person with TBI: Spouses. Age of person with TBI: Not reported; Severity of TBI: Not reported; Time since TBI: Not reported.
Degeneffe & Olney (2008)[6]	To gain a comprehensive and contextual understanding of future concerns of siblings of people with TBI.	Data collection: Written surveys including open ended questions. Analysis: Grounded theory. Setting: Recruitment through state chapters of the Brain Injury Association of America and rehabilitation organisations. USA.	Sample size: n=280; Age range: 18 years and over; Gender: Female (n=201), male (n=79); Relationship to person with TBI: Siblings. Age of person with TBI: Range not reported, M=36.73; Severity of TBI: Not reported; Time since TBI: >6 months.

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[5] Assumption made that caregivers and individuals with TBI are adults (spouses)
[6] Assumption made that individuals with TBI are adults (M=36.73).

Paper	Research aim/question	Methodology	Participant demographics and setting
Engström & Söderberg (2011)[7]	To describe transitions as experienced by the close relatives of people with TBI.	Data collection: Interviews. Analysis: Qualitative interpretative method. Setting: Participants' homes. Sweden.	Sample size: n=5; Age range: 36-76 years; Gender: All female; Relationship to person with TBI: Mother (n=3), sister (n=1), wife (n=1). Age of person with TBI: Not reported; Severity of TBI: Not reported; Time since TBI: 10-26 years.
Hammond et al. (2011)	To examine how a spouse who has experienced TBI affects the marital relationship.	Data Collection: Gender specific focus groups. Analysis: Constructivist approach to grounded theory. Setting: Recruitment through rehabilitation service. USA	Sample size: n=10; Age range: 40-75 years; Gender: Female (n=5), male (n=5); Relationship to person with TBI: Spouse. Age of person with TBI: Over 18 years of age; Severity of TBI: Complex mild to severe; Time since TBI: 4-12 years.
Jumisko et al. (2007)	To elucidate the meaning of close relatives' experiences of living with a person with moderate or severe TBI.	Data Collection: Qualitative research interviews. Analysis: Phenomenological hermeneutic method of interpretation. Setting: Participants' homes. Sweden.	Sample size: n=11; Age range: 28-56 years; Gender: Not reported; Relationship to person with TBI: mother (n=2), father (n=1), partner (n=2), sibling (n=2), child (n=1). Age of person with TBI: 23-50 years; Severity of TBI: Moderate-Severe; Time since TBI: Unknown.
Kao & Stuifbergen (2004)	What is the experience of having a traumatic brain injury? What is mothers' experience of having a traumatic brain injured child?	Data collection: Interviews with guide. Analysis: Phenomenologic analysis techniques across mother-child dyads and then for each data set individually. Setting: Participants were recruited through the Brain Injury Association of Colorado. USA.	Sample size: n=12; Age range: 44-58 years; Gender: All female; Relationship to person with TBI: Mother. Age of person with TBI: 18-25 years; Severity of TBI: Severe; Time since TBI: 2-12 years.

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[7] Assumption made that people with TBI are adults (caregivers aged 36-76)

Paper	Research aim/question	Methodology	Participant demographics and setting
Knox et al. (2015)[8]	To develop an understanding of decision-making grounded in the experiences of the spouses of adults with severe TBI.	Data collection: Interviews on two occasions. Analysis: Grounded theory Setting: Recruited through community-based brain injury services and service provider networks. Australia.	Sample size: n=4; Age range: Not reported; Gender: male (n=3), female (n=1); Relationship to person with TBI: Spouse (n=2), partner (n=2). Age of person with TBI: 42-47 years; Severity of TBI: Severe; Time since TBI: 8-19 years.
Kratz et al. (2017)	To examine how parent and partner caregivers of individuals with moderate-severe TBI describe their quality of life in the context of their caregiving role.	Data collection: Focus groups. Analysis: Thematic content analysis. Setting: Rehabilitation centres. USA.	Sample size: n=52; Age range: 34-78 years; Gender: Female (n=40), male (n=12); Relationship to person with TBI: Father (n=8), mother (n=23), husband (n=4), wife (n=17). Age of person with TBI: 23-75 years; Severity of TBI: moderate-severe; Time since TBI: <18 months (n=3), 18 months to 3 years (n=10), >3 years (n=39).
Lefebvre et al. (2008)	To describe the social participation of persons with TBI. To identify factors that play key roles in social participation. To describe the long-term impacts of TBIs on family and friends. To identify how the health and social services network is used.	Data collection: Semi-structured interviews. Analysis: Thematic content analysis. Setting: Participant's homes. Canada.	Sample size: n=21; Age range: 18-29 years (4.8%), 30-39 years (28.6%), 40-49 years (23.8%), 50 years and over (42.9%); Gender: Female (57.1%), male (42.9%); Relationship to person with TBI: Parent (n=6), child (n=2), sibling (n=1), spouse (n=4), common law spouse (n=4), friend (n=2), ex-spouse (n=1), other (n=1). Age of person with TBI: 30-39 years (45.5%), 40-49 years (36.4%), 50-59 years (9%), 60 years and over (9%); Severity of TBI: Moderate-severe; Time since TBI: M=12.8 years.

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[8] Assumption made that caregivers are adults (spouses and partners)

Paper	Research aim/question	Methodology	Participant demographics and setting
Mbakile-Mahlanza et al. (2016)	To focus on the experience of caregiving for individuals with TBI in Botswana. To examine levels of caregiver anxiety and depression, and their association with functional outcome in their TBI relative.	Data collection: Mixed-methods approach, quantitative and qualitative data gathered from semi-structured interviews and questionnaires. Analysis: Thematic analysis for qualitative data. Setting: Referral hospitals selected as recruitment points. Botswana.	Sample size: n=18; Age range: 23-70 years; Gender: Female (n=15), male (n=3); Relationship to person with TBI: Spouse (n=7), parent (n=4), sibling (n=7). Age of person with TBI: 19-53 years; Severity of TBI: Moderate (n=12), severe (n=6); Time since TBI: >6months.
Tam et al. (2015)	To gain an understanding of family caregiver experiences of challenging behaviours and the impact on community participation for the TBI individual. To understand the lived experience of caregivers in the face of challenging behaviours.	Data collection: Interviews and questionnaires. Analysis: Thematic analysis. Setting: Participants' homes. Australia.	Sample size: n=6; Age range: 41-71 years; Gender: Not reported; Relationship to person with TBI: Mother (n=4), sister (n=1), spouse (n=1). Age of person with TBI: 28-43 years; Severity of TBI: Severe; Time since TBI: 9-23 years.
Wongvatunyu & Porter (2005, 2008, 2008b)	To describe the essence of the experience of mothers who provided regular help for young adults who had suffered TBI (2005). To describe perceived changes in family life reported by mothers after their young adult child had suffered a TBI (2008). What is the personal–social context of the experience of mothers who help young adult survivors of moderate or severe TBI? (2008b).	Data collection: Three interviews with each participant. Analysis: Descriptive analysis and "inter-subjective dialogue" (2005), Phenomenological method for describing life-world or the personal-social context of an experience (2008), Phenomenological method for understanding life-worlds (2008b). Setting: Participant homes or university. USA.	Sample size: n=7; Age range: 46-64 years; Gender: All female; Relationship to person with TBI: Mothers. Age of person with TBI: 20-36 years; Severity of TBI: Moderate-severe; Time since TBI: 8 months- 20 years.

Table 3. Metasummary abstracted findings with frequency effect sizes > 25%

Abstracted finding	ES%
Perceived changes in the person with TBI	
7. Caregivers observed personality and behaviour changes in the person with TBI which could be difficult to manage and hard to understand.	54
10. Caregivers observed difficulties in relationships for the person with TBI, due to their own social limitations, their vulnerability to being taken advantage of, and the withdrawal of their previous friends.	53
8. Caregivers perceived cognitive and intellectual losses for the person with TBI following the injury, including problems with memory, attention, planning, initiation and decision making.	43
9. Caregiver's observed that the person with TBI had reduced ability to continue with their occupation and to complete activities of daily living independently.	43
4. Caregivers considered the person with TBI to be fundamentally changed as a person by their injury.	40
11. Caregivers observed physical changes and ongoing health problems as a result of, or in addition to, the person's TBI.	38
12. Caregiver's perceived emotional, psychological and adjustment difficulties for the person with TBI, resulting in need for support and sometimes medication.	36
1. Caregiver's perceived increased physical or verbal aggression, anger and irritability in the person with TBI.	33
3. Spouses in particular perceived a lack of affection, empathy and concern from the person with TBI, experiencing them as more cold and indifferent than before the injury.	33
13. Caregiver's perceived communication difficulties on the part of the person with TBI, following their injury.	27
Negative impact of care giving	
22. Caregivers faced financial difficulties and the pressures of managing this.	53
28. Caregivers felt isolated and stuck, bearing sole responsibility for the person with TBI.	47
30. Caregivers described feeling burdened, stressed, desperate, and overwhelmed.	47
25. Caregivers described significant demand on the time, energy, and emotional resources, of which there was a limited supply.	40
27. Caregivers had to put their own plans for the future aside, rearranging their lives and sometimes giving up their occupation.	40
29. Caregivers had worries, fears and concerns regarding: (1) the wellbeing of the person with TBI, including whether they might sustain further injury; (2) leaving the person with TBI, even for a short time; (3) future care giving responsibilities, whether becoming unable to provide care or taking on responsibility for care; (4) judgement from others; (5) the future in general.	40
32. Caregivers experienced anger, frustration and resentment towards the person with TBI, towards others, and towards the general situation. In the long term some caregiver's expressed bitterness regarding the sacrifices they had made.	40
33. Caregivers experienced feelings of helplessness and loss of hope for future change.	40
21. Caregivers experienced feelings of sadness and loss, due to changes in the person with TBI and changes to their own lives.	33
23. Caregivers described their own deteriorating physical health and physical symptoms of stress.	33
26. Caregivers lives had changed suddenly and been thrown into chaos; life was like being 'on a rollercoaster'.	33
31. Caregivers felt confused, upset and hurt by the changed behaviour of the person with TBI, sometimes traumatised by aggressive behaviours that had occurred soon after the injury.	27
Positive aspects of care giving	
35. Caregivers felt thankful that things were not worse and appreciative of the positive aspects of the situation; changes were not always experienced as negative.	40
37. Caregivers embraced the opportunity to care for their loved one, gaining a mission in life and feeling proud of themselves.	33

34. Caregivers felt hopeful about the future.	27
Coping and adaptation	
53. Caregivers focused on rehabilitation and establishing a ‘normal life’ for the person with TBI, through encouraging them, supporting them, and helping them to learn, even after formal rehabilitation had ended.	60
40. Caregivers worked to learn about brain injury and to understand and make sense of the changes to the person with TBI, which could lessen the emotional impact.	50
46. Caregivers developed proactive strategies for managing communication, cognitive and behavioural difficulties on the part of the person with TBI.	33
49. Caregivers focused on protecting the person with TBI, taking control of decision making and speaking up on their behalf.	29
42. Caregivers sought support from family, friends, and others in the same situation.	27
44. Caregivers maintained hope that things would improve or return to the way they were before the injury, some hopes were scaled down as compared to pre-injury.	27
45. Caregivers took time out from the situation to be alone as a way of coping or, more rarely, coped by sharing space with the injured person.	27
50. Caregivers reported that spirituality and religion helped them to cope.	27
54. Caregivers identified the need for respite and assistance with daily duties, with some hiring a paid carer.	27
Relationships and roles	
61. Caregivers took on a new role which absorbed responsibilities and tasks previously carried out by the person with TBI, for example providing emotional, financial, material and physical support. This caused difficulties for both the caregiver and the person with TBI.	60
62. Caregivers experienced problems maintaining their relationship with other family members, due to decreased available time and energy, some reported making a special effort to spend time with other family members.	54
56. Family relationships became closer following the injury.	47
55. Fundamental nature of the relationship changed to that of caregiver and care recipient or parent and child. On occasion, care giving was seen as a natural extension of the spouse role.	36
58. Caregivers expressed continuing feelings of love and positive regard for the person with TBI.	33
59. Relationship dynamics between the caregiver and the person with TBI changed following the injury, becoming more distant or lacking the same level of intimacy. Caregiver partners sometimes continued the relationship for pragmatic reasons, such as providing a stable home for children.	33
64. Caregivers found that others could not understand their situation and did not always provide the support they would have hoped for.	33
63. Caregivers made observations of relationships between other family members and the person with TBI, with problems arising between the injured person and their children as well as family members struggling to adjust.	27
Professionals and services	
68. Caregivers expressed a desire for more information and advice about brain injury and related services; some regretted that they did not get much needed information sooner.	43
69. Caregivers felt that available services were insufficient, particularly following acute care.	43
67. Caregivers expressed the view that the professionals and paid carers they had contact with did not know enough about TBI.	33
65. Caregivers expressed the need for ongoing professional support for all members of the family which was suited to the stage of rehabilitation.	27
66. Caregivers felt supported by professionals and appreciative of their assistance.	27
70. Caregivers experienced tensions and frustration within their relationship with specific healthcare professionals, feeling that their own views were not heard and they were not kept fully informed.	27

Table 4. Reciprocal translation of themes in metasynthesis

Papers	Extracted themes	Metasynthesis themes
Bodley-Scott & Riley (2015) Chwalisz & Stark-Wroblewski (1996) Degeneffe & Olney (2008) Engström & Söderberg (2011) Hammond et al. (2011) Jumisko et al. (2007) Knox et al. (2015) Kratz et al. (2017) Mbakile-Mahlanza et al. (2016) Tam et al. (2015) Wongvatunyu & Porter (2008b)	“Impact on the relationship, “Emotional impact”, “Changes in the caregiver and his or her life”, “Changes in the marital relationship as a result of the injury”, “Changes in the spouse with the injury”, “Relationships and family”, “Recovery”, “Independence”, “The starting point of the transitions”, “Transitions in the pattern of daily life”, “Volatility of the relationship”, “Gender role stereotypes”, “Chaotic relationships”, “Fighting not to lose one’s foothold”, “Seeing the person in a positive light”, “Being committed to the relationship”, “Changes in person with TBI”, “Heavy demands on caregivers”, “Family experience”, “Families reflections on the changes they find challenging”, “Impact of challenging behaviours on participation”, “Perceiving that life really has changed”, “Having a child who survived a TBI as a young adult”	A new path with an unknown person Subthemes: Changed identity of the injured relative Committing to the journey
Bodley-Scott & Riley (2015) Chwalisz & Stark-Wroblewski (1996) Degeneffe & Olney (2008) Engström & Söderberg (2011) Hammond et al. (2011) Kao & Stuifbergen (2004) Knox et al. (2015) Kratz et al. (2017) Mbakile-Mahlanza et al. (2016) Tam et al. (2015) Wongvatunyu & Porter (2008b) Wongvatunyu & Porter (2005)	“Emotional impact”, “Desire to be helpful to the researcher and others in the same situation”, “Personal resources helpful for the caregiving role”, “Coping strategies used by the caregiver”, “Future caregiver”, “Transitions in the pattern of daily life”, “Temporality – comparing the past to the present”, “We-ness versus separateness”, “Staying married”, “Volatility of the relationship”, “The period of uncertainty”, “The process of decision making”, “Being committed to the relationship”, “Understanding the functional implications of the brain injury on their partner”, “Learning from experience”, “Finding a way to communicate”, “Caregiver role demands”, “Family devotion”, “Faith in God”, “Family strategies”, “Families reflections on the changes they find challenging”, “Believing that my child is still able”, “Believing that I can help my child”, “Advocating for my child”, “Dealing with our biggest problem”, “Reconnecting my child’s brain”, “Making our lives as normal as possible”, “Considering my child’s safety”	Navigating the new terrain Subthemes: Establishing direction Finding a way to keep going
Chwalisz & Stark-Wroblewski (1996) Degeneffe & Olney (2008) Engström & Söderberg (2011) Jumisko et al. (2007) Kratz et al. (2017) Lefebvre et al. (2008) Mbakile-Mahlanza et al. (2016) Tam et al. (2015) Wongvatunyu & Porter (2008) Wongvatunyu & Porter (2008b)	“Miscellaneous stressors ancillary to the injury”, “Others don’t understand and may be unsupportive”, “Enigmatic nature of brain injury”, “Problems with/advice for medical professionals”, “Sources of support and assistance”, “Professional care”, “Transitions in social life”, “Transitions in relationships”, “Fighting not to lose one’s foothold” , “Cross cutting codes”, “Impact on family caregivers”, “Social isolation and lack of community support”, “Lack of information”, “Financial burden”, “Family experience”, “Family strategies”, “Splitting the family apart against our will”, “Going our separate ways down this new path”, “Getting along with each other since the injury”, “Getting attention from each other for different reasons now”, “Facing new financial hurdles”, Having sufficient support/feeling bereft of any help”	Strong supports or crumbling foundations Subthemes: Having a wider team Availability of resources

Figure 1. PRISMA flow diagram

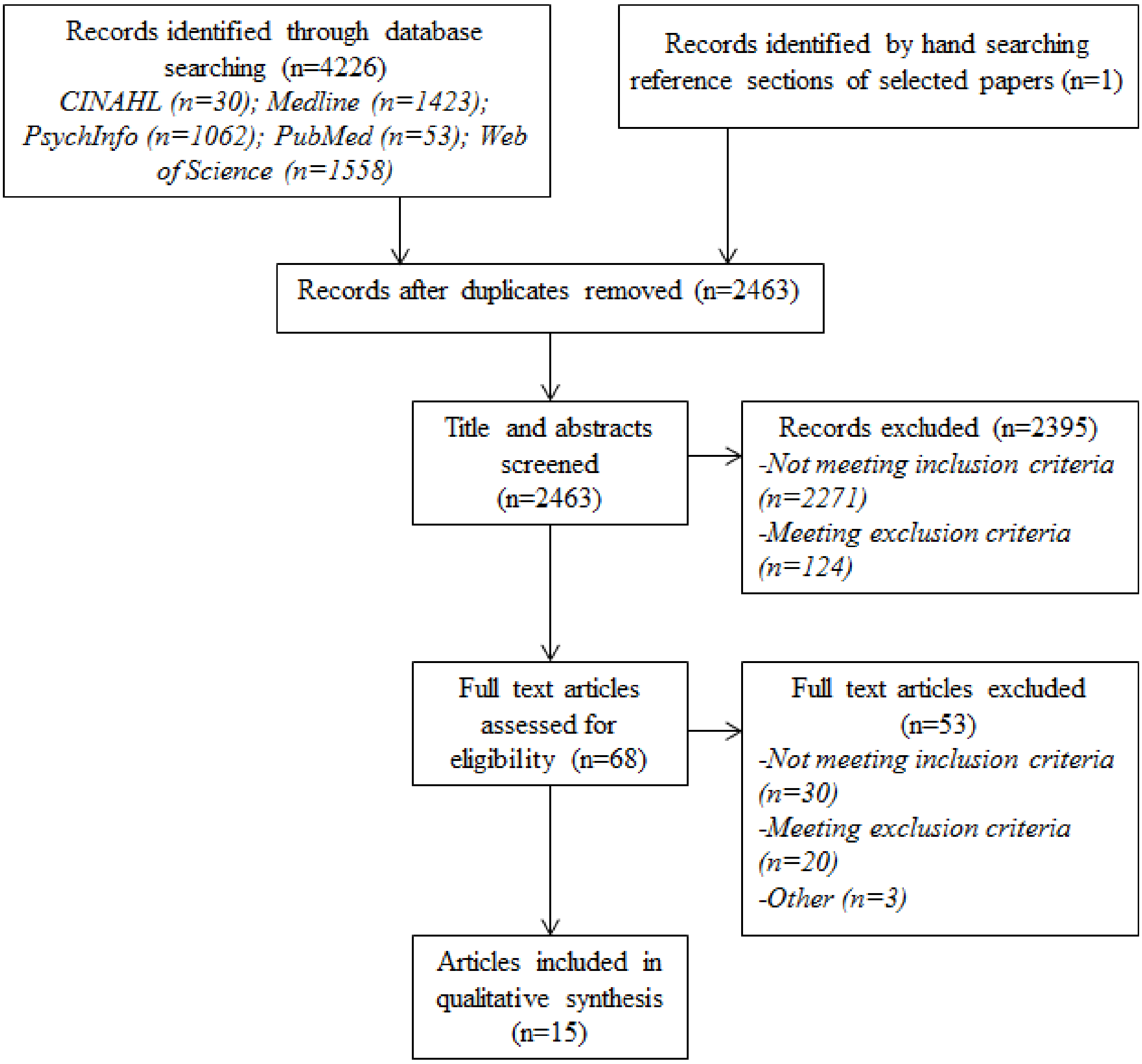
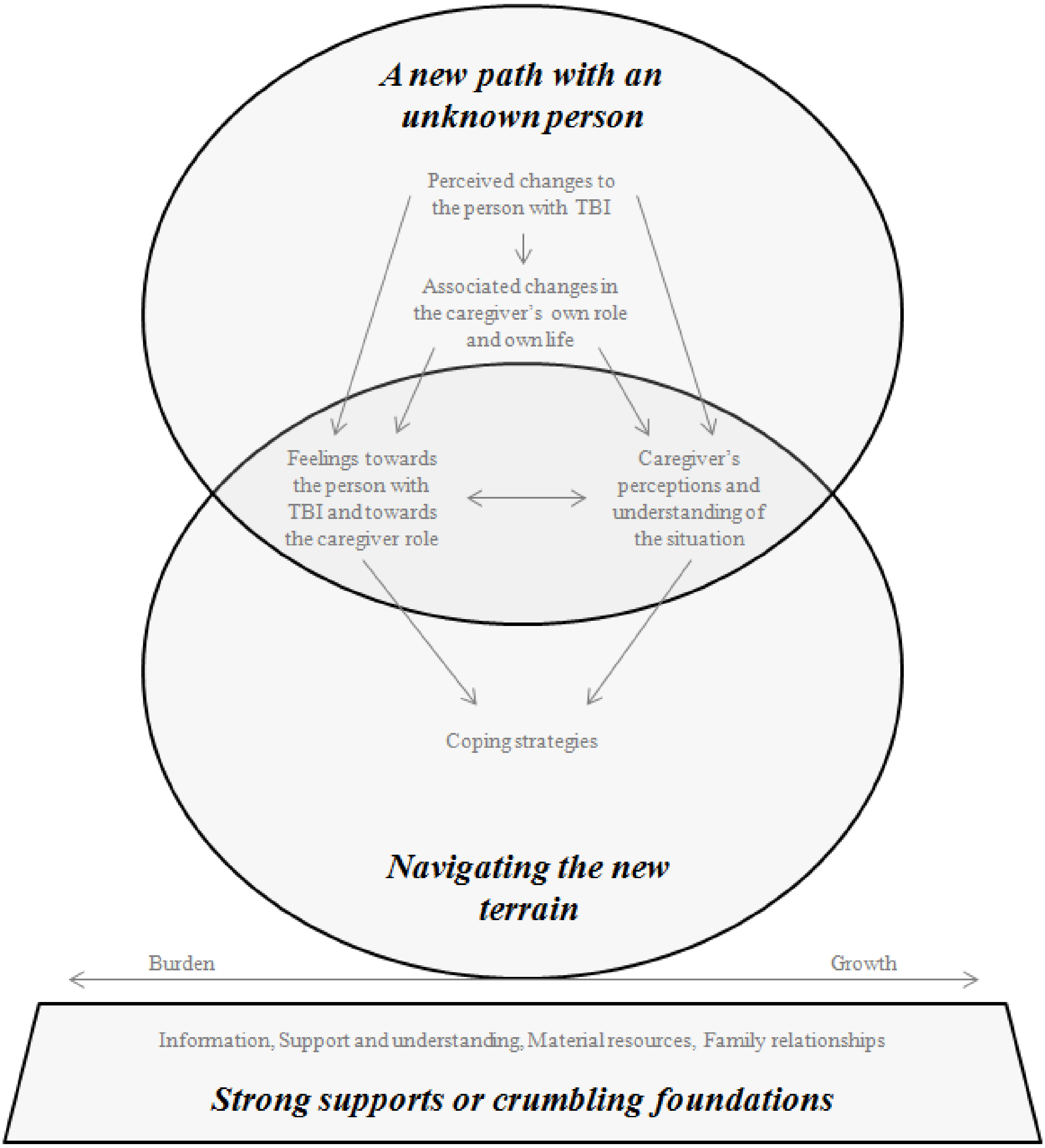


Figure 2. Model of care giving in TBI with metasummary findings and metasynthesis themes



Appendix 1-A

Search strategy

Table 1-A1. Search terms for PsychINFO

	TRAUMATIC BRAIN INJURY	**AND**	**CARERS**	**AND**	**QUALITATIVE**
KEY WORDS (Title and Abstract)	“Brain Injur*” “Head Injur*”		Carer* Caregiv* “Care giv*” Relative* Family Families Spouse* Sibling* Parent*		Qualitative Experienc* Interview* “Focus group* Narrative* Phenomenolog* Ethnograph* Thematic “Grounded theory”
	OR		**OR**		**OR**
THESAURUS TERMS	“Traumatic brain injury” “Brain damage” “Head injuries”		Caregivers “Family members” Couples Spouses Siblings Parents Significant others		“Qualitative research”
RESTRICTIONS					
Publication date: No restrictions Source type: Select academic journals					

Table 1-A2. Search terms for CINAHL

	TRAUMATIC BRAIN INJURY	**AND**	**CARERS**	**AND**	**QUALITATIVE**
KEY WORDS (Title and Abstract)	“Brain Injur*” “Head Injur*”		Carer* Caregiv* “Care giv*” Relative* Family Families Spouse* Sibling* Parent*		Qualitative Experienc* Interview* “Focus group* Narrative* Phenomenolog* Ethnograph* Thematic “Grounded theory”
	OR		**OR**		**OR**
CINAHL HEADINGS	“Brain Injuries” “Head Injuries”		Caregivers Family “Nuclear family” Siblings Spouses Parents		“Qualitative studies” “Ethnographic research” “Phenomenological research”
RESTRICTIONS					
Publication date: No restrictions Source type: Select academic journals Select NOT Medline					

Table 1-A3. Search terms for MEDLINE

	TRAUMATIC BRAIN INJURY	**AND**	**CARERS**	**AND**	**QUALITATIVE**
KEY WORDS (Title and Abstract)	“Brain Injur*” “Head Injur*”		Carer* Caregiv* “Care giv*” Relative* Family Families Spouse* Sibling* Parent*		Qualitative Experienc* Interview* “Focus group* Narrative* Phenomenolog* Ethnograph* Thematic “Grounded theory”
	OR		**OR**		**OR**
MEDICAL SUBJECT HEADINGS	“Brain injuries” “Brain haemorrhage, traumatic” “Brain injury, chronic”		Caregivers Family “Nuclear family” Parents Siblings Spouses		“Qualitative research” Hermeneutics “Personal narratives as topic” “Personal narratives”
RESTRICTIONS					
Publication date: No restrictions Source type: Select academic journals					

Table 1-A4. Search terms for PubMed

	TRAUMATIC BRAIN INJURY	**AND**	**CARERS**	**AND**	**QUALITATIVE**
KEY WORDS (Title and Abstract)	“Brain Injur*” “Head Injur*”		Carer* Caregiv* “Care giv*” Relative* Family Families Spouse* Sibling* Parent*		Qualitative Experienc* Interview* “Focus group* Narrative* Phenomenolog* Ethnograph* Thematic “Grounded theory”
	OR		**OR**		**OR**
MEDICAL SUBJECT HEADINGS	“Brain injuries” “Brain injuries, traumatic” “Brain injuries, diffuse” “Brain Hemorrhage, traumatic” “Brain injury, chronic”		Caregivers Family “Nuclear family” Parents Siblings Spouses		“Qualitative research” Hermeneutics “Personal narratives as topic” “Interviews as topic/method”
RESTRICTIONS					
Publication date: Jan 2016 - present Species: Humans					

Table 1-A5. Search terms for Web of Science

	TRAUMATIC BRAIN INJURY		**CARERS**		**QUALITATIVE**
KEY WORDS (Title and Abstract)	“Brain Injur*” “Head Injur*”	**AND**	Carer* Caregiv* “Care giv*” Relative* Family Families Spouse* Sibling* Parent*	**AND**	Qualitative Experienc* Interview* “Focus group* Narrative* Phenomenolog* Ethnograph* Thematic “Grounded theory”
RESTRICTIONS					
Publication date: No restrictions Select ‘articles’					

Appendix 1-B

Excluded Papers

Table 1-B1. Breakdown of excluded papers

Criteria	Title/Abstract	Full text
Total duplicate papers excluded	1764	0
Total papers not meeting inclusion criteria	2271	30
Research articles published in peer reviewed journal	2	0
Experiences of adult (18+ years) informal carers/family members	1948	4
Caring for adults (18+ years) with TBI	175	12
Community setting	23	1
Qualitative methods (grounded in participant quotes)	123	13
Total papers meeting exclusion criteria	124	20
Primary focus on development/evaluation of measures/services	88	0
Primary focus on outcomes following TBI or beliefs about TBI	13	0
Research involving individuals with disorders of consciousness	20	1
Research involving a mixed sample where findings related to caregivers are not presented separately	0	16
Articles needing translation	3	0
Research involving veterans with TBI	0	3
Additional papers excluded	0	3
Unable to obtain a full text	0	1
Unable to obtain sufficient demographic information	0	2

Appendix 1-C

Metasummary Effect Sizes

Table 1-C1. Abstracted findings and manifest frequency effect sizes

Abstracted finding	Papers	Frequency Effect Size
Perceived changes in the person with TBI		
1. Caregiver’s perceived increased physical or verbal aggression, anger and irritability in the person with TBI.	Bodley-Scott & Riley (2015); Kratz et al. (2017); Lefebvre et al. (2008); Tam et al. (2015); Wongvatunyu & Porter (2005)	33%
2. Caregiver’s perceived increased controlling behaviour on the part of the person with TBI.	Bodley-Scott & Riley (2015); Kratz et al. (2017)	13%
3. Spouses in particular perceived a lack of affection, empathy and concern from the person with TBI, experiencing them as more cold and indifferent than before the injury.	Bodley-Scott & Riley (2015); Chwalisz & Stark-Wroblewski (1996); Hammond et al. (2011); Jumisko et al. (2007); Kratz et al. (2017)	33%
4. Caregivers considered the person with TBI to be fundamentally changed as a person by their injury.	Bodley-Scott & Riley (2015); Hammond et al. (2011); Jumisko et al. (2007); Knox et al. (2015); Kratz et al. (2017); Wongvatunyu & Porter (2008)	40%
5. Caregivers recognised continuity in the injured person’s identity, despite the changes since the TBI.	Bodley-Scott & Riley (2015); Knox et al. (2015); Wongvatunyu & Porter (2008b)	20%
6. Caregivers perceived that the person with TBI lacked control of their own behaviour following the injury.	Bodley-Scott & Riley (2015)	7%
7. Caregivers observed personality and behaviour changes in the person with TBI which could be difficult to manage and hard to understand.	Bodley-Scott & Riley (2015); Hammond et al. (2011); Jumisko et al. (2007); Kratz et al. (2017); Lefebvre et al. (2008); Tam et al. (2015); Wongvatunyu & Porter (2005); Wongvatunyu & Porter (2008); Wongvatunyu & Porter (2008b)	54%

8. Caregivers perceived cognitive and intellectual losses for the person with TBI following the injury, including problems with memory, attention, planning, initiation and decision making.	Chwalisz & Stark-Wroblewski (1996); Degeneffe & Olney (2008); Knox et al. (2015); Lefebvre et al. (2008); Tam et al. (2015); Wongvatunyu & Porter (2005); Wongvatunyu & Porter (2008b)	43%
9. Caregiver's observed that the person with TBI had reduced ability to continue with their occupation and to complete activities of daily living independently.	Chwalisz & Stark-Wroblewski (1996); Degeneffe & Olney (2008); Hammond et al. (2011); Knox et al. (2015); Tam et al. (2015); Wongvatunyu & Porter (2005); Wongvatunyu & Porter (2008b)	43%
10. Caregivers observed difficulties in relationships for the person with TBI, due to their own social limitations, their vulnerability to being taken advantage of, and the withdrawal of their previous friends.	Chwalisz & Stark-Wroblewski (1996); Degeneffe & Olney (2008); Engström & Söderberg (2011); Jumisko et al. (2007); Kratz et al. (2017); Lefebvre et al. (2008); Tam et al. (2015); Wongvatunyu & Porter (2005)	53%
11. Caregivers observed physical changes and ongoing health problems as a result of, or in addition to, the person's TBI.	Chwalisz & Stark-Wroblewski (1996); Degeneffe & Olney (2008); Jumisko et al. (2007); Mbakile-Mahlanza et al. (2016); Wongvatunyu & Porter (2005); Wongvatunyu & Porter (2008); Wongvatunyu & Porter (2008b)	38%
12. Caregiver's perceived emotional, psychological and adjustment difficulties for the person with TBI, resulting in need for support and sometimes medication.	Chwalisz & Stark-Wroblewski (1996); Degeneffe & Olney (2008); Mbakile-Mahlanza et al. (2016); Tam et al. (2015); Wongvatunyu & Porter (2005); Wongvatunyu & Porter (2008b)	36%
13. Caregiver's perceived communication difficulties on the part of the person with TBI, following their injury.	Hammond et al. (2011); Knox et al. (2015); Lefebvre et al. (2008); Wongvatunyu & Porter (2005)	27%
14. Caregivers perceived the changes in the person with TBI as ongoing and lifelong.	Tam et al. (2015); Wongvatunyu & Porter (2005); Wongvatunyu & Porter (2008b)	14%
15. Caregivers perceived the situation for the person with TBI as improving.	Kratz et al. (2017); Tam et al. (2015); Wongvatunyu & Porter (2008b)	20%
16. Caregivers perceived the situation for the person with TBI as degenerating.	Lefebvre et al. (2008)	7%
17. Partners observed sexual difficulties or dysfunction in the person with TBI.	Chwalisz & Stark-Wroblewski (1996)	7%

18. Caregivers observed sensory difficulties for the person with TBI.	Wongvatunyu & Porter (2005)	7%
Negative impact of care giving		
19. Caregivers felt as though they were ‘walking on eggshells’ when around the injured person, trying to avoid triggering certain behaviours or waiting for the next incident to occur.	Bodley-Scott & Riley (2015); Kratz et al. (2017)	13%
20. Caregivers experienced feelings of guilt and blame.	Bodley-Scott & Riley (2015); Chwalisz & Stark-Wroblewski (1996); Kratz et al. (2017)	20%
21. Caregivers experienced feelings of sadness and loss, due to changes in the person with TBI and changes to their own lives.	Bodley-Scott & Riley (2015); Engström & Söderberg (2011); Hammond et al. (2011); Kratz et al. (2017); Tam et al. (2015)	33%
22. Caregivers faced financial difficulties and the pressures of managing this.	Chwalisz & Stark-Wroblewski (1996); Degeneffe & Olney (2008); Hammond et al. (2011); Knox et al. (2015); Kratz et al. (2017); Lefebvre et al. (2008); Mbakile-Mahlanza et al. (2016); Wongvatunyu & Porter (2008)	53%
23. Caregivers described their own deteriorating physical health and physical symptoms of stress.	Chwalisz & Stark-Wroblewski (1996); Jumisko et al. (2007); Kratz et al. (2017); Lefebvre et al. (2008); Mbakile-Mahlanza et al. (2016)	33%
24. Caregivers felt embarrassed by some of the changes in the person with TBI, including inappropriate behaviour.	Jumisko et al. (2007); Tam et al. (2015); Wongvatunyu & Porter (2008)	20%
25. Caregivers described significant demand on the time, energy, and emotional resources, of which there was a limited supply.	Engström & Söderberg (2011); Jumisko et al. (2007); Kratz et al. (2017); Lefebvre et al. (2008); Mbakile-Mahlanza et al. (2016); Wongvatunyu & Porter (2008)	40%
26. Caregivers lives had changed suddenly and been thrown into chaos; life was like being ‘on a rollercoaster’.	Chwalisz & Stark-Wroblewski (1996); Hammond et al. (2011); Jumisko et al. (2007); Kratz et al. (2017); Mbakile-Mahlanza et al. (2016)	33%
27. Caregivers had to put their own plans for the future aside, rearranging their lives and sometimes giving up their occupation.	Chwalisz & Stark-Wroblewski (1996); Knox et al. (2015); Kratz et al. (2017); Lefebvre et al. (2008); Mbakile-Mahlanza et al. (2016)	40%

28. Caregivers felt isolated and stuck, bearing sole responsibility for the person with TBI.	Chwalisz & Stark-Wroblewski (1996); Degeneffe & Olney (2008); Engström & Söderberg (2011); Jumisko et al. (2007); Kratz et al. (2017); Lefebvre et al. (2008); Mbakile-Mahlanza et al. (2016)	47%
29. Caregivers had worries, fears and concerns regarding: (1) the wellbeing of the person with TBI, including whether they might sustain further injury; (2) leaving the person with TBI, even for a short time; (3) future care giving responsibilities, whether becoming unable to provide care or taking on responsibility for care; (4) judgement from others; (5) the future in general.	Bodley-Scott & Riley (2015); Degeneffe & Olney (2008); Engström & Söderberg (2011); Kratz et al. (2017); Lefebvre et al. (2008); Mbakile-Mahlanza et al. (2016)	40%
30. Caregivers described feeling burdened, stressed, desperate, and overwhelmed.	Bodley-Scott & Riley (2015); Chwalisz & Stark-Wroblewski (1996); Jumisko et al. (2007); Knox et al. (2015); Kratz et al. (2017); Lefebvre et al. (2008); Mbakile-Mahlanza et al. (2016)	47%
31. Caregivers felt confused, upset and hurt by the changed behaviour of the person with TBI, sometimes traumatised by aggressive behaviours that had occurred soon after the injury.	Bodley-Scott et al. (2015); Hammond et al. (2011); Kratz et al. (2017); Tam et al. (2015)	27%
32. Caregivers experienced anger, frustration and resentment towards the person with TBI, towards others, and towards the general situation. In the long term some caregiver's expressed bitterness regarding the sacrifices they had made.	Bodley-Scott & Riley (2015); Chwalisz & Stark-Wroblewski (1996); Hammond et al. (2011); Jumisko et al. (2007); Knox et al. (2015)	40%
33. Caregivers experienced feelings of helplessness and loss of hope for future change.	Bodley-Scott & Riley (2015); Chwalisz & Stark-Wroblewski (1996); Kao & Stuifbergen (2004); Knox et al. (2015); Mbakile-Mahlanza et al. (2016); Tam et al. (2015)	40%
Positive aspects of care giving		
34. Caregivers felt hopeful about the future.	Chwalisz & Stark-Wroblewski (1996); Degeneffe & Olney (2008); Kratz et al. (2017); Wongvatunyu & Porter (2008b)	27%
35. Caregivers felt thankful that things were not worse and appreciative of the positive aspects of the situation; changes were not always experienced as negative.	Bodley-Scott & Riley (2015); Chwalisz & Stark-Wroblewski (1996); Engström & Söderberg (2011); Hammond et al. (2011); Jumisko et al. (2007); Kratz et al. (2017)	40%

36. Caregiver felt able to offer advice to others.	Chwalisz & Stark-Wroblewski (1996); Wongvatunyu & Porter (2005)	13%
37. Caregivers embraced the opportunity to care for their loved one, gaining a mission in life and feeling proud of themselves.	Degeneffe & Olney (2008); Engström & Söderberg (2011); Jumisko et al. (2007); Mbakile-Mahlanza et al. (2016); Wongvatunyu & Porter (2008b)	33%
38. Care giving was perceived as a learning experience through which caregivers developed strength and resilience.	Jumisko et al. (2007); Kratz et al. (2017); Lefebvre et al. (2008)	20%
Coping and adaptation		
39. Caregivers went along with the wishes of the person with TBI or ‘opted out’ of decision making at times, either to promote their independence or due to the behavioural consequences of not doing so.	Bodley-Scott & Riley (2015); Knox et al. (2015); Tam et al. (2015)	20%
40. Caregivers worked to learn about brain injury and to understand and make sense of the changes to the person with TBI, which could lessen the emotional impact.	Bodley-Scott & Riley (2015); Chwalisz & Stark-Wroblewski (1996); Jumisko et al. (2007); Knox et al. (2015); Lefebvre et al. (2008); Tam et al. (2015); Wongvatunyu & Porter (2005); Wongvatunyu & Porter (2008b)	50%
41. Caregivers shut themselves off emotionally or withdrew from spending time with others in order to cope.	Chwalisz & Stark-Wroblewski (1996); Jumisko et al. (2007)	13%
42. Caregivers sought support from family, friends, and others in the same situation.	Chwalisz & Stark-Wroblewski (1996); Jumisko et al. (2007); Tam et al. (2015); Wongvatunyu & Porter (2008)	27%
43. Caregivers put contingency plans in place to reduce worries regarding future care for the person with TBI.	Degeneffe & Olney (2008); Wongvatunyu & Porter (2005)	13%
44. Caregivers maintained hope that things would improve or return to the way they were before the injury, some hopes were scaled down as compared to pre-injury.	Hammond et al. (2011); Kao & Stuifbergen (2004); Mbakile-Mahlanza et al. (2016); Wongvatunyu & Porter (2008b)	27%
45. Caregivers took time out from the situation to be alone as a way of coping or, more rarely, coped by sharing space with the injured person.	Bodley-Scott & Riley (2015); Hammond et al. (2011); Kratz et al. (2017); Tam et al. (2015)	27%

46. Caregivers developed proactive strategies for managing communication, cognitive and behavioural difficulties on the part of the person with TBI.	Bodley-Scott et al. (2015); Hammond et al. (2011); Knox et al. (2015); Tam et al. (2015); Wongvatunyu & Porter (2005)	33%
47. Caregivers engaged in self-care and maintained some of their focus on their own lives.	Kratz et al. (2017); Wongvatunyu & Porter (2008b)	13%
48. Caregivers modified their approach to the person with TBI through trial and error.	Knox et al. (2015); Wongvatunyu & Porter (2005)	13%
49. Caregivers focused on protecting the person with TBI, taking control of decision making and speaking up on their behalf.	Jumisko et al. (2007); Knox et al. (2015); Kratz et al. (2017); Wongvatunyu & Porter (2005); Wongvatunyu & Porter (2008b)	29%
50. Caregivers reported that spirituality and religion helped them to cope.	Chwalisz & Stark-Wroblewski (1996); Jumisko et al. (2007); Mbakile-Mahlanza et al. (2016); Tam et al. (2015)	27%
51. Caregivers noted pre-existing personal characteristics of their own and of the person with TBI which helped them to cope.	Chwalisz & Stark-Wroblewski (1996); Wongvatunyu & Porter (2008b)	13%
52. Caregivers reconsidered their living situation, considering renovation of their home, moving to a more suitable home, or living apart from the person with TBI.	Kratz et al. (2017); Tam et al. (2015); Wongvatunyu & Porter (2005); Wongvatunyu & Porter (2008)	21%
53. Caregivers focused on rehabilitation and establishing a ‘normal life’ for the person with TBI, through encouraging them, supporting them, and helping them to learn, even after formal rehabilitation had ended.	Bodley-Scott & Riley (2015); Chwalisz & Stark-Wroblewski (1996); Engström & Söderberg (2011); Jumisko et al. (2007); Kao & Stuifbergen (2004); Knox et al. (2015); Lefebvre et al. (2008); Tam et al. (2015); Wongvatunyu & Porter (2005)	60%
54. Caregivers identified the need for respite and assistance with daily duties, with some hiring a paid carer.	Chwalisz & Stark-Wroblewski (1996); Kratz et al. (2017); Tam et al. (2015); Wongvatunyu & Porter (2005)	27%
Relationships and roles		
55. Fundamental nature of the relationship changed to that of caregiver and care recipient or parent and child. On occasion, care giving was seen as a natural extension of the spouse role.	Bodley-Scott & Riley (2015); Hammond et al. (2011); Jumisko et al. (2007); Kratz et al. (2017); Wongvatunyu & Porter (2008); Wongvatunyu & Porter (2008b)	36%

56. Family relationships became closer following the injury.	Bodley-Scott & Riley (2015); Engström & Söderberg (2011); Jumisko et al. (2007); Knox et al. (2015); Lefebvre et al. (2008); Mbakile-Mahlanza et al. (2016); Wongvatunyu & Porter (2008)	47%
57. Caregivers' feelings of love and trust were undermined by the changes in the person with TBI.	Bodley-Scott & Riley (2015); Chwalisz & Stark-Wroblewski (1996); Hammond et al. (2011)	20%
58. Caregivers expressed continuing feelings of love and positive regard for the person with TBI.	Bodley-Scott & Riley (2015); Engström & Söderberg (2011); Hammond et al. (2011); Knox et al. (2015); Mbakile-Mahlanza et al. (2016)	33%
59. Relationship dynamics between the caregiver and the person with TBI changed following the injury, becoming more distant or lacking the same level of intimacy. Caregiver partners sometimes continued the relationship for pragmatic reasons, such as providing a stable home for children.	Bodley-Scott & Riley (2015); Chwalisz & Stark-Wroblewski (1996); Hammond et al. (2011); Knox et al. (2015); Kratz et al. (2017)	33%
60. Caregivers reported marital conflict, with the difficulties arising from both parties.	Chwalisz & Stark-Wroblewski (1996); Knox et al. (2015)	13%
61. Caregivers took on a new role which absorbed responsibilities and tasks previously carried out by the person with TBI, for example providing emotional, financial, material and physical support. This caused difficulties for both the caregiver and the person with TBI.	Chwalisz & Stark-Wroblewski (1996); Degeneffe & Olney (2008); Engström & Söderberg (2011); Hammond et al. (2011); Jumisko et al. (2007); Knox et al. (2015); Lefebvre et al. (2008); Mbakile-Mahlanza et al. (2016); Tam et al. (2015)	60%
62. Caregivers experienced problems maintaining their relationship with other family members, due to decreased available time and energy, some reported making a special effort to spend time with other family members.	Chwalisz & Stark-Wroblewski (1996); Degeneffe & Olney (2008); Engström & Söderberg (2011); Jumisko et al. (2007); Lefebvre et al. (2008); Tam et al. (2015); Wongvatunyu & Porter (2005); Wongvatunyu & Porter (2008); Wongvatunyu & Porter (2008b)	54%
63. Caregivers made observations of relationships between other family members and the person with TBI, with problems arising between the injured person and their children as well as family members struggling to adjust.	Degeneffe & Olney (2008); Kratz et al. (2017); Tam et al. (2015); Wongvatunyu & Porter (2008)	27%
64. Caregivers found that others could not understand their situation and did not always provide the support they would have hoped for.	Chwalisz & Stark-Wroblewski (1996); Degeneffe & Olney (2008); Engström & Söderberg (2011); Jumisko et al. (2007); Mbakile-Mahlanza et al. (2016)	33%

Professionals and services		
65. Caregivers expressed the need for ongoing professional support for all members of the family which was suited to the stage of rehabilitation.	Chwalisz & Stark-Wroblewski (1996); Kratz et al. (2017); Tam et al. (2015); Wongvatunyu & Porter (2008b)	27%
66. Caregivers felt supported by professionals and appreciative of their assistance.	Chwalisz & Stark-Wroblewski (1996); Kratz et al. (2017); Tam et al. (2015); Wongvatunyu & Porter (2008b)	27%
67. Caregivers expressed the view that the professionals and paid carers they had contact with did not know enough about TBI.	Chwalisz & Stark-Wroblewski (1996); Degeneffe & Olney (2008); Jumisko et al. (2007); Tam et al. (2015); Wongvatunyu & Porter (2008b)	33%
68. Caregivers expressed a desire for more information and advice about brain injury and related services; some regretted that they did not get much needed information sooner.	Chwalisz & Stark-Wroblewski (1996); Jumisko et al. (2007); Knox et al. (2015); Lefebvre et al. (2008); Mbakile-Mahlanza et al. (2016); Wongvatunyu & Porter (2005); Wongvatunyu & Porter (2008b)	43%
69. Caregivers felt that available services were insufficient, particularly following acute care.	Degeneffe & Olney (2008); Engström & Söderberg (2011); Knox et al. (2015); Lefebvre et al. (2008); Tam et al. (2015); Wongvatunyu & Porter (2005); Wongvatunyu & Porter (2008b)	43%
70. Caregivers experienced tensions and frustration within their relationship with specific healthcare professionals, feeling that their own views were not heard and they were not kept fully informed.	Chwalisz & Stark-Wroblewski (1996); Degeneffe & Olney (2008); Jumisko et al. (2007); Wongvatunyu & Porter (2008b)	27%
71. Caregivers thought that the quality of services depended on where you lived and whether you were able to pay for private services.	Degeneffe & Olney (2008); Engström & Söderberg (2011)	13%
72. Caregivers viewed residential care negatively, as they did not believe services were appropriately resourced and managed in order to support their injured relative’s independence.	Degeneffe & Olney (2008); Wongvatunyu & Porter (2005)	13%

Table 1-C2. Papers and manifest intensity effect sizes

Paper	Intensity Effect Size
Bodley-Scott & Riley (2015)	36%
Chwalisz & Stark-Wroblewski (1996)	51%
Degeneffe & Olney (2008)	29%
Engström & Söderberg (2011)	21%
Hammond et al. (2011)	26%
Jumisko et al.(2007)	40%
Kao & Stuifbergen (2004)	6%
Knox et al. (2015)	32%
Kratz et al. (2017)	46%
Lefebvre et al. (2008)	29%
Mbakile-Mahlanza et al. (2016)	28%
Tam et al. (2015)	39%
Wongvatunyu & Porter (2005)	32%
Wongvatunyu & Porter (2008)	17%
Wongvatunyu & Porter(2008b)	33%

Appendix 1-D

Journal Submission Guidelines for Rehabilitation Psychology

Prior to submission, please carefully read and follow the submission guidelines detailed below. Manuscripts that do not conform to the submission guidelines may be returned without review.

Submission

Rehabilitation Psychology® is now using a software system to screen submitted content for similarity with other published content. The system compares each submitted manuscript against a database of 25+ million scholarly publications, as well as content appearing on the open web.

This allows APA to check submissions for potential overlap with material previously published in scholarly journals (e.g., lifted or republished material). A similarity report will be generated by the system and provided to the *Rehabilitation Psychology* editorial office for review immediately upon submission.

All new and revised manuscripts are to be submitted electronically (Word Documents are preferred) through the Manuscript Submission Portal.

To prevent institutional spam filters from preventing transfer of files from APA and Journals Back Office

- Add apa.org to your list of "safe addresses" and consider asking your IT department to add it to their "white list"
- Contact Charles Retzlaff if you do not receive confirmation of your submission within three business days

When necessary, paper correspondence and express mail may be directed to:

Dawn M. Ehde, PhD, Editor
Rehabilitation Psychology
University of Washington School of Medicine
Department of Rehabilitation Medicine, Box 359612
Harborview Medical Center
325 9th Avenue
Seattle, WA 98104-2499
Email: Editorial Office

Suitable Submissions

Rehabilitation psychology deals with the interplay of biological, psychological, social, environmental, and political factors that affect the functioning of persons with chronic health conditions or disability. Given the breadth of rehabilitation psychology, the journal's scope is broadly defined.

Suitable submissions include:

- **Empirical Articles**
  This format reports original empirical research which can include experimental investigations, survey research, evaluations of interventions, and outcome studies research.
- **Brief Reports**
  This format may be appropriate for empirically sound studies that are limited in scope, contain novel or provocative findings that need further replication, or represent replications and extensions of prior published work. Brief Reports must

use a 12-point Times New Roman type and 1-in. (2.54-cm) margins, and not exceed 265 lines of text plus references. These limits do not include the title page, abstract, author note, footnotes, tables, or figures.

- **Review Articles**
  This format includes reviews of various types and formats. Reviews can include state-of-the art review of empirical research (meta-analysis), reviews of professional, theoretical or public policy issues, or reviews designed to help practitioners solve common clinical problems (clinical management reviews).
- **Commentaries**
  This format supports a submitted or previously published manuscript including explanation, critique or illustration of rehabilitation related issues or topics.
- **Case studies**
  This format includes written analyses of one or more particular cases or case histories with a view to making generalizations in rehabilitation and that are of sufficient import to warrant attention.
  Submissions are welcomed from authors in psychology and other health related disciplines.

Cover Letter

The cover letter accompanying the manuscript submission must include all authors' names and affiliations, addresses and phone numbers, as well as electronic mail addresses and fax numbers for possible use by the editorial office and later by the production office.

The cover letter should identify the type of submission category and include

- a statement of compliance with APA ethical standards in the conduct of the work reported in the manuscript
- a statement that the manuscript or data have not been previously published and that they are not presently under consideration for publication elsewhere
- a statement that all listed authors have contributed significantly to the work submitted for consideration
- a statement that the paper has been seen and approved by all authors

When the manuscript contains data or observations from a larger study, the cover letter should clarify the relationship between this submission and other papers from the study, specifically addressing potential overlap. Authors must be prepared to provide copies of related manuscripts or papers as part of the editorial review process.

Authors may suggest qualified reviewers of the manuscript, but these are considered advisory only.

Title

Should be accurate, descriptive, and no longer than 12 words. If the report is a clinical trial or a brief report this should be included in the title.

Abstract and Keywords

All manuscripts must include a structured abstract containing a maximum of 250 words typed on a separate page (page 2 of the manuscript). Abstracts must contain a brief statement about each of the following:

- Purpose/Objective
- Research Method/Design - including the number and type of participants
- Results
- Conclusions/Implications

After the abstract, please supply up to five keywords.

Impact and Implications Statement

At the start of each paper the authors should provide 2-3 bullet points, with the header "Impact", that states what the current paper adds to the literature and one to two practice or policy implications the findings. This is not a statement of the conclusions, rather a thoughtful series of statements highlighting the novel contribution of the work and translation of the findings for practice or policy. This section should be no more than 200 words.

Data Source

It is important that readers have an accurate understanding of the data source the study is based on. Please include details in the Methods section as to the source of the data for this study.

If the study is based on original data collected for the purpose of testing the hypotheses in this manuscript, please make a statement to that effect. If the paper is based on secondary data analyses of data collected for another purpose please indicate that in the Methods.

If the data set used in this manuscript was also used in previous publications, please include these citations when describing the Methods in this submission.

Human Participants

The research section should include a statement indicating the Institutional Review Board that provided oversight for the research.

Style of Manuscripts

The journal considers theoretical, empirical, and commentary papers relevant to rehabilitation psychology. Brief reports are considered.

Additional Information for Specific Publication Categories

Randomized Clinical Trials

Rehabilitation Psychology **requires** the use of the CONSORT (Consolidated Standards of Reporting Trials) reporting standards (i.e., a checklist and flow diagram) for randomized clinical trials. The checklist may be placed in an Appendix of the manuscript for review purposes.

Visit the CONSORT Statement Web site for more details and resources.

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You may also read "Ethical Principles," December 1992, *American Psychologist*, Vol. 47, pp. 1597–1611.

Section Two: Research Paper

Work capability assessments: The experiences of individuals with traumatic brain injury

Word count: 8259 (excluding tables, figures, references and appendices)

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Abstract[1]

BACKGROUND: Traumatic brain injury (TBI) is a leading cause of disability and many working-age adults claim state benefits following their injury. The Work Capability Assessment (WCA) was introduced in the UK to assess functional ability to work, thereby deciding upon benefits received. The WCA has been widely criticised and may not be suited to the heterogeneity of impairment following TBI.

OBJECTIVE: This qualitative study aimed to explore how people with TBI experience the WCA.

METHODS: Nine adults with TBI took part in narrative interviews and the resulting data was analysed using critical narrative analysis.

RESULTS: Four key messages were identified: (1) Work with me to really understand my struggles; (2) Reduce the barriers that I face; (3) Acknowledge that I am not a ‘scrounger’; and (4) Use your power to help me, not to punish or demean me.

CONCLUSIONS: People with TBI experienced the WCA as inaccessible, demeaning, and neglecting the complexity of their situation. Wider context should be considered when assessing disability following TBI and issues with accessibility addressed. Participants wanted assessors to have knowledge of TBI and to use their positions of relative power to provide support. Clinical implications are also discussed.

Keywords: traumatic brain injury, disability, rehabilitation, social policy, qualitative

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[1] Section two is written in accordance with guidelines for the Journal of Vocational Rehabilitation (Appendix 2-D). Where the paper deviates from these guidelines, it is in favour of instructions for Lancaster University Doctorate in Clinical Psychology Theses.

1. Introduction

Traumatic brain injury (TBI) “results from external forces” and the global incidence is rising (Maas, Stocchetti, & Bullock, 2008, p.729). The prevalence of TBI with loss of consciousness in the general adult population has been estimated at 12% and is 2.2 times higher for males than females (Frost, Farrer, Primosch, & Hedges, 2012). Within the United Kingdom (UK), the incidence of head injuries was 254 per 100,000 in 2013-14, rising by 6% since 2005-6 (Headway, 2017). TBI is the leading cause of disability among young people in high-income countries, although the exact number of individuals experiencing deficits following head injury is not known (Maas et al., 2008). Consequently, there is likely to be a relatively large proportion of working-age individuals with TBI who are unable to work.

Return-to-Work (RTW) following TBI is associated with a range of demographic and injury-related data, including: age; gender; educational level; geographic region; pre-injury occupation; level of depression and anxiety; severity of TBI; and extra cranial injuries. (Cancelliere et al., 2014; Saltychev, Eskola, Tenovuo, & Laimi, 2013). However, TBI is a heterogeneous condition; it is important to assess how the injury affects the individual, as well as characteristics of the work environment (Donker-Cools, Daams, Wind, & Frings-Dresen, 2016). RTW is a “process of rediscovery” which is “influenced by multiple factors”, rather than a single event (Stergiou-Kita, Rappolt, & Dawson, 2012, p.185)

TBI is a “hidden disability”, as the extent of physical, cognitive and emotional difficulties tends to remain unseen by others (Simpson, Simons, & McFadyen, 2002, p.1). Cognitive difficulties are common (Schretlen & Shapiro, 2003), and standardised neuropsychological measures may provide a superior model of functional outcome (Atchison et al., 2004; Sherer et al., 2002; Spitz, Ponsford, Rudzki, & Maller, 2012) when compared to demographic and injury-related variables (e.g. Ownsworth & McKenna, 2004). Furthermore, functional outcome may be most closely associated with executive functioning, highlighting the importance of these specific thinking skills in RTW (Boake et al., 2001; Green et al., 2008; Spitz et al., 2012). However, this may be due to greater challenge in integrating compensatory strategies for deficits in executive skills (Spitz et al., 2012).

Psychosocial and emotional sequelae also make rehabilitation and reintegration difficult (Morton & Wehman, 1995). Individuals with TBI experience loss of identity which impacts upon experience of RTW; the 'meaning' of work to the individual may change (Stergiou-Kita et al., 2012). Stigma and discrimination may cause difficulties when interacting with others (Levack, Kayes, & Fadyl, 2010). Furthermore, anxiety (Moore, Terryberry-Spohr, & Hope, 2006), depression (Bombardier et al., 2010), and post-traumatic stress disorder (McMillan, Williams, & Bryant, 2003) often interact with other sequelae, constituting a further barrier to employment (McCrimmon & Oddy, 2006).

Individuals with TBI and their families experience a complex process of adjustment (Verhaeghe, Defloor, & Grypdonck, 2005). There is a tendency to focus on returning to previous levels of functioning as a way of coping (Maestas et al., 2014; Shotton, Simpson, & Smith, 2007). People with TBI may therefore unintentionally minimise or underestimate their difficulties in a way that is not inevitably associated with cognitive deficits in self-awareness. Premature RTW may confront individuals with the extent of their disability before they are emotionally prepared to cope (Hooson, Coetzer, Stew, & Moore, 2013; Stergiou-Kita et al., 2012). Consequently there is a risk of destabilisation, whether this is a disruption to early protective coping mechanisms or long-term processes of adjustment and acceptance (Jumisko, Lexell, & Söderberg, 2009; Levack et al., 2010).

Overall, while it is important to acknowledge that RTW post-injury is likely to have a positive impact on those who are able (McCrimmon & Oddy, 2006), this process requires comprehensive consideration. Unpaid voluntary work (Hooson et al., 2013; Ouellet, Morin, & Lavoie, 2009) and/or specialist vocational rehabilitation programs (Fadyl & Macpherson, 2009) may be more suitable for some individuals.

Western governments have focused on paid work as a way of promoting social inclusion and rehabilitation for people with a disability (Hall & Wilton, 2011). However, those with disabilities remain less likely to be in employment (MacInnes, Tinson, Gaffney, Horgan, & Baumberg, 2014). In many western countries, there is an acknowledgement that state funded financial support should be available to those unable to access paid employment because of disability. Consequently, there is need for an assessment to establish a person's capacity for work, thereby also deciding whether they should receive financial benefit.

The Work Capability Assessment (WCA) is a checklist introduced by the UK government in 2008 to assess functional ability to hold employment (Litchfield, 2014), upon which receipt of Employment and Support Allowance (ESA) is contingent. Individuals are assigned to one of the following categories: a support group (SG); a work related activity group (WRAG); or 'fit for work' and ineligible for ESA (Department for Work and Pensions: DWP, 2010). The introduction of the WRAG involves the extension of the principle of 'conditionality' within the welfare state to disabled people (Patrick, 2011), as 'work-related activity' is required in order to receive allocated benefits.

The WCA has been widely criticised by those assessed and organisations supporting them (e.g. Burgess et al., 2014; Mind, 2014; Spartacus Network, 2012). Independent reviews have repeatedly noted flaws in the design and the delivery of the assessment (e.g. Litchfield, 2014). Healthcare professionals have expressed concerns about the impact of the WCA and resulting decisions on the mental health of their patients (Blane & Watt, 2012; British Psychological Society: BPS, 2015; McCartney, 2012; Royal College of Nursing: RCN, 2013).

Barr et al. (2016) found the WCA programme was “independently associated with an increase in suicides, self-reported mental health problems and antidepressant prescribing” (p.1). Furthermore, a report by the United Nations Convention on the Rights of Persons with Disabilities (2016) found evidence of “significant hardship, including financial, material and psychological, experienced by persons with disabilities undergoing [work capability] assessments” (p.18). Concerns were outlined regarding the focus on functional skills and abilities at the expense of exploration of personal circumstances, needs and barriers.

The way in which TBI translates into functional disability is complex and the WCA may not be sensitive enough to take these difficulties into account, despite many changes to the process since its inception (Headway, 2015). A brain injury may also result in problems taking part in the process of WCA itself. Moreover, the impact of TBI may be under-represented as a result of reduced self-awareness associated with executive dysfunction or coping strategies involving denial. Therefore, a full and accurate portrayal of functioning may not be communicated. Many people with brain injury have appealed decisions after being refused ESA or placed in an inappropriate group (Headway, 2014).

1.1. Study rationale

Studies investigating rates of RTW among people with TBI have published statistics ranging from 12.5 - 70%; however, these studies often do not take into account long-term maintenance or whether the work is at pre-morbid level (Shames, Treger, Ring, & Giaquinto, 2007). Healthcare professionals within this field are likely to have a majority of clients claiming benefits; this raises questions for those professionals. Firstly, how can clinicians mitigate the emotional and psychological impact of disability assessments? Secondly, what can they advise benefit system administrators in terms of: minimising the emotional demands placed upon those assessed; providing appropriate information and support; and meaningfully assessing the functional impact of TBI?

There is need for an in-depth study exploring experiences of people with TBI who undertake the WCA. Such a study would not only help healthcare professionals understand how to provide support to this client group, but inform the ongoing development of the WCA. Optimal rehabilitation and support requires that the welfare system is not contributing to distress.

1.2. Aim

This study aimed to explore experiences of adults with TBI regarding the WCA. The following research questions were specified: (1) How do adults with TBI experience the WCA? (2) What are their views regarding how disability might best be assessed in the context of TBI?

2. Method

2.1. Design

This qualitative study drew on narrative interviews conducted individually and analysed using critical narrative analysis (Langdridge, 2007). This required researchers to combine phenomenological philosophy with a social constructionist stance. Although the focus was on individual lived experience, it was acknowledged that the act of telling one’s story does not occur in isolation and that the researcher is invariably part of the co-construction of knowledge. Stories were seen as reconstructions of participants’ experiences, situated within a wider context.

2.2. Participants

Participants were adults with a TBI. Demographic information included: age; gender; ethnicity; education; and employment status prior to TBI. The severity and approximate date of the TBI, where participants could provide the information, was also recorded. Participants were asked whether they received any support, either from family or formal care packages, in order to obtain an indication of their level of disability.

2.2.1. Recruitment

The study was advertised via brain injury charities and professional networks, who were provided with information sheets and adverts (see section four). Organisations were asked to advertise through available channels including: web pages; online forums; social media; and notice boards. Posters and information sheets contained contact information, allowing participants to opt in by email or telephone if they were interested in taking part.

2.2.2. Inclusion and exclusion criteria

Participants had received a diagnosis of TBI; were working-age adults, aged 16-65 years; had taken part in a WCA following a TBI; and had contact with the WCA process within the last 36 months. Exclusion criteria applied to: individuals with degenerative brain conditions; individuals whose brain injury, or first of multiple brain injuries, occurred during childhood (under the age of 16 years); and non-English speaking individuals. Individuals with a language barrier in addition to TBI may be at a double disadvantage within the WCA. This is considered an important area that warrants specific future research.

2.2.3. Sample

The study aimed to recruit a convenience sample of 8-15 individuals responding to advertising, in order to balance time constraints with gaining adequate data. The decision to cease recruiting was based on the richness of the data collected and the pragmatics of time-limited research. Six male and three female participants, ranging in age from 23-62 years, took part. All participants were white British or European ethnicity. Demographics are summarised in Table 1.

[INSERT TABLE 1 HERE]

2.2.4. Consent

Participants initiated contact with the researcher and were given access to an information sheet at least 24 hours prior to interview. An ‘easy read’ information sheet accommodated any difficulties with reading and comprehension. The information sheet stated that participants were free to withdraw from the study at any time, without any negative consequences. This was also communicated verbally prior to the interview. Capacity was assumed at the outset (Mental Capacity Act, 2005) and efforts were made to present material in a way that participants could understand.

2.3. Data Collection

Participation in qualitative research interviews may present a challenge for individuals with TBI, due to difficulties with communication, attention, memory, abstract thinking, and fatigue (Carlsson, Paterson, Scott-Findlay, Ehnfors, & Ehrenberg, 2007; Paterson & Scott-Findlay, 2002). The researcher enquired in advance about potential barriers so that adjustments could be put in place to meet participants’ needs. Interviews took place in participants’ homes or at a suitable venue. Time of day was chosen in consideration of individual patterns of fatigue and breaks were agreed as needed. A copy of the ESA-50 form, which initiates the WCA process, was utilised as a concrete prompt to support orientation to the topic at hand.

The interviews were unstructured, as narrative methods intend for individuals to have space to share their own story. The researcher held in mind the research questions while maintaining a neutral position so that individuals could develop their account. Questions were asked to prompt elaboration and clarification as needed (Murray, 2015). In order to support retrieval of information, follow-up questions were constructed so as to provide cues for participants, for example, “Who was in the room?” or “What happened after ___?”. The researcher also attempted to note occasions where participants expressed an intention to return to a particular topic, so that a prompt could be provided if needed. Where the focus of conversation appeared to have shifted to tangential issues, this was raised by the researcher so that participants could decide whether to return to the topic of the WCA. Participants had the opportunity to receive support from a family member or carer. All participants chose to take part independently, with one individual asking for brief clarification from their spouse during the interview. Interviews were audio recorded and transcribed.

2.4. Analysis

Participant accounts were analysed using critical narrative analysis (Langdridge, 2007). This approach provides a structure for analysing individual lived experience, while considering broader context and the position from which narratives are being created. The method is consistent with the epistemological stance, with a focus on lived experience and an acknowledgement that the researcher is part of the co-construction of meaning. Furthermore, the use of social theory to interrogate both one’s own position and the interview data was considered appropriate to the inherently political topic. Finally, the method includes an exploration of identity work within participant accounts, which creates potential for experiences of changed identity following TBI to be considered. It was therefore hoped that interpretations would capture experiences of the WCA, as situated within ongoing psychosocial adjustment and rehabilitation.

The critical narrative analysis framework (Langdridge, 2007) comprised of six stages: (1) critique of the illusions of the subject (i.e. reflecting upon the position from which one views the data); (2) identifying narratives, narrative tone, and rhetorical function; (3) identities and identity work; (4) thematic priorities and relationships; (5) destabilising the narrative; and (6) critical synthesis.

During stage one, the researcher engaged in reading of critical theory relevant to disability and social responsibility, while reflecting upon their own viewpoint (Appendix 2-A). Stages 2-4 involved repeated reading of interview texts with a focus on each particular aspect of the narrative in turn (Appendix 2-B). Relationships were drawn between the texts in a dynamic process to reach a final set of themes (Appendix 2-C). Stages 5-6 involved revisiting theory and connecting this to the findings, before drawing the process together in a written synthesis.

2.5. Validity

Validity indicators specifically designed for qualitative research are important and Yardley’s (2015) criteria were considered from the outset. Sensitivity to context was achieved through familiarity with available literature across disciplines. Open ended interview questions were used so as not to constrain participants’ responses. An auditable trail of analysis was maintained and connections between participant quotes and researcher interpretations were demonstrated within the write-up. Reflexivity was ensured through the use of a reflective log and the methodology (Langdridge, 2007) involved explicit consideration of one’s own viewpoint. Given the researcher’s concurrent clinical work with people with TBI, personal anticipations were reflected upon as they developed (Elliott, Fischer, & Rennie, 1999).

2.6. Ethics

The Faculty of Health and Medicine Research Ethics Committee at Lancaster University approved this study (section four: ethics section).

3. Results

A critical synthesis is presented below in the structure of four key themes, organised across levels of context. Figure 1 provides a visual display of the findings with the aim of locating participants' experiences and privileging their voices. Presentation of themes is followed by a summary of work drawing on the social model of disability to 'destabilise the narrative', or provide an alternative perspective on the findings.

[INSERT FIGURE 1 HERE]

3.1. Work with me to really understand my struggles

> *"There's a lot to get your head round yourself... let alone explaining it to other people" (John)*

TBI was a significant, life-changing incident which resulted in transformed identity and increased challenges. The one-off event of the WCA was situated amidst an ongoing process of rehabilitation and learning about limitations. Assessors were seen as insufficiently qualified to assess functional ability within the complexity of the situation, as well as lacking the inclination to form a connection and truly listen to participants' experiences.

Throughout their narratives, participants focused on interactions with others and how these others understood or misunderstood their brain injury. For some participants, you needed to be an expert in order to understand the effects of TBI; this might be an expert by experience or a professional specialising in brain injury: "I think... unless you know about brain injury... or... you've got a specialism in it... it's so hard to know... I mean before my brain injury I didn’t know... anything really about the- the brain” (Mark). Generally, others were presented as having no interest or understanding regarding TBI, with assessors falling into this category: “a few things that he said... we knew then that he had no experience of head injury” (Peter). Nonetheless, exceptions to this rule appeared, as participants described unique individuals in their lives who somehow understood: “She knew that I was different... and she knew that there must be a- something fairly big going on that had caused... the difference” (Claire).

The stability of constructed identity differed depending on the stage of rehabilitation. John was living an ongoing process of gaining insight into the effects of his TBI and making sense of what that meant in terms of identity. He variably presented himself as someone with a head injury who needed support versus someone who was able and wanting to prove himself: “One of the sad things is I don’t recognise it... if I feel ok on the day”. Amidst anger at being misunderstood, he described how he would push himself to complete tasks, and that it might be impossible for an assessor to realise the extent of his struggles: “I’ve got to hold my hand up and say it’s probably me own fault for saying ‘Oh yeh... I can do that’”. Alternatively, there were healthcare professionals who supported him to see beyond his “good day” and consider the “cost” of pushing himself: “She [neuropsychologist] says... ‘If you do something on one day... you’ll er hammer away at it and do it... but you’ll pay for it for the next three days... you’re tired... you’re grumpy... you’re forgetful’”. John reflected on the fact that if assessors asked more exploratory questions, they too might gain an understanding: “‘What happens *after* doing that?’... that’s the important key question”. However, his relationships with known healthcare professionals were ones of trust and assessors would need to work with him to establish a real connection.

In contrast, Peter was 20 years post-injury; the lasting effects of TBI had become a fact of life and a more stable part of his identity. He was more likely to overlook his life previously than to dismiss his brain injury: “I’ve never paid a bill in my life... well since my accident... I used to do all the bills”. For Peter, this meant there was no means of justifying the assessor’s view of his TBI, other than them lacking in knowledge and inclination to understand: “Assumptions again... there were a lot of assumptions”. Having worked hard to incorporate compensatory strategies, he was frustrated when he was seen as being able to complete tasks with ease. Like John, he felt that assessors could resolve this by asking the right kind of questions: “I don’t even think that was asked... ‘*how* do you remember?’”.

Overall, participants saw assessors as neglecting the complexity of their situation, seeing TBI as an event rather than an ongoing process of rehabilitation with fluctuating presentation. The hidden effort needed to complete tasks, the sustainability of effort, and the costs of effort all needed to be considered. The role of insight was highlighted, in its potential to contribute to misunderstanding, as well as the ongoing importance of hope and maintaining a positive outlook. Assessors needed to have empathy to understand the difficulty in acknowledging and explaining one’s difficulties: “Thinking about your worst day... if you are feeling good and stuff... that can put you down” (Mark). Superficial cognitive assessments were also criticised, particularly when in-depth assessments had been carried out by known healthcare professionals and made available: “Asking me just typical questions erm... he asked me to... repeat what he was saying and all that” (Dominik). Participants wanted assessors to abandon a generic process in favour of real dialogue: “You stick it in the machine... is it a yes or is it a no... type thing”; “Start a conversation maybe” (Michelle).

Where narratives had an overall or partially optimistic tone, it tended to be because they culminated with the person with TBI overcoming adversity and finally feeling heard: “I broke down crying... it was- it was a relief to hear... someone at last... see what they had in front of them” (Carl). The key message here was that no amount of explanation or written evidence would result in the right outcome, unless the receiver was prepared to genuinely open themselves up to it.

3.2. Reduce the barriers that I face

“When I was reading it was causing headaches... I couldn’t handle [a] fifty page application form” (Dominik)

There was seen to be a lack of consideration of barriers when setting government agendas. Participants perceived the benefits system as inaccessible and this was variably attributed to a lack of reasonable adjustments in the ESA process and to their impairment following TBI. Furthermore, the benefits system was not seen to take into account the relative inaccessibility of the job market for people with TBI.

Regardless of whether participants identified as disabled, they did identify as struggling with the ESA process and needing support. Michelle’s story conveyed a complete lack of ability to deal with the benefits system in the early stages following her TBI, from the point of view of her present, more recovered self. She described herself as lucky to have friends who pushed forward with her ESA application: “Cause I wouldn’t have done it... when I came out of hospital I was just like... it wasn’t in my headset to even think ‘fight for this fight for that’ (Michelle).

The face-to-face WCA was described as a distinct event within all texts. The scene was set either with an acknowledgement that a home assessment had been granted or a description of the assessment centre environment. Buildings were described as being far away and difficult to navigate to, with a lack of disabled access. Uncomfortable chairs were a common feature: “pokey little ... building... up the top of this tower block... and... these very uncomfortable blue chairs” (Peter).

Participants listed multiple effects of their TBI, which limited their own ability to take part in the process. Communication difficulties acted as a barrier and could be intensified during the assessment: “I’m talking now but when I’m under like pressure and stuff... I lose me words” (Mark). Participants also described memory and attention problems, difficulties completing tasks on time, and problems with seeing the ‘big picture’ or the potential consequences of the assessment outcome.

Focus was also placed on the style and structure of assessors’ questioning; this was significant to participants due to the lack of adaptation to their needs and was perceived as an inherent part of the system as a whole. Some described a lack of structure which obscured the point of the questions for the person with TBI. Support was not given to stay on track: “... they don’t ever ask... ‘Would you like to come back to the conversation about what we were here for?’... They just let you wander” (Carl). Conversely, the structure could be rigid; time pressures on retrieval of information meant that details were only recalled on later reflection, when the assessment was over and the opportunity had passed.

Some participants maintained the goal of returning to work. Dan’s narrative was accordingly centred on the lack of reasonable adjustments made later in the process. Although he was granted a home assessment and initially felt optimistic about being supported back to work through WRAG, he found his needs were not met: “... even a company that’s supposed to be tasked with achieving that objective of getting people [back to work]... won’t make reasonable adjustments” (Dan). He felt there were a lack of flexible employment opportunities for someone with TBI in a competitive job market. Additionally, the ESA system did not fit with his goal of part time work, resulting in a sense of an unfinished narrative where he could see no path forward: “... when it gets to that point... that- I can do a little bit... it’s not gonna be possible that... I can just do one or two days a week because... it won’t leave me enough money to live on” (Dan).

3.3. Acknowledge that I am not a ‘scrounger’

“I know there are people that don’t want to work... but that doesn’t mean that everybody’s like that” (Claire)

Participants’ stories were situated in the context of wider societal narratives regarding claimants; people claiming any kind of benefits could be seen as ‘scroungers’. Within their stories, participants were working to place themselves outside of this rhetoric, while perceiving the government Department of Work and Pensions (DWP) as complicit with it.

Specific societal narratives in regards to disability, as opposed to unemployment, benefits revolved around the idea of not being ‘genuinely disabled’ and were seen as perpetuated by media. Some participants subscribed to this view and supported it with examples of undeserving ‘others’. This was accompanied by concurrent rhetorical features in their own narratives to justify their TBI as genuine and place themselves outside of this category: “... they did a documentary on... benefit cheats or something... and they had people followed... I said to [my husband] ‘they’re more than welcome to follow me... because then perhaps they would actually get a picture” (Claire). Identities were generally constructed as honest, diligent, grateful, and having paid one’s own way prior to TBI: “... my background isn’t from... claiming benefits... my background is from... working for me money” (Mark). Participants talked about the financial reality of living on benefits to illustrate that they wouldn’t choose it over being able to work: “There’s no luxuries... they’ve gone” (Carl).

Despite locating themselves outside of the ‘scrounger’ category, the hidden nature of TBI resulted in participants feeling judged by the general public: “they’ll think I’m drunk cause I start to stagger about” (John). This feeling of judgement was present within the ESA process and some participants perceived the stance of the DWP to be intertwined with societal narratives. Sometimes this was seen as a result of undeserving claimants taking up resources and forcing the DWP to use a more stringent disability assessment: "I can imagine they get a lot of time wasters and people trying to... play the game" (Mark). Consequently, the DWP were perceived as having an agenda to reduce spending on benefits while the 'scrounger' narrative was perpetuated within the ESA system.

Participants felt treated with suspicion by a system that was aiming to treat them as fit for work. With an incredulous tone, Jayne described how people with strikingly visible disabilities were having their right to benefits assessed: "I know a fella whose got... both his legs amputated... and his arm is amputated... he still has to go through all that system... he's got no legs... he's got one arm...what's he supposed to do?!". The lead up to the event of the WCA was characterised by anxiety and apprehension, as the responsibility was on the person with TBI to prove the hidden aspects of their disability.

The WCA itself was viewed as attempting to uncover a reason that claimants are fit for work: "to make person lie on purpose... there is many tricks" (Dominik). Similarly, Jayne approached the assessment feeling as though "all it needs is one word wrong" and assessors were thought to look for evidence of ability outside of the structured assessment: "they have got their own agenda because... you are assessed from the moment you arrive at the medical centre" (Peter). Reports from known healthcare professionals, including specialists in brain injury, were disregarded in favour of a more limited assessment; participants struggled to make sense of this happening for any other reason than the system being intentionally set up that way.

John felt as though his report was written about a "different person" and saw the assessor as a "smiling assassin" who had lured him into a false sense of security during the WCA, while judging him as a scrounger who was "swinging the lead". Ultimately, most participants found themselves receiving a report of their assessment which was at odds with their own experience of disability.

3.4. Use your power to help me, not to punish or demean me

"Please sir... can I have some more?" (Carl)

A tension between two aspects of identity existed within the narratives; participants experienced vulnerability following TBI while working to maintain a fighting spirit. Experiences of being mistreated in daily social interactions were mirrored within the benefits system. The DWP's position of power was illustrated through reference to its systematic use of conditionality as well as to interactions with individual assessors. Participants' experiences of power and vulnerability could be seen permeate all levels of experience from the social, to the political and societal.

Assessment centres were described as having an unwelcoming atmosphere and participants felt as though they were an "easy target" (Mark), due to having a TBI. They provided examples of feeling powerless in their assessments, for example having to follow instructions to perform physical movements when it felt scary and unsafe: "I remember sitting there saying 'do I have to?'... And she says 'yes'... and I looked at [my friend] and [my friend] went…" [demonstrates helpless shoulder shrug] (Michelle). Claire described hoping for her assessor to have a "friendly face" and being disappointed when she found them to be "abrupt and kind of uncaring". Some participants used exceptionally emotive language, drawing on historical examples for maximum impact in illustrating their experience of power within the benefits system and wider oppression of disabled people: "you line up... like you're at Auschwitz" (Carl); "shocking way of relating it to but... the Nazi's in the second world war" (John).

Pursuing justice was often felt to be more important than money, but having a greater level of financial need, combined with impairments due to TBI, eliminated the possibility of successfully fighting back. Understandings were powerfully communicated of how one could reach a point of feeling that suicide is the only option: "... there's so many people... ending it... committing suicide... because of... the pressures... they've got no money" (Jayne). Peter described how his lack of problem solving skills following TBI led to rumination over being declared fit for work: "...if I didn't get rid of those feelings you know you'd be suicidal... you would be... you're very nearly bordering on... 'why?'... you know".

Carl and Dominik delivered contrasting overarching narratives which illustrated vulnerability and the desire to take back control. Carl's story conveyed a vulnerability in relationships following TBI: "I don't make it public that I- I can't remember what I'm doing [laughs]... cause people are cruel". In a wider societal and political context, he presented disabled claimants as "second class" citizens at the mercy of decisions made by a government exercising control: "There's no two ways about it... they want to put their size elevens round your throat and keep it there... that's how they make you feel" (Carl). Despite holding on to a continued identity of being a "militant at heart", his financial needs meant "fighting for survival" and inherently being in a position of vulnerability within the ESA process. Although his appeal was successful, his narrative ended on a continued tone of apprehension due to the ongoing power of the DWP to impact his finances and continue contact: "they want a piece of you all the time" (Carl).

Dominik told a story of being let down and mistreated by the benefits system, appealing unsuccessfully against a decision that he was fit to work: "... this makes me angry... the way they look at you... they completely kind of ignoring you" (Dominik). However, the narrative ultimately ended with him taking back a sense of control. The key factor appeared to be a less desperate financial situation, which allowed him to make a conscious decision to opt out of the system: “... so I decided no... I’m just not gonna do it anymore... cause... all these process... has caused more bad than good” (Dominik).

Conditionality was brought to the forefront, with those who had been placed in the WRAG abandoning a chronological structure to focus plot on consequences of their assessment, rather than the assessment itself. However, flexibility and understanding, even within an ongoing framework of conditionality, could have a significant positive impact. Jayne and Michelle experienced their WRAG advisors as empathic and understanding allies, which led them to feel supported despite still having to meet criteria: “She says ‘you’ve got this and you can’t do this... why are you here?’... she- she was good she said ‘right well come every four weeks... not every week’” (Jayne). For most participants, the message was that they wanted those in positions of power to use that power to provide help: “they’re in a position to make your life better... but they don’t” (Claire).

3.5. Destabilising the narrative

Whereas the presentation of themes above aimed to focus on the subjectivity of participants, the following section explicitly utilises the social model of disability to view the text from an alternative standpoint. This model adopts a medical definition of ‘impairment’ while arguing that social and environmental barriers, attitudes and stereotypes have an impact in ‘disabling’ people with impairments (Barnes & Mercer, 2003).

Participants talked about the impact of their impairments during the ESA process, but correspondingly were able to suggest actions that would have accommodated them within the system. For those wanting to return to work, this experience was reflected within the job market. Interpreted from the perspective of the social model of disability, these participants can be seen to experience disablement not solely as a result of their TBI, but due to the design of government services and the focus on a competitive capitalist society. However, when those in positions of power ignore the barriers, an individualistic explanation of disability is perpetuated and the fault placed with the individual with TBI. Indeed, reported experiences of the WRAG as aiming to teach new skills, or to simply force the person with TBI into a job, are suggestive of a view that the individual can improve their own circumstances by ‘trying harder’. It is then possible for those in power to continue to neglect the changes that are really needed.

The identity work within participants’ stories demonstrates further oppression of disabled people through dominant narratives that create stereotypes. While disabled people may have traditionally been seen as ‘deserving’ within the welfare state, an additional category of the ‘undeserving disabled’ is present. Participants’ efforts to present themselves as honest, diligent and grateful for their benefits were specifically present at times when they were working against a perceived counterview of being a ‘scrounger’. This seems to represent an active use of the ‘good’ and ‘deserving’ disabled claimant stereotype, as it is preferable over the alternative. Ultimately both disability stereotypes may be reinforced, as participants work to separate themselves from the undeserving ‘other’ but still remain “set apart from the ordinary” (Hunt, 1966, p.146). With the texts viewed from this perspective, it is possible to see that barriers constrain not only participants’ everyday options, but the narratives that they create around particular topics within accepted ways of viewing the world.

4. Discussion

This study employed critical narrative analysis to explore the experiences of individuals with TBI who had taken part in the WCA. Four themes represented key messages from participants in relation to the assessment: (1) Work with me to really understand my struggles; (2) Reduce the barriers that I face; (3) Acknowledge that I am not a ‘scrounger’; (4) Use your power to help me, not to punish or demean me.

Experiences of the WCA were universally negative; even where participants felt positive during the assessment, this positivity was lost upon receiving the decision. Anxiety and apprehension were experienced prior to the WCA, due to financial concerns and hearing about other claimants' experiences. Some participants found the assessment itself highly distressing, echoing the powerlessness and degradation previously reported by people with disabilities (e.g. Burgess at al., 2014). Indeed, Barr et al. (2016) evidenced that the WCA was independently associated with an increase in suicides and self-reported mental health difficulties. Two participants in this study spontaneously reflected on how one might understandably reach the point of suicide.

Participants were at differing stages in processes of rehabilitation and adjustment, which highlighted how the negative impact of the WCA was qualitatively different depending on its positioning within ongoing journeys. Participants in the early stage of rehabilitation were still trying to resolve interpersonal and self discrepancies between pre- and post-injury identity (Carroll & Coetzer, 2011; Gracey, Evans, & Malley, 2009). There was a focus on returning to previous levels of functioning (Maestas et al., 2014; Shotton, Simpson, & Smith, 2007) and self-awareness was still developing (Sherer et al., 2003). The WCA was in direct opposition to the nature of support needed at this stage. Rehabilitation services would generally be aiming to create non-threatening therapeutic relationships, where identity might be explored safely and insight gradually developed (Gracey et al., 2009). In contrast, the WCA and subsequent written report confronted participants with a stark presentation of identity discrepancies; this occurred within a process that was inherently threatening due to potential financial consequences.

Where more time had passed since injury, participants tended to have made adjustments to life following TBI. They had a more coherent sense of identity and had found new meaning within their lives, possibly indicating the presence of post-traumatic growth (e.g. Collicutt

McGrath & Linley, 2006; Powell, Gilson, & Collin, 2012). In this case, the WCA seemed to be a destabilising event; routines and feelings of safety were disrupted and the outcome of the assessment was invalidating.

Assessments used to establish capacity for work have been criticised as having the inherent assumption that they are “seeking to root out undeserving malingerers” (Warren, Garthwaite, & Bambra, 2014, p.1321). Participants described the impact of wider societal narratives and reflected on how these were perpetuated by the media. This is also demonstrated within research showing an increase in UK newspaper reporting of disability, accompanied by a decrease in articles describing disabled people in “deserving terms” (Briant, Watson, & Philo, 2013). Qualitative research with long-term sickness benefit recipients has highlighted an impact of this political and media rhetoric on the wellbeing of disabled individuals (Garthwaite, 2014). People with TBI in the present study felt particularly vulnerable to judgement from others, due to the hidden nature of their disability; this potentially contributed to heightened fear of being placed within the ‘undeserving category’.

Experiences of power and vulnerability were present throughout participant narratives. They felt that others were in positions of relative power and this was intensified within the WCA process. The power of the DWP to deny or sanction benefits was salient; for participants who relied on this money to survive, there was little chance of escaping this situation. The extension of conditionality within the welfare state to disabled people (Patrick, 2011) has been mirrored across the international context, with countries such as Switzerland, Luxemburg and Australia showing similar trends (Garthwaite, 2014). Early research regarding the effects of sanctions suggests a damaging impact on people with disabilities (Dwyer, Jones, McNeill, Scullion, & Stewart, 2016). For participants in this study, none had been sanctioned but the possibility was sufficient to cause distress in some cases.

The United Nations Convention on the Rights of Persons with Disabilities (2016) outlined concerns regarding how the WCA approaches the assessment of disability. Their investigation found evidence that personal circumstances, needs, and barriers were not taken into account. The participants in this study noted that their context was not explored. This suggests that theories of disability developed by disabled people (e.g. Union of the Physically Impaired Against Segregation: UPIAS, 1976) or internationally accepted biopsychosocial models (e.g. World Health Organization, 2001) are not being drawn upon to inform policy and practice. The narrow and generic feel of the assessment was felt to disadvantage individuals dealing with the complexity of impairment following TBI.

The World Health Organisation put forward the International Classification of Functioning, Disability and Health (ICF; WHO, 2001) with the intent of shifting international focus towards the role of environmental factors in disability. It is also more compatible with rehabilitation strategy (Stucki, Cieza, & Melvin, 2007) than previous biomedical models. The ICF is useful for TBI as it considers how tasks are performed in both standardised environments and the individual’s own environment (Bilbao et al., 2003). This allows assessment of how compensatory strategies and technological supports may be facilitating performance. In addition, it allows assessment of actual levels of activity and participation, rather than having a narrow focus on capacity (Bilbao et al., 2003). Indeed, participants in this study wanted the WCA to take into account their compensatory strategies and support received from others, as well as the costs and sustainability of effort. A shift towards a biopsychosocial model of assessment would also highlight the barriers experienced by participants within the WCA process itself and within the job market they were expected to access.

4.1. Implications for Clinical Practice

It was notable that issues were raised regarding the lack of support with benefits during initial hospital admissions. Improved integration of health and social care is needed to address these issues. Incorporating routine enquiry about finances in assessments conducted early in the rehabilitation process would highlight cases where support is needed.

There is also an argument for routinely asking about benefits status further along the rehabilitation journey. First, in a practical sense, professionals are in a position to provide information to support claims. Participants in this study generally valued the input they received from services and felt more able to be open and honest where there was an existing relationship. Secondly, the findings suggest that complications with the benefits system may result in significant levels of distress for this client group. Assessing the situation proactively would allow early intervention in regards to management of distress. Furthermore, distress arising from the WCA could constitute a non-organic factor impacting on cognition; this should be considered when carrying out cognitive assessment following TBI.

Finally, professionals supporting people with TBI have valuable expertise in assessing the viability of RTW following a TBI. They are in a more powerful position than clients in terms of providing recommendations to benefits system administrators regarding prevention of distress and meaningful assessment of disability.

4.2. Recommendations for the WCA

Participants provided clear direction in terms of how functional ability can be meaningfully assessed following TBI. Additionally, the experiences suggest a number of necessary changes in terms of the accessibility of the benefits system. The assessment process currently places significant emotional demands on those needing financial support, causing additional distress at a vulnerable point in their lives.

Participants wanted assessors to understand the WCA as a snapshot within a complex process of ongoing rehabilitation, insight development, and adjustment. The generic nature of the assessment questions was not suited to TBI and more exploratory questions were needed to access key information. Participants wanted expertise of their family members to be included, as they provided insight and support with recall. Adopting a biopsychosocial approach (WHO, 2001) would bring the WCA in line with international recommendations for disability assessment.

Participants valued the input of known healthcare professionals who had often completed in-depth assessments. It was frustrating to see these assessments apparently dismissed in favour of something more superficial. Involving healthcare professionals at an early stage of the process may allow the assessor to gain a sense of the important issues to ask about, addressing any gaps in knowledge about TBI. There is also an economic argument for including these professionals; the need for an assessment may be negated where there is sufficient existing evidence, meaning that pressure on WCA resources may be reduced.

A range of substantial barriers were encountered within the assessment process. It is vital that this is positively addressed and that people with TBI receive reasonable adjustments, in line with equality legislation (e.g. Equality Act 2010). There is need for an alternative means of initiating the process, as the ESA-50 form is not accessible. Physical barriers also need to be considered and people with TBI may need breaks or changes in position. Finally, assessors should have specific training in working with people with cognitive difficulties, including supporting people with memory, attention and communication. Assessments need to be flexible, with options to feed in information recalled at a later time.

Most importantly, an understanding of the inherent power imbalance during a WCA is needed. People with TBI have been through traumatic experiences and ongoing impairments may result in them being vulnerable in interactions. Above all, participants wanted to be treated with empathy and understanding, with those in positions of power offering support. Too often they were left feeling punished and demeaned by the process.

4.3. Strengths and Limitations

A key strength of this study was the qualitative design and use of narrative interviews, which created space for participants to set their own context and give rich accounts of their experience. Critical narrative analysis allowed consideration of context as well as the challenges to identity commonly experienced following a TBI. The analysis followed a detailed framework (Langdridge, 2007), which allows the reader to evaluate the steps taken. Recruitment through social media ensured access for people no longer involved with services, allowing a sense of the continued journey following discharge. Participants were recruited across a large geographical area and demographics were broad.

The study utilised opportunistic recruitment and overall negative experiences of the WCA were reported. It is important to acknowledge that individuals with difficult experiences may have been more likely to take part. The study did not recruit through a particular service, with access to records, and participants were generally not able to recall the severity of their brain injury. However, from the perspective of the narrative method it was clear that their focus was understandably directed towards what TBI meant for them in function. A final possible limitation relates to the analysis being carried out by one researcher. However, the epistemological stance and the critical narrative analysis method acknowledged that the researcher was part of the co-creation of meaning. Qualitative standards for validity were considered throughout (Yardley, 2015)

4.4. Future research directions

This is the first study to explore the experience of people with TBI regarding the WCA with an in-depth qualitative design. Consequently, further research is required. Potential directions might include using triangulation to gain perspectives from other significant people in the process; for example, interviewing people with TBI, their family members, and a known healthcare professional. In addition, there is need for research to explore the experience from the perspective of the WCA assessors. Healthcare professionals with training in research methods can bring an important perspective to this topic and arguably have a duty to advocate on behalf of clients who are struggling with the benefits system.

5. Conclusion

This qualitative study drew key messages from the narratives of adults with TBI regarding the WCA. The assessment was experienced as unsuitable for the complexity of TBI and assessors were seen as lacking in knowledge and interest. Participants experienced multiple barriers, due to impairments not being accommodated within the WCA process or job market. Societal narratives regarding ‘undeserving’ disabled benefit claimants resulted in participants feeling as though they were treated with suspicion. Experiences of vulnerability following TBI permeated the narratives, with participants feeling punished and demeaned by the process.

Participants made clear recommendations for improvement of the WCA. There is a need for assessors to demonstrate empathy and interest, and barriers within the process need to be reduced. Contextual factors, fluctuating presentation, and stage of rehabilitation should be considered within the assessment, with a move towards a biopsychosocial approach. Finally, participants wanted acknowledgement that they would work if they could, and for those in positions of power to provide support rather than punishment. It is notable for healthcare professionals that these participants reported negative emotional and psychological experiences; there is need for assessment and early intervention in regards to this distress. The support of rehabilitation professionals was valued and participants wanted them to have more input into the process of assessment.

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Table 1. Participant demographics

Name[2]	Gender	Age (years)	Years since TBI	Experience of WCA	ESA status	Employment status prior to injury	Education level	Reported levels of support
Carl	Male	50	7	ESA-50 form Assessment Appeal	Support group	Full time employment	Left school at aged 16 after C.S.Es	Daily prompts from family to complete all activities of daily living, with follow up reminders. Support to travel and attend appointments. Electronic system fitted for kitchen safety. Family help with cooking.
Claire	Female	38	1	ESA-50 form Assessment	Found fit for work, unemployed	Off work with sickness and had been due to return	A levels	Husband has taken on more of the housework and childcare tasks. Also supports with paperwork and monitoring medication. Support from family and electronic devices to support memory and planning.
Dan	Male	45	18	ESA-50 form Assessment	Support group	Had left fulltime employment as not able to cope	Post-graduate qualification	Independent in activities of daily living. Receives support from family members during meetings due to anxiety. Accesses support in navigating benefits system and return to work from a range of charities.
Dominik	Male	23	2	ESA-50 form Assessment Appeal	Found fit for work, attending college	Working for an agency	Level 3 course currently being completed	Receives daily prompts from family members regarding activities of daily living, particularly risks in kitchen. Family monitor medication.

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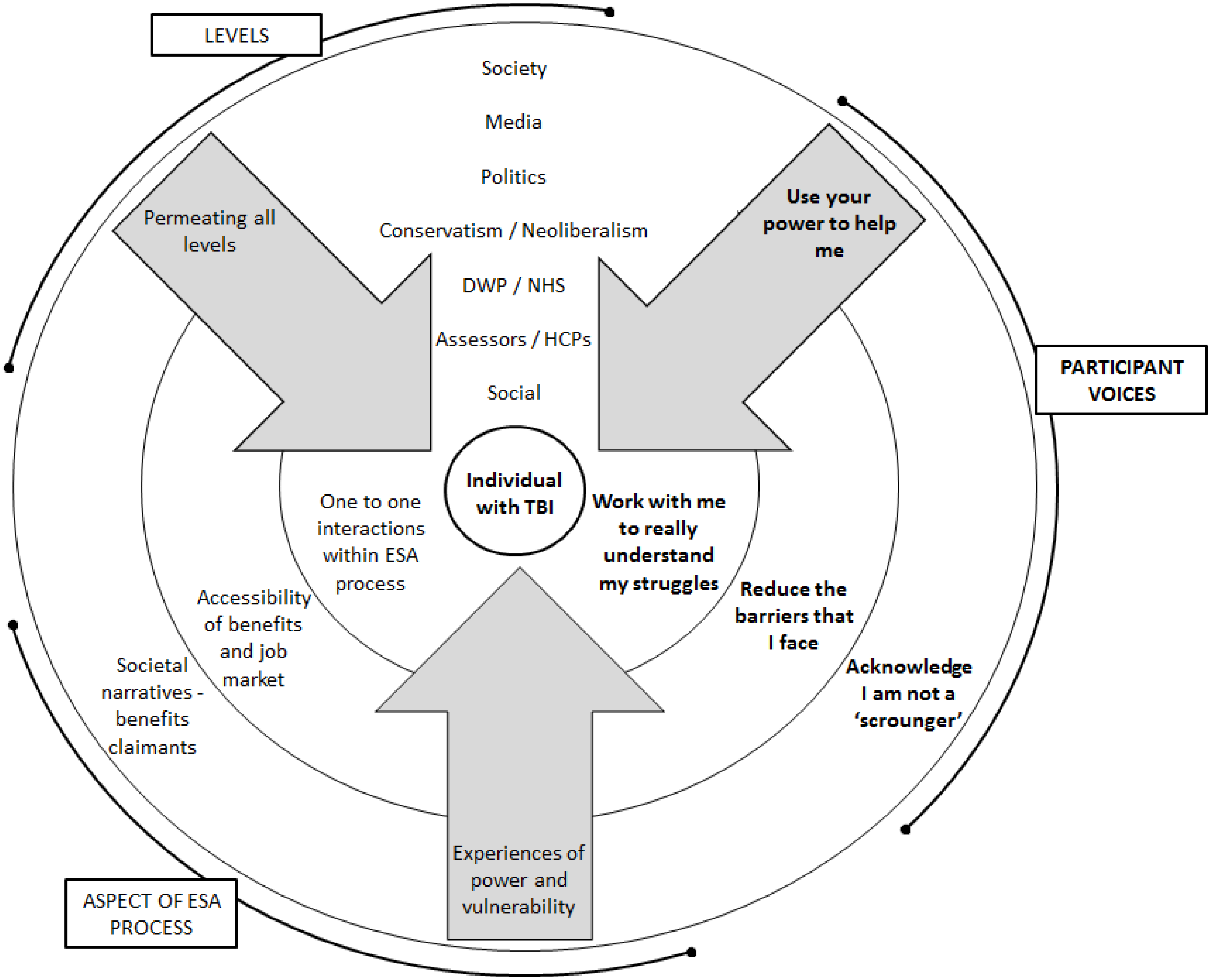
[2] All participants were asked whether they would like to use their own names, or have a pseudonym assigned, in line with approved protocol.

Jayne	Female	42	6	ESA-50 form Assessment	Work related activity group	Claiming ESA due to mental health difficulties.	Undergraduate degree	Receives support from husband in activities of daily living, supporting safe personal care due to physical limitations, and taking medication.
John	Male	55	2	ESA-50 form Assessment Appeal	Support group	Full time employment	Undergraduate degree	Receives support from wife and son in the form of reminders to complete tasks and to manage fatigue. Support in decision making, navigating social interactions, shopping and managing finances.
Mark	Male	34	2	ESA-50 form Assessment	Support group	Full time employment	A levels	Uses electronic device to support organisation, planning and memory. Support from wife when attending appointments. Support with expressive communication when under pressure.
Michelle	Female	48	6	ESA-50 form Assessment Appeal	Returned to work	Full time employment	Undergraduate degree	Receives support from a friend once a week to cook meals which can be stored, due to ongoing physical impairments.
Peter	Male	62	20	ESA-50 form Assessment	Found fit for work and requested mandatory reconsideration	Full time employment	Left school at age 15 years and gained vocational experience.	Receives support from wife in the form of prompts for all activities of daily living. Support with recalling information and making decisions. Wife manages finances.

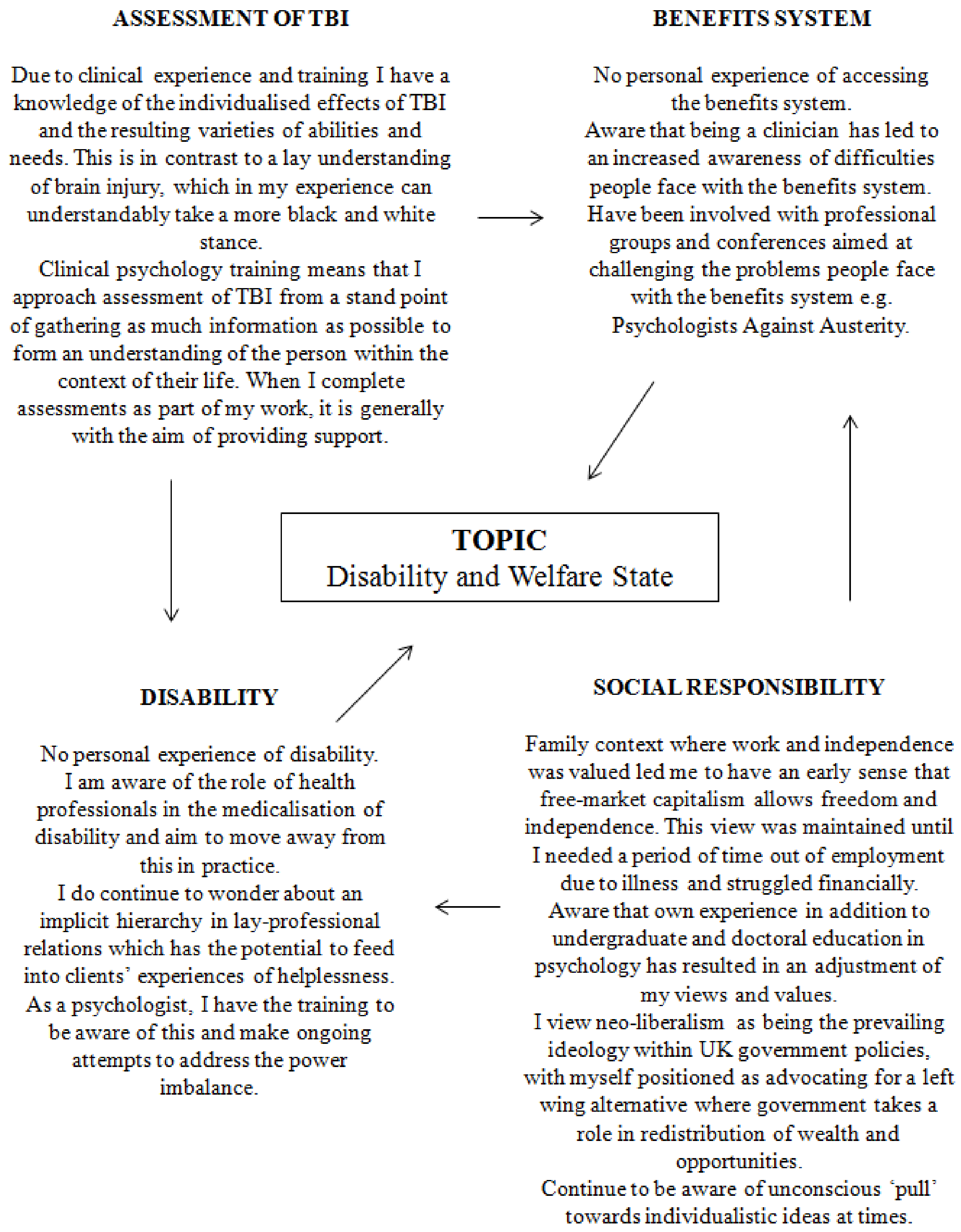
Figure 1. Visual representation of participants' experiences and voices



Appendix 2-A

A Critique of the Illusions of the Subject

Figure A1. Personal map of topic



ASSESSMENT OF TBI

Due to clinical experience and training I have a knowledge of the individualised effects of TBI and the resulting varieties of abilities and needs. This is in contrast to a lay understanding of brain injury, which in my experience can understandably take a more black and white stance.

Clinical psychology training means that I approach assessment of TBI from a stand point of gathering as much information as possible to form an understanding of the person within the context of their life. When I complete assessments as part of my work, it is generally with the aim of providing support.

BENEFITS SYSTEM

No personal experience of accessing the benefits system.

Aware that being a clinician has led to an increased awareness of difficulties people face with the benefits system.

Have been involved with professional groups and conferences aimed at challenging the problems people face with the benefits system e.g. Psychologists Against Austerity.

TOPIC

Disability and Welfare State

DISABILITY

No personal experience of disability.

I am aware of the role of health professionals in the medicalisation of disability and aim to move away from this in practice.

I do continue to wonder about an implicit hierarchy in lay-professional relations which has the potential to feed into clients' experiences of helplessness. As a psychologist, I have the training to be aware of this and make ongoing attempts to address the power imbalance.

SOCIAL RESPONSIBILITY

Family context where work and independence was valued led me to have an early sense that free-market capitalism allows freedom and independence. This view was maintained until I needed a period of time out of employment due to illness and struggled financially.

Aware that own experience in addition to undergraduate and doctoral education in psychology has resulted in an adjustment of my views and values.

I view neo-liberalism as being the prevailing ideology within UK government policies, with myself positioned as advocating for a left wing alternative where government takes a role in redistribution of wealth and opportunities.

Continue to be aware of unconscious 'pull' towards individualistic ideas at times.

Appendix 2-B

Example of Transcript Analysis

CARL

Events in overarching narrative

Attacked – came out of hospital – 12 months to recover from physical injuries
Moved in with family member – tried going home a few times but didn't "sit well"
Realised something wasn't right when back at home
Shop owner noticing memory difficulties
Had been living off savings but money ran out
Went to doctor and applied for ESA – didn't feel comfortable going back to job
Welfare rights filled in the form and a letter came through to go for the medical
Went to the medical which seemed to focus only on the physical – didn't feel like had been given right assessment.
Received a letter to say been put in the WRAG and inviting to programme
Didn't initially understand that there were two different ESA groups
Attended job centre and informed about going to work programme – would get reimbursed for travel. They didn't understand brain injury as "really ill".
Attended work programme for a week. Sat in front of a computer doing very little. Would not reimburse travel for taxis. Carl refused to go back.
[redacted]
Concerned would be sanctioned but this didn't happen
Put in mandatory reconsideration.
Two mandatory considerations "knocked back"
Advised to go to appeal
Went to appeal court and was asked "why are you here?" It was a relief to have someone understand.
Feels as though directives must be coming from the government to the DWP - to not give out benefits and to take back mobility cars.
A big weight was lifted after the appeal.
But it didn't end there.
Still worrying each time benefits are due that they won't be paid
"Grateful for what I've got but the road to getting it is wrong"
-
Natural end of narrative and move into reflections and elaborations

Narratives in the text

Look out for new beginnings, marked shift in content, especially new settings and new characters (Langdridge, 2007).

Self and others beginning to recognise changes
Setting: Back at home and trying to complete daily tasks
Characters: Local shop owner
Time: 1.50; Lines: 22-45
Shop owner noticing changes, i.e. going into shop several times in one day

Attending the medical
Setting: Not sure but local
Characters: Brother in law, ESA assessor
Time: 3.35; Lines: 72-103
Being at the medical – not one question asked about brain injury, assessor only interested in whether could do physical tasks, felt deflated, didn't feel like had been given the right assessment.
Time: 29.23; Lines: 640-702
Somewhere local. Can't remember the assessor. Know it was a lady. Assessment was not relevant to difficulties, "beyond a joke". "If they'd asked me anything that was going on with my memory". Reeling off examples of questions. The questions were "like a scarring… you don't forget". Not long ago been attacked and it's there in the notes. Don't know if they're proper doctors because the questions are not relevant.
Time: (2) 5.20; Lines: 1350-1415
Don't know what they perceive when you're "wandering". They don't ask "would you like to come back to the

conversation”. They just let you wander and then make their decision. The time to put your case across is lost. You can’t articulate what you need to. Struggling to remember and might make it up because can’t remember. Need an opportunity to feed in forgotten information after the fact.

Attending the job centre
Setting: Job centre
Characters: DWP employee at job centre
Time: 5.27; Lines: 109-183
Attending job centre – informed about local work programme. Explained about not being able to take public transport and asked about reimbursement. Told that he would be reimbursed. “What they don’t tell you is…” it’s only for public transport, not taxis. Job centre worker said support group was “only for people who are really ill”. Blood was boiling. People don’t recognise invisible impairments. Already on high rate for PIP.

Attending the work programme
Setting: Work programme
Characters: Employees at work programme, other benefit claimants
Time: 8.35; Lines: 184-330
Work programme – every day for a week. They’re not a work provider, they’re a recruitment agency. “You’re not fit just yet but you will be”. How are people with no medical training able to assess work capabilities for someone who is ill? Asked if could work a computer. Asked if had a CV. Just sat there. Put on a computer to look for work [redacted] They want you to find a job. Don’t reimburse taxi receipts. “It’s your responsibility to find the cheapest mode of transport”. They refused so I refused to go. “I lost the plot a bit” “Why are you discriminating against me?”
Time: (2) 8.03; Lines: 1441-1492
Never got reimbursed, could have done after appeal but didn’t get round to it. The work programme “still harassing me now”. They text with inappropriate jobs [redacted]

Experience with the decision maker
Setting: Over the telephone and through post
Characters: Decision maker
Time: 16.21; Lines: 322-394
Decision maker sent out for more evidence. No time to send back before decision came through. The decision was made without the additional evidence. Phone up and decision maker said “my advice to you is to go to appeal”. “The government have given them directive” (to keep telling people no).
Time: (2) 1.39; Lines: 1257-1294
Decision maker never asked “how’s your illness affecting you?” He wasn’t interested.

Going to the appeal court
Setting: Appeal court
Characters: Brother in law, judge, panel member experienced in brain injury, clerk
Time: 18.08; Lines: 355-430
Went to appeal courts. It was “comical” they had already looked at the notes. Judge said “why are you here?” A relief at last for someone to look at what they had in front of them. “I broke down” (Only defence of DWP is that they didn’t have the brain scans at the time. But didn’t pay attention to barriers of struggling to articulate self.)
Time: 33.35; Lines: 740-795
On the panel happened to be someone who dealt in brain injury – it was her that said “why are you here?” Told by the clerk before going in “you don’t have to go in if you don’t want… the decision’s already been made… its good news”. Wanted to go in anyway and speak when offered the chance. The people on the panel knew the background. In and out in two minutes.

Hearing horror stories about others experiences
Setting: Local neighbourhood
Characters: Another benefit clamant, “they” (the DWP)
Time: 19.10; Lines: 395-402
Horror stories you hear – guy round the corner with no legs – they’ve taken his car of him. Another directive they’ve given - to take the cars back.

Attempting to go back to work
Setting: [redacted]
Characters: Hiring manager, other employees
Time: 20.50; Lines: 427-446
Tried to get a job. Sat in the house going insane and missing being active. “I have to get out of here, I have to get a job”. Given a job but only lasted a short time (8 weeks).
Time: 25.45; Lines: 534-575
Forgetting routine of job and having to ask questions. “You’re not gonna babysit a grown man”. “I was asking the same questions all the time.” “It becomes as frustrating for them as it is for you”.

[redacted]

[redacted]

Controlling who knows the full story about brain injury
Setting: Various
Characters: Strangers, family, neighbours, professionals
Time: 39.30; Lines: 872-929
I don’t make my brain injury public. This area is “a bit rum”. “If they see a sign of weakness they’ll jump on it”. Immediate neighbours know and keep an eye. “I know what to say and how to say it” to appear like nothing has changed. “As soon as I got diagnosed… my family’s attitude changed… in a good way”. But saying what you can’t do anymore.

Political campaigning
Setting: Home, watching TV
Characters: David Cameron, the conservatives
Time: (2) 3.30; Lines: 1321-1346
The Tories, general election. Talking about “your blinds being closed”, “the work shy that have their blinds and curtains closed”, “for the record… I keep my blinds and curtains closed because I was attacked and I don’t want to see anyone coming up my path”. It’s not about being work-shy, it’s about being incapable. What they say is “shameful”.

Tone
The tone of a narrative also provides important insights into the meanings being expressed, e.g. optimistic, pessimistic, comic, or tragic. Note changes in tone, e.g. beginning optimistic and then it becomes clear that the story is more tragic. Phenomenologically speaking, it is best to use the most appropriate descriptor available rather than try to slot the narrative into some predetermined framework (Langdridge, 2007).

Neither optimistic nor pessimistic overall
Indignant, angry, suspicious in relation to experience with the benefits system
Presence of optimism following the appeals process towards the end of the narrative, before ending on a note of continued apprehension.

Rhetorical features (e.g. excuses, explanations, justification, criticism – seen in opinions)
Rhetorical features of the text, e.g. excuses, justifications, criticisms – explicit and implicit. Rhetorical discourse is argumentative talk designed to persuade and involves explanation, justification, and criticism, seen in opinions. People invariably present a position against perceived counter positions, at once justifying and explaining their own view and criticising the counter view (Langdridge, 2007).

- Justification of need/impairment/inability to work (lines 136-168; 247-260; 309-323; 548-571; 585-590; 769-782; 1350-360)
- Assessors do not respond to attempts to communicate difficulties (lines 77-103)
- Implication that DWP intentionally withhold necessary information, e.g. there are two ESA groups (lines 109-135)
- DWP are deceptive and hide their intentions, e.g. work programme is about pushing you into work, not helping you get fit for work (lines 187-225)
- DWP intentionally avoid acknowledging need (lines 170-182)
- Staff in WRAG programme are not qualified to assess fitness for work, yet are in a position of power (lines 193-202)
- WRAG staff use of power in a way that demeans people, wrong and unethical, “line up like you’re at Auschwitz” , response of embarrassment then defiance (lines 227-253)
- Examples of demeaning treatment, embarrassed in front of others (lines 309-320)
- DWP “refusing” to provide needed travel support (lines 235-253), lack of understanding of travel needs (lines 1435-1440)
- Showing moderation of criticism of the DWP, conveying reasonableness (lines 296-302; 379-387), from the DWP’s point of view maybe they shouldn’t be interested? It’s from disabled people’s point of view that they should (lines 1267-1286)
- Evidence from medical professionals shows that the DWP are in the wrong (lines 300-304)
- Examples of the DWP dismissing or avoiding evidence, e.g. not waiting to receive it (lines 335-353), pretence of asking for information (364-373)
- Demonstrating presence of hidden DWP agenda – keep saying no and people will give up (lines 355-373), reduce benefit payouts (lines 395-411)
- Justifying level of own knowledge – you pay attention when the subject matter affects you (lines 406-415)
- Showing oppression of disabled people through physical metaphor “they want to put their size elevens round your throat and keep it there”, seen as second class (lines 406-425)
- Positive outcome of appeal immediately clouded by example of further negative treatment by the DWP (lines 427-451)
- Presenting self as upfront/honest and not at fault (lines 440-446; 497-502), surprise at accusation (lines 469-471)
- Example of the power the DWP hold, what would you do without benefits? (lines 581-587)
- Illustration of how the DWP can use their power to act suddenly in restricting benefits (lines 604-511)
- People in need are entitled to benefits and care e.g. I am entitled to benefits (lines 621-631), certain groups of people should be given support (lines 1317-1322)
- Examples of how hard life on benefits is, financially (lines 627-631)
- Grateful for benefits and don’t complain about financial limitations (lines 629-631)
- The “road” to getting benefits is wrong, word “wrong” repeated twice (lines 627-635)
- Assessors are not qualified, they don’t ask relevant questions (interviewers phrasing corrected to stating of fact) (lines 646-654), reeling off inappropriate questions (lines 644-654), incredulous that feeding yourself is a “black mark” (lines 650-657), not “proper doctors” (lines 692-733), its “wrong” to assess someone with a brain injury when you’re not a doctor (lines 711-727), demonstrating the difference in outcome when assessed by someone suitably qualified (appeal) (lines 745-788)
- Illustrating the trauma of being attacked and the dismissal of this by assessor (lines 676-683)
- Long standing opinions regarding inequality and abuse of power in oppressing and taking advantage of people (lines 797-831)
- Politics: incredulous that the conservatives would expect his vote (lines 845-862), government wasting money (lines 854-862), criticism of current government but also blaming lack of opposition (lines 861-867), criticism of conservative government talking about the “work shy” and powerful example if this not being the case “For the record I keep my blinds and curtains closed because I was attacked with a ____” (lines 1322-1342)
- Illustration of why it’s not always safe to reveal brain injury (“weakness”), “people are cruel” (lines 871-894)

- Appreciate support of family but they are also taking things away, e.g. independence (lines 905-920)
- DWP not meeting people’s needs, lacking in empathy, not giving due attention to information (lines 1250-1264), DWP show through their actions that they don’t care if you get your needs across (lines 1350-1372), lack of knowledge and care from assessors in gaining a full picture (1381- 1415)
- Unfair and unacceptable not to allow someone the chance to represent themselves, example of decision makers behaviour (lines 1267-1280)
- Clapping hands to indicate how quickly you are expected to “perform” in assessments (lines 1281-1286)
- You are powerless in the situation because you are essentially “fighting for survival” (lines 1288-1294)
- Showing that calling ourselves a “modern progressive society” is a misrepresentation through examples of other cultures compared to this country’s treatment of vulnerable people (lines 1293-1322)
- Financial impact for someone on benefits to have to phone DWP (lines 1419-1440)
- WRAG group hold continued power to “harass”, demonstrated through continued contact by phone, powerless to sever connection, “they want a piece of you all the time” (lines 1455-1492)

Function of narrative

The rhetorical function of a narrative may change through the course of the narrative or remain consistent but, regardless, it will be doing work to position the speaker in relation to the wider world of stories that the speaker inhabits (Langdridge, 2007).

Justifying own genuine level of need, someone who is entitled to claim benefits. Certain groups of people should be given support.
Newly situated within “disabled” group but long standing opinions on the lack of equality and oppression of poor people. Lack of power to change things but presenting self as having clear knowledge of systems leading to own lack of power.
DWP as under direction from the government with hidden agendas of reducing benefit pay-outs. Unacceptable lack of knowledge and qualifications, demonstrated through the different result when assessed by someone who knows about brain injury. There is a right and wrong and the WCA process is wrong.

Possible perceived counter view:
Individualistic society, conservatism
Societal narratives around undeserving benefit claimants or “work shy”

Identities and identity work

The particular self being brought into being in the narrative. Who is this person? What kind of person does this particular narrative construct and how does this relate to what we know of the person (sex, sexuality, age, ethnicity etc.) and the topic being discussed? (Langdridge, 2007)

Previous life and identity
Used to be an active person (lines 431-437; 931-936), making more money – great life (lines 613-616)

Continuity of identity
Stands up for self (lines 235-253; 752-761), “I’m a militant at heart (lines 795), prepared to challenge and question (lines 476-495; 820-831; 1056-1059), forms own opinions (lines 1089-1092)
Someone who questions things beyond surface level (lines 355-373)
Upfront and honest (lines 439-446; 497-502)
Wouldn’t ask for more than is deserved (lines 621-625), would only be complaining if something was really wrong with the process (lines 644-654)
“I might be ill but I’m not stupid” (lines 491)
Strong political and moral opinions, social justice, against oppression and the powerful taking advantage, but believes in reward for hard work[redacted] (lines 795-813; 839-856)
Trying to maintain old identity, e.g. being as active as possible (lines 961-966)

New identity
No longer a “normal” person, but can look normal (lines 35-38; 1350-1360)
An “ill” person (lines 145-158; 384-390)
Can’t be held responsible anymore (lines 534-537)
Less sure of self (lines 722-727)
No longer as able (lines 738-739)
Now need to be looked after/ receive support (lines 548-569; 1281-1291; 1469-1470)
It’s not always safe to reveal new identity “sign of weakness” (lines 875-892)

Different identity within family "things are getting taken away from you"
Loss of independence (lines 941-942)
Getting older – gaining happiness from simple things "I think it's an age thing you know" "It gives me happiness" (lines 986-998)
Lost internal sense of structure (lines 1017-1020)
Limited in valued activities by serious financial hardship (lines 1429-1433)

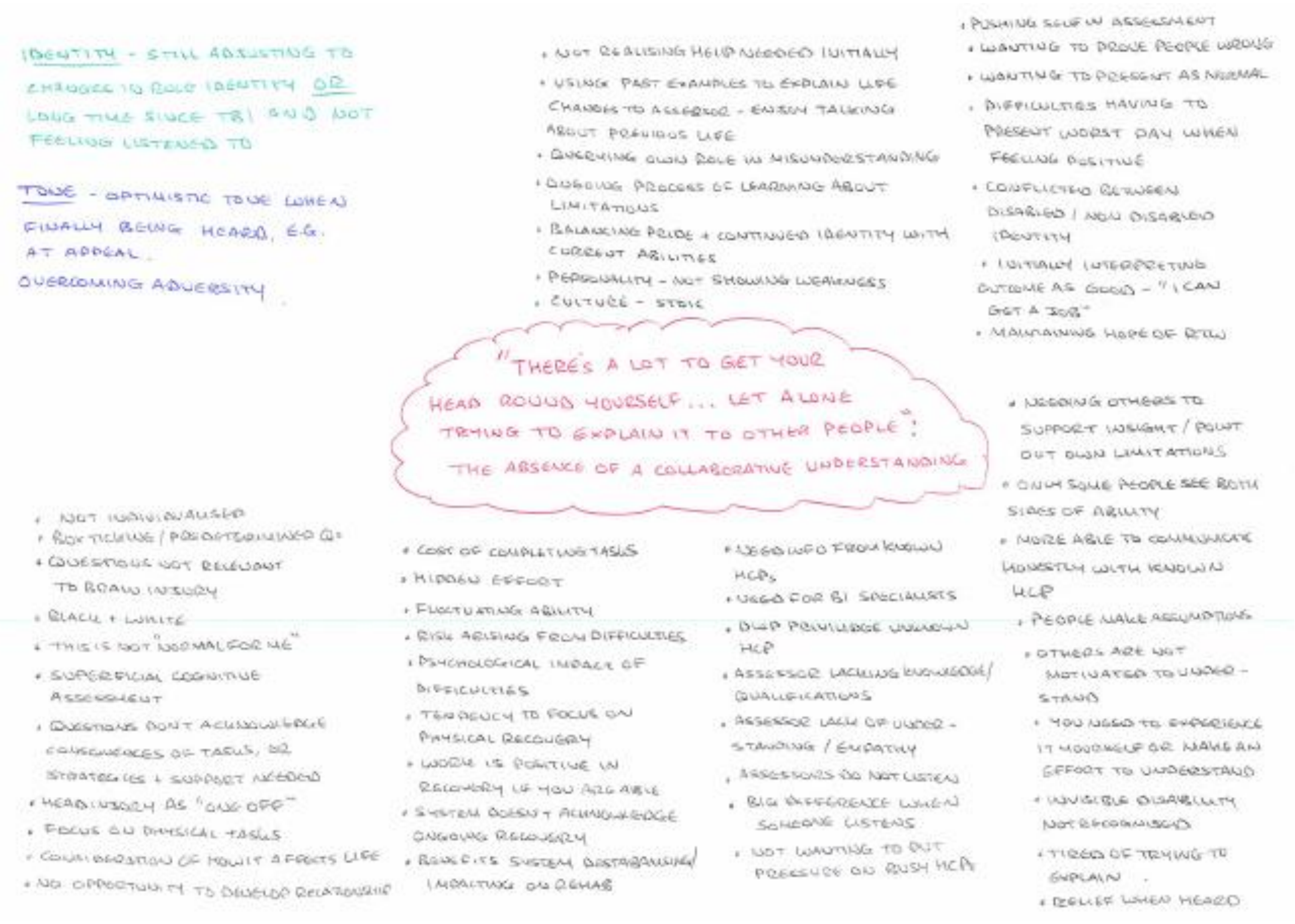
Initial notes on key themes

- Process of gaining insight into difficulties (lines 22-63; 548-550)
- Needing support completing ESA paperwork (lines 72-75)
- Assessment questions not relevant to brain injury (lines 77-103; 643-654; 698-699)
- Responsibility on person with TBI to prove their disability (lines 77-103; 384-398)
- Not understanding the benefits system, e.g. support v. WRAG (lines 105-131)
- Not being given needed information (lines 124-135)
- Invisible disability not recognised (lines 145-162)
- Unclear purpose of WRAG: support to get fit for work, or to find a job – should be doing the former? (lines 184-226; 210-225)
- Demeaning treatment by WRAG staff (lines 227-253; 309-320)
- Inconsistency in information given (lines 235-253)
- Lack of qualifications of WRAG staff (lines 200-202)
- Conditionality (lines 245-304)
- Importance of known medical professional's opinion (lines 248-260; 1257-1267)
- Apprehension of sanctions/losing money (lines 296-299; 524-537; 581-593; 599-611)
- Discrimination re. reasonable adjustments (lines 309-317)
- Decision maker not making effort to gain important information (sense of deliberately avoiding?) (lines 335-353; 364-373)
- Hidden agendas/directive from government (lines 355-362; 417-425)
- Relief at finally being heard (appeal) (lines 375-398; 427-428)
- TBI as a barrier to communicating difficulties (lines 384-398; 1278-1286; 1350-1364; 1381-1387)
- Hearing horror stories about other claimants (lines 398-402)
- Power and oppression in society – disabled benefit claimants are second class (lines 403-425)
- Failed attempt at RTW (lines 431-446; 542-577)
- Balancing pride and continued identity with current abilities (lines 491-495)
- Inability to work (lines 585-593)
- Power of DWP to impact financially (lines 604-611)
- Entitlement to benefits when you've paid your way (lines 621-625)
- Reality of living on benefits (lines 627-631; 944-946)
- Feeling grateful for benefits v. mistreatment in process (lines 630-635)
- Family/friend support at assessment doesn't change outcome (lines 646-642)
- Black and white assessment questions – yes/no (lines 644-654)
- Penalised for being able to manage a task (lines 644-653)
- Not remembering much about the assessor (lines 666-672)
- Assessors not looking at information they've been given (lines 676-683)
- Assessors not considering traumatic experiences (lines 676-683)
- Assessors lacking in qualifications/knowledge (lines 692-716)
- There is a need for assessment from a specialist in brain injury (lines 713-727; 749-789)
- Wanting the chance to respond/speak up for self (lines 790-795; 816-826)
- Inequalities in society, unethical use of power (lines 797-813)
- Not disclosing difficulties unless safe to do so (lines 875-907)
- TBI as a sign of weakness/vulnerability (lines 884-886)
- Risk of people taking advantage (lines 888-892)
- More able to honestly communicate with known HCP (lines 900-903)
- Family treat you differently after TBI (lines 905-920)
- Loss of independence after TBI (lines 914-916; 941-942)
- Loss of previous identity/valued activities (lines 931-939)
- Need for external routine and structure (lines 1000-1020)

- Difficulties with attention following TBI (lines 1017-1034)
- Assessors lack of understanding/empathy (lines 1250-1255)
- Assessors do not listen (lines 1250-1255)
- Staff at DWP don’t wait for important information (lines 1257-1261; 1372-1379)
- Lack of opportunity to respond/ communicate own difficulties in assessment (lines 1267-1279)
- Time pressure on retrieval of information in assessments (lines 1281-1286; 1386-1397)
- Fighting for survival – power in the hands of DWP (lines 1288-1294)
- Societal attitudes to caring for people in need (lines 1293-1322)
- Societal narratives around benefit claimants “work shy” (lines 1323-1434)
- Assessment not structured to support someone with TBI to provide a full picture (lines 1363-1372)
- Need opportunities to contribute information remembered later (lines 1399-1415)
- System causing further financial pressures (lines 1419-1438)
- Constant continued contact from WRAG when no longer appropriate (lines 1356-1492)
- No power to sever contact (lines 1488-1492)

Appendix 2-C

Example of Early Development of Themes across Transcripts



IDENTITY - STILL ADJUSTING TO CHANGES IN ROLE IDENTITY OR LONG TIME SINCE TBI AND NOT FEELING LISTENED TO

TONE - OPTIMISTIC TONE WHEN FINALLY BEING HEARD, E.G. AT APPEAL.

OVERCOMING ADVERSITY

- NOT REALISING HELP NEEDED INITIALLY
- USING PAST EXAMPLES TO EXPLAIN LIFE CHANGES TO ASSESSOR - EASIER TALKING ABOUT PREVIOUS LIFE
- OVERLOOKING OWN ROLE IN MISUNDERSTANDING
- ONGOING PROCESS OF LEARNING ABOUT LIMITATIONS
- BALANCING PRIDE + CONTINUED IDENTITY WITH CURRENT ABILITIES
- PERSONALITY - NOT SHOWING WEAKNESSES
- CULTURE - STOIC

- PUSHING SELF IN ASSESSMENT
- WANTING TO PROVE PEOPLE WRONG
- WANTING TO PRESENT AS NORMAL
- DIFFICULTIES HAVING TO PRESENT WORST DAY WHEN FEELING POSITIVE
- CONFLICTED BETWEEN DISABLED / NON DISABLED IDENTITY
- INITIALLY INTERPRETING OUTCOME AS GOOD - "I CAN GET A JOB"
- MAINTAINING HOPE OF RTW

"THERE'S A LOT TO GET YOUR HEAD ROUND YOURSELF... LET ALONE TRYING TO EXPLAIN IT TO OTHER PEOPLE":

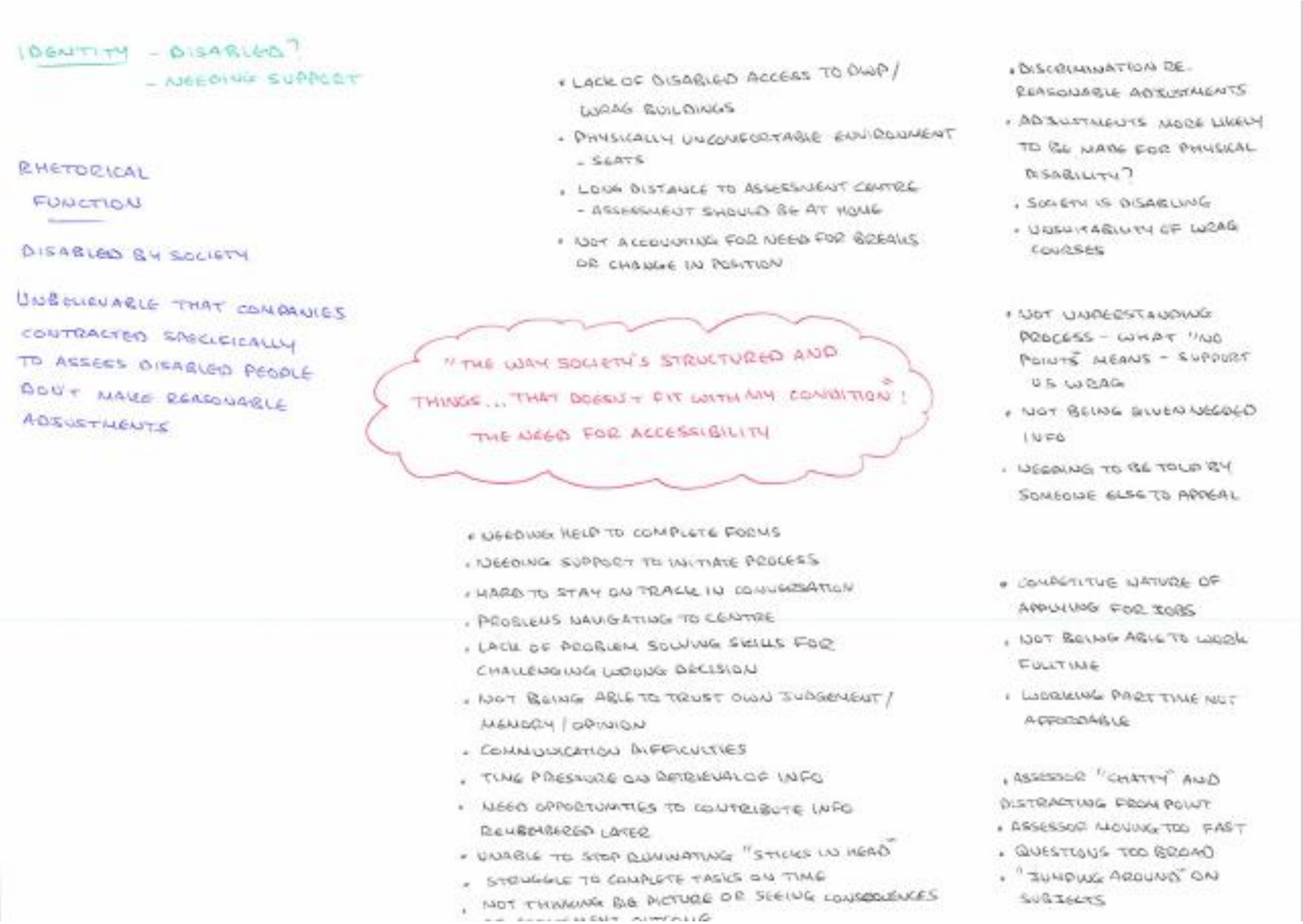
THE ABSENCE OF A COLLABORATIVE UNDERSTANDING

- NOT INDIVIDUALISED
- BOX TICKING / PREDETERMINED Qs
- QUESTIONS NOT RELEVANT TO BRAIN INJURY
- BLACK + WHITE
- "THIS IS NOT NORMAL FOR ME"
- SUPERFICIAL COGNITIVE ASSESSMENT
- QUESTIONS DON'T ACKNOWLEDGE CONSEQUENCES OF TASKS, OR STRATEGIES + SUPPORT NEEDED
- HEAD INJURY AS "ONE OFF"
- FOCUS ON PHYSICAL TASKS
- CONSIDERATION OF HOW IT AFFECTS LIFE
- NO OPPORTUNITY TO DEVELOP RELATIONSHIP

- COST OF COMPLETING TASKS
- HIDDEN EFFORT
- FLUCTUATING ABILITY
- RISK ARISING FROM DIFFICULTIES
- PSYCHOLOGICAL IMPACT OF DIFFICULTIES
- TENDENCY TO FOCUS ON PHYSICAL RECOVERY
- WORK IS POSITIVE IN RECOVERY IF YOU ARE ABLE
- SYSTEM DOESN'T ACKNOWLEDGE ONGOING RECOVERY
- BENEFITS SYSTEM DESTABILISING/ IMPACTING ON REHAB

- NEED INFO FROM KNOWN HCPs
- NEED FOR BI SPECIALISTS
- DWP PRIVILEGE UNKNOWN HCP
- ASSESSOR LACKING KNOWLEDGE/ QUALIFICATIONS
- ASSESSOR LACK OF UNDERSTANDING / EMPATHY
- ASSESSORS DO NOT LISTEN
- BIG DIFFERENCE WHEN SOMEONE LISTENS
- NOT WANTING TO PUT PRESSURE ON BUSY HCPs

- NEEDING OTHERS TO SUPPORT WEIGHT / POINT OUT OWN LIMITATIONS
- ONLY SOME PEOPLE SEE BOTH SIDES OF ABILITY
- MORE ABLE TO COMMUNICATE HONESTLY WITH KNOWN HCP
- PEOPLE MAKE ASSUMPTIONS
- OTHERS ARE NOT MOTIVATED TO UNDERSTAND
- YOU NEED TO EXPERIENCE IT YOURSELF OR MAKE AN EFFORT TO UNDERSTAND
- INVISIBLE DISABILITY NOT RECOGNISED
- TIRED OF TRYING TO EXPLAIN
- RELIEF WHEN HEARD



IDENTITY – DISABLED?
– NEEDING SUPPORT

RHETORICAL FUNCTION

DISABLED BY SOCIETY

UNBELIEVABLE THAT COMPANIES CONTRACTED SPECIFICALLY TO ASSESS DISABLED PEOPLE DON'T MAKE REASONABLE ADJUSTMENTS

- LACK OF DISABLED ACCESS TO DWP / WRAG BUILDINGS
- PHYSICALLY UNCOMFORTABLE ENVIRONMENT
  - SEATS
- LONG DISTANCE TO ASSESSMENT CENTRE
  - ASSESSMENT SHOULD BE AT HOME
- NOT ACCOUNTING FOR NEED FOR BREAKS OR CHANGE IN POSITION

"THE WAY SOCIETY'S STRUCTURED AND THINGS… THAT DOESN'T FIT WITH MY CONDITION"!
THE NEED FOR ACCESSIBILITY

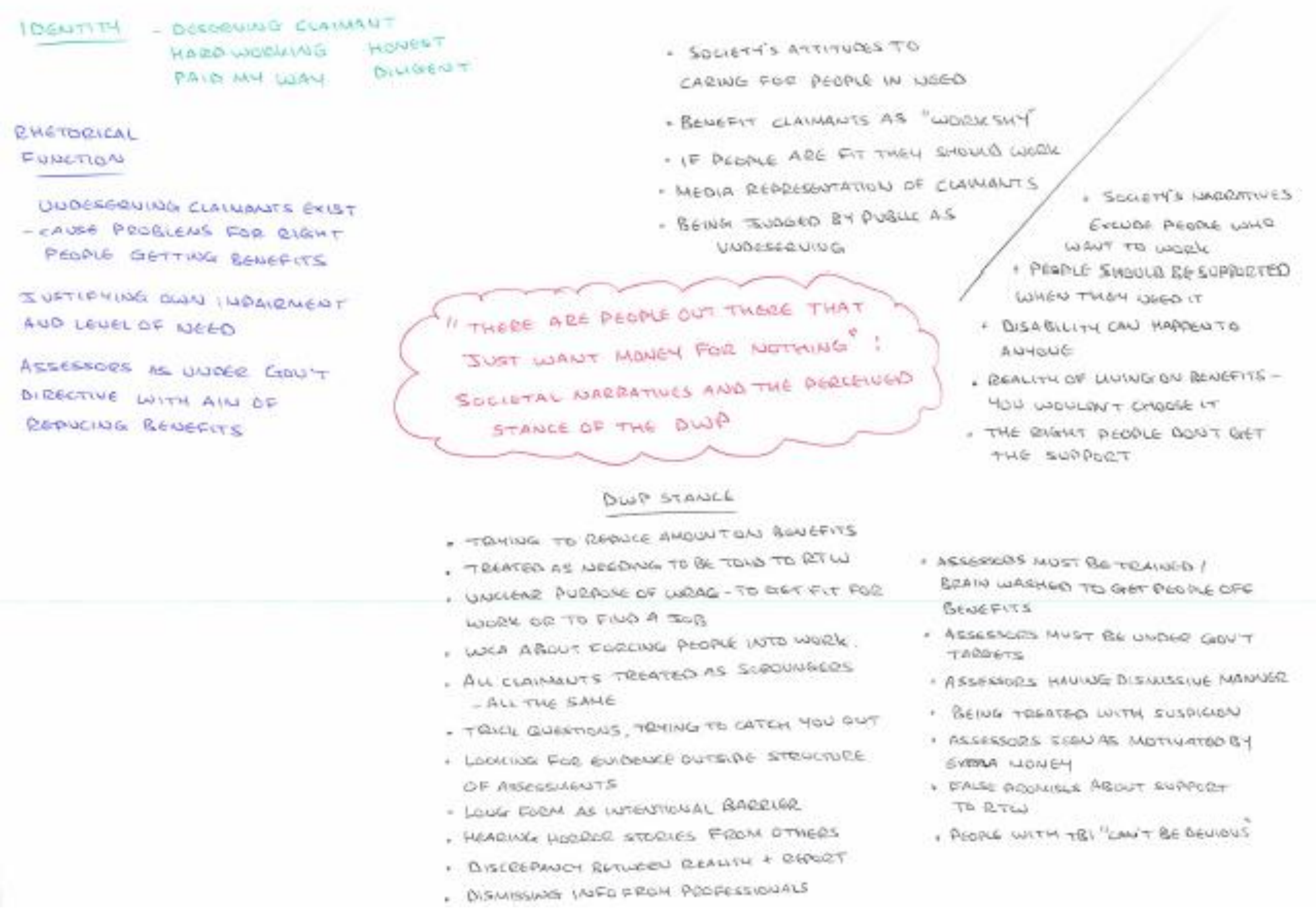
- NEEDING HELP TO COMPLETE FORMS
- NEEDING SUPPORT TO INITIATE PROCESS
- HARD TO STAY ON TRACK IN CONVERSATION
- PROBLEMS NAVIGATING TO CENTRE
- LACK OF PROBLEM SOLVING SKILLS FOR CHALLENGING WRONG DECISION
- NOT BEING ABLE TO TRUST OWN JUDGEMENT / MEMORY / OPINION
- COMMUNICATION DIFFICULTIES
- TIME PRESSURE ON RETRIEVAL OF INFO
- NEED OPPORTUNITIES TO CONTRIBUTE INFO REMEMBERED LATER
- UNABLE TO STOP RUMINATING "STICKS IN HEAD"
- STRUGGLE TO COMPLETE TASKS ON TIME
- NOT THINKING BIG PICTURE OR SEEING CONSEQUENCES

- DISCRIMINATION RE. REASONABLE ADJUSTMENTS
- ADJUSTMENTS MORE LIKELY TO BE MADE FOR PHYSICAL DISABILITY?
- SOCIETY IS DISABLING
- UNSUITABILITY OF WRAG COURSES

- NOT UNDERSTANDING PROCESS – WHAT "NO POINTS" MEANS – SUPPORT VS WRAG
- NOT BEING GIVEN NEEDED INFO
- NEEDING TO BE TOLD BY SOMEONE ELSE TO APPEAL

- COMPETITIVE NATURE OF APPLYING FOR JOBS
- NOT BEING ABLE TO WORK FULLTIME
- WORKING PART TIME NOT AFFORDABLE

- ASSESSOR "CHATTY" AND DISTRACTING FROM POINT
- ASSESSOR MOVING TOO FAST
- QUESTIONS TOO BROAD
- "JUMPING AROUND" ON SUBJECTS



IDENTITY
- DESERVING CLAIMANT
HARDWORKING HONEST
PAID MY WAY DILIGENT

RHETORICAL FUNCTION

UNDESERVING CLAINANTS EXIST
- CAUSE PROBLEMS FOR RIGHT PEOPLE GETTING BENEFITS

JUSTIFYING OWN IMPAIRMENT AND LEVEL OF NEED

ASSESSORS AS UNDER GOV'T DIRECTIVE WITH AIM OF REDUCING BENEFITS

- SOCIETY'S ATTITUDES TO CARING FOR PEOPLE IN NEED
- BENEFIT CLAIMANTS AS "WORKSHY"
- IF PEOPLE ARE FIT THEY SHOULD WORK
- MEDIA REPRESENTATION OF CLAIMANTS
- BEING JUDGED BY PUBLIC AS UNDESERVING

- SOCIETY'S NARRATIVES EXCLUDE PEOPLE WHO WANT TO WORK
- PEOPLE SHOULD BE SUPPORTED WHEN THEY NEED IT
- DISABILITY CAN HAPPEN TO ANYONE
- REALITY OF LIVING ON BENEFITS – YOU WOULDN'T CHOOSE IT
- THE RIGHT PEOPLE DON'T GET THE SUPPORT

" THERE ARE PEOPLE OUT THERE THAT JUST WANT MONEY FOR NOTHING" :
SOCIETAL NARRATIVES AND THE PERCEIVED STANCE OF THE DWP

DWP STANCE

- TRYING TO REDUCE AMOUNT ON BENEFITS
- TREATED AS NEEDING TO BE TOLD TO RTW
- UNCLEAR PURPOSE OF WRAG - TO GET FIT FOR WORK OR TO FIND A JOB
- WCA ABOUT FORCING PEOPLE INTO WORK.
- ALL CLAIMANTS TREATED AS SCROUNGERS – ALL THE SAME
- TRICK QUESTIONS, TRYING TO CATCH YOU OUT
- LOOKING FOR EVIDENCE OUTSIDE STRUCTURE OF ASSESSMENTS
- LONG FORM AS INTENTIONAL BARRIER
- HEARING HORROR STORIES FROM OTHERS
- DISCREPANCY BETWEEN REALITY + REPORT
- DISMISSING INFO FROM PROFESSIONALS

- ASSESSORS MUST BE TRAINED / BRAIN WASHED TO GET PEOPLE OFF BENEFITS
- ASSESSORS MUST BE UNDER GOV'T TARGETS
- ASSESSORS HAVING DISMISSIVE MANNER
- BEING TREATED WITH SUSPICION
- ASSESSORS SEEN AS MOTIVATED BY EXTRA MONEY
- FALSE PROMISES ABOUT SUPPORT TO RTW
- PEOPLE WITH TBI "CAN'T BE DEVIOUS"

IDENTITY - VULNERABLE NOW
VS
- FIGHTER, STAND UP
FOR SELF

TONE

PESSIMISTIC TONE EVEN WHEN
ASSESSED AS DESERVING BENEFITS
- DUE TO ONGOING APPREHENSION
OF POWER OF DWP

RHETORICAL
FUNTION

USE OF EMOTIVE LANGUAGE
TO ILLUSTRATE USE OF POWER
BY DWP AND OPPRESSION
OF DISABLED PEOPLE
"NAZIS" "AUSCHWITZ"

"PLEASE SIR CAN I HAVE SOME MORE?":
EXPERIENCES OF POWER AND
VULNERABILITY

- DEMEANING TREATMENT
- UNWELCOMING ATMOSPHERE
- WATCHED AND JUDGED
- TALKED DOWN TO
- BEING POORLY TREATED NORMALISED BY OTHER STAFF
- PUNISHED FOR APPEALING
- UNETHICAL USE OF POWER
- OPPRESSION / GENOCIDE (NAZIS)

- VULNERABLE W/ TBI
- WANTING TO LEAVE BUT HAVING NO CHOICE
- UNABLE TO STAND UP FOR SELF
- HAVING TO BEG + PLEAD
- FEELING FRIGHTENED AND UNSAFE IN ASSESSMENT
- HELPLESS - OPT OUT OF SYSTEM
  - GIVING UP TRYING

- WILL TAKE ADVANTAGE IF YOU DON'T FIGHT
- IMPORTANCE OF BEING HEARD
- INVOLVING MP
- THIRD PARTY @ ASSESSMENT

- CONDITIONALITY
- POWER OF DWP TO IMPACT FINANCIALLY
- APPREHENSION OF SANCTIONS
- YOU ARE FIGHTING FOR SURVIVAL
- UNDERSTANDING HOW PRESSURE CAN END IN SUICIDE.

- BEING A VICTIM IN RELATIONSHIPS / INTERACTIONS
- BENEFITS SYSTEM MIRRORING OTHER EXPERIENCES OF MISTREATMENT

- ASSESSORS UNDER PRESSURE?
- ASSESSORS CUTTING ANSWERS SHORT

Appendix 2-D

Guidelines for Journal of Vocational Rehabilitation

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Manuscripts should be organized in the following order:

- Title page
- Body of text (divided by subheadings)
- Acknowledgements
- References

- Tables
- Figure captions
- Figures

Headings and subheadings should be numbered and typed on a separate line, without indentation.

SI units should be used, i.e., the units based on the metre, kilogramme, second, etc.

Title page
The title page should provide the following information:

- Title (should be clear, descriptive and not too long)
- Name(s) of author(s); please indicate who is the corresponding author
- Full affiliation(s)
- Present address of author(s), if different from affiliation
- Complete address of corresponding author, including tel. no., fax no. and e-mail address
- Abstract
- Keywords

Abstract
The abstract should be clear, descriptive, self-explanatory and not longer than 200 words, it should also be suitable for publication in abstracting services.
The abstract for research papers should follow the “structured abstract” format. Section labels should be in bold uppercase letters followed by a colon, and each section will begin on a new line.
BACKGROUND:
OBJECTIVE:
METHODS:
RESULTS:
CONCLUSIONS:

Tables
Number as Table 1, Table 2 etc, and refer to all of them in the text.

Each table should be provided on a separate page of the manuscript. Tables should not be included in the text.

Each table should have a brief and self-explanatory title.

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Vertical lines should not be used to separate columns. Leave some extra space between the columns instead.

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Anderson, A. K. (2005). Affective influences on the attentional dynamics supporting awareness. Journal of Experimental Psychology: General, 154, 258–281.

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

Armony, J. L., & Dolan, R. J. (2002). Modulation of spatial attention by fear-conditioned stimuli: An event-related fMRI study.Neuropsychologia, 40, 817–826.

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

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

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

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Section Three: Critical Appraisal

Word count: 3520 (excluding references)

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This doctoral thesis has consisted of two pieces of research. I initially planned the study into how people with traumatic brain injury (TBI) experience the Work Capability Assessment (WCA), before deciding on a suitable area to carry out a literature review. Research regarding the WCA is relatively new, and this was the first qualitative study to explore the experiences of people with TBI in particular. In considering disability following TBI and the significance of the wider context, I decided that a literature review of the experiences of informal caregivers would complement the research project. The current paper aims to review the research process and provide additional reflections on my personal experience of carrying out the research. I will particularly focus on aspects of the research regarding the WCA, drawing on reflections associated with the literature review where relevant.

Brief Summary of Methodology and Findings

As I outlined above, the research project reported in Section Two explored the experiences of people with TBI in relation to the WCA. The United Kingdom (UK) government introduced the WCA in 2008, as a means of measuring functional ability to work against a threshold of disability required to receive state financial benefits. The WCA has been widely criticised by people with disabilities, and the healthcare professionals and charities that support them (e.g. Burgess et al., 2014; Mind, 2014; Spartacus Network, 2012). In addition, I had observed through my clinical work that difficulties with the WCA were contributing to the distress of clients within neuro-rehabilitation services. I carried out interviews with nine individuals who had sustained a TBI and analysed the data using critical narrative analysis (Langdridge, 2007).

The findings emphasised the voices of participants in relation to their experience of the WCA. The process caused significant distress and participants wanted change at all levels, from one to one interaction with assessors to wider societal narratives. People with TBI wanted assessors to work with them to understand their struggles and wanted the government to consider accessibility issues relating to the WCA and job market when setting agendas. Participants were aware of wider societal narratives regarding ‘undeserving’ benefit claimants and wanted an acknowledgement that they would work if they were able to. Finally, they reported feeling punished and demeaned within the system; they wanted others to use their relative power to provide help and support.

The literature review in Section One explored relatives’ experiences of providing informal care to adults with TBI. A systematic literature search identified 15 relevant qualitative papers, the findings of which were analysed using Sandelowski and Barroso’s (2007) guidelines for metasynthesis. The synthesis was presented as three themes: (1) A new path with an unknown person; (2) Navigating the new terrain; and (3) Strong supports or crumbling foundations. It was noted that negative experiences on the part of caregivers were more frequently reported than positive ones. Amidst difficulties in adjusting to a relationship with a changed relative and finding a way forward, wider supports were often experienced as falling away. This was particularly true after discharge from hospital. Financial difficulties were one of the areas where secure foundations were not felt to be present, which drew parallels with the empirical research paper.

Clinical Psychology and Social Policy

Throughout clinical psychology training, I have felt frustrated and often helpless in regards to the wider context that can have a negative impact on clients. Extensive research has found that inequality in society has a negative impact on physical and mental health (Commission on Social Determinants of Health, 2008; Wilkinson & Pickett, 2009). While I do believe that collaborative individual therapy can build meaningful change, I question the utility and ethics of work within the therapy room when formulation indicates that the wider context is contributing to distress (Cromby et al., 2012; Smail, 2005). Indeed, clinical psychology as a profession seems to be increasingly acknowledging the need for psychologists to apply their knowledge and expertise to influencing wider policy. This has also extended to using our relatively powerful positions to influence government policy, promoting agendas that are likely to increase wellbeing and presenting evidence to the contrary when we see agendas that are causing distress (e.g. British Psychological Society: BPS, 2015; Psychologists Against Austerity, 2015).

When discussing the topic of my research paper with others in the profession, I received a lot of positive responses and often people shared their own experiences of working with clients who were struggling with the benefits system. There was no doubt that this was seen to be an important topic, but I also felt at times that there was an element of surprise for some. I wondered whether perhaps the choice of a clinical psychology doctorate thesis topic aimed so explicitly at evaluating policy at the political level was still relatively unusual. In my experience, this does seem to be the case. Nonetheless, I have felt optimistic as a result of communicating with other trainees, both within and outside my own doctorate course, who have approached similar research questions for their thesis.

Although I strongly believe that there is a need for increased focus on the wider societal factors that contribute to distress. I found myself often questioning my own ability to do this. I have been an active member of current psychologist driven movements within the UK, aimed at using knowledge to influence policy. This has included critiquing government ideologies that reduce resources for health and social services as well as restricting disability benefits for people unable to work. I have had regular discussions with colleagues regarding how one might feel somehow ‘unqualified’ to comment on government policy, despite having relevant psychological knowledge. This aspect of personal doubt has certainly arisen at times throughout my research, where I have questioned whether I have the skills and expertise required to complete this project well. My confidence has grown throughout the project as I have come to realise how much the study was appreciated by participants and the relevance of psychological and neuropsychological knowledge when analysing their accounts.

Epistemology

The 'wider focus' of this research was important in establishing an epistemological stance. I have often struggled with the language around epistemology and have felt that being a developing researcher involves having to choose a certain label that communicates your epistemology to other academics. However, this may also leave my position open to interpretation by others, as the label might mean something different to them. I spent time reading literature and considering the nature of the knowledge I was seeking from participant accounts. I was looking to gain a sense of participants' subjective lived experience, which may differ from the way in which others would experience the same event. In this sense I was incorporating phenomenological philosophy, looking for individual meaning.

However, I do not view language as a direct reflection of these experiences. I believe that I am able to access a reconstruction of participants' experience, which I have been involved in creating. The way in which people create narratives of their experience is inevitably influenced by their own aims, the context they live within, and how they perceive the listener. At the same time, the position of the researcher influences their own responses to the narrative and the questions they ask, regardless of attempts to 'bracket' experiences and beliefs (Langdridge, 2007). I therefore summarised my epistemological stance as social constructionist.

Having described my default stance as social constructionist, it was interesting to think about how this applied when carrying out a literature review and meta-synthesis. There are conflicting views regarding whether a synthesis of qualitative literature should incorporate papers produced by authors who have stated differing epistemologies and methodologies. Indeed, as Sandelowski and Barroso (2007) state in their guidelines, if one is synthesising findings, then there is an inherent assumption that these ‘findings’ exist. I believe that there is a need for practicality in research and we should be looking to produce literature that furthers understanding and makes research accessible for the benefit of people needing support. I therefore subscribed to Sandelowski and Barroso’s (2007) view; in carrying out a meta-synthesis, we cannot say that we are summarising the experiences of participants, only that we are synthesising author interpretations of participant accounts. My own views will then inherently further impact upon these findings during synthesis. Provided I am open about this to the reader, the practical benefit of summarising research findings and making them accessible outweighs the argument that there is too much distance from original participant accounts.

Recruitment

In terms of recruitment strategy, my primary aim was to make the research as inclusive as possible. Although the demands placed on vulnerable populations during research need to be carefully considered, people with TBI may still want the opportunity to decide for themselves whether to take part (Theadom, Fadyl, Hollands, Foster, & McPherson, 2014). I felt that the research was aiming to include people in a relatively powerless position in regards to the benefits system, and was an opportunity for them to have their voices heard. I also considered it important to include people who may have been: (1) further along in their journey following TBI and no longer involved with rehabilitation services or (2) experiencing significant difficulties following a mild head injury but had not met criteria to receive rehabilitation services. Recruiting through social media, charities and professional networks was a useful way to ensure advertising reached people with a variety of circumstances over a large geographic area. This method of recruitment is relatively new (National Institute of Health Research, 2014) and any use of social media requires consideration of boundaries to uphold the reputation of the profession (BPS, 2009).

A number of difficulties did arise with recruitment as the research progressed. I found very early on that charities and professional networks were expressing keen interest in the research and wanted to support with recruitment. However, it could be difficult for people with TBI to remember to follow up with making contact, even if they had intended to take part. In addition, some of the more local organisations were understandably interested in having me attend meetings to talk to their members about the research. I therefore put in an ethics amendment within the first few months of the research which allowed me to attend relevant meetings in person to explain the nature of the research to potential participants.

The ethics amendment was important, as the people I spoke with seemed to appreciate the concrete experience of meeting me in person and getting a sense of how comfortable they might feel taking part in an interview. In hindsight, I would have liked this to have been in place from the beginning as, by the time this amendment was approved, my dedicated study leave had ended and I was working on a clinical placement. This meant that there was only one study day a week scheduled for research and I experienced difficulties in attending some of the meetings I was invited to.

Throughout recruitment, I was mindful of conforming to ethical procedures for establishing consent to take part. Although I had worked with people with brain injury on previous and current clinical placements, I had not done so in a researcher role. The recruitment process involved a learning curve for me in terms of establishing how best to support people with TBI and maximise their ability to take part in research, where they wished to do so. To begin with, I was rightly concerned with making sure that potential participants were given the chance to ‘opt in’ to the research, with me having simply extended the offer. However, I do feel that there may have been participants who did not follow up on the offer due to memory impairments, despite them having an interest in taking part.

Within supervision, I brought up the fact that I felt I was being overly cautious about utilising my skills in supporting people with cognitive difficulties, as I was concerned about how appropriate this was in a research context. We were then able to reflect on the fact that providing full support to people to follow through with their intentions and wishes was an ethical way of approaching the situation. I established a routine when people expressed interest, so that they could go away and consider the information and choose whether to receive a phone call to follow up regarding their decision. I was clear throughout the process that there were no negative consequences for withdrawing and that there was no obligation to take part. I found that potential participants expressed appreciation of the option of a follow-up phone call, regardless of whether they eventually decided to participate. Indeed, research has shown that people with TBI wanted researchers to be proactive in asking about required supports (Theadom et al., 2014).

A final issue arising with the recruitment protocol was that information regarding the severity of TBI was not readily available. Had I attached my research to a particular service, we might have designed the process such that consent was gained for clinical information to be accessed. I reflected on the fact that this would have been useful demographic information in terms of analysis and for professionals drawing any generalisations from the research. Despite the challenges, my opinion has ultimately remained that the recruitment process we used was suitable for achieving the aims of the research. I wanted anyone with a TBI who had experienced a WCA to be able to contribute to this research and have their voice heard. Participants also communicated that they appreciated the opportunity to take part. This is the first piece of research on the topic and the recruitment strategy achieved a sample appropriate to the research aims.

Reflections on anonymity

I have felt as though there is an inherent power imbalance in research, with academics being in a position of owning the resulting publication. Participant anonymity might be seen as them not being included in the research community (Dominelli, 2005). In addition, there may be a sense of “loss of ownership” for participants in terms of the stories themselves (Grinyer, 2002). As such, some researchers have offered a choice for participants regarding whether they would like to use their own name, or have a pseudonym assigned (Grinyer & Thomas, 2001). The current study involved individuals who felt disempowered by the systems around them and I wanted to ensure that I did not perpetuate this feeling within the research. I felt that participants, regardless of their decision, experienced conversations around anonymity as being positive. This is a small step towards more inclusive research, although inequalities are often present at many levels (Dominelli, 2005).

Interestingly, I also found myself reflecting on my own experience of anonymity, or lack thereof. I did find it somewhat uncomfortable to consider that details I shared about myself would be published within my thesis, which would be available to a potentially wide audience following submission. This led me to reflect on the fact that when a researcher chooses to share information about themselves, there is no option for anonymity. There is an expectation within academia to create a research profile attached to your name and professional qualifications do add impact to our publications. Concurrently, there are necessarily standards for qualitative researchers to meet in terms of demonstrating transparency and reflexivity to the reader. I attempted to strike a balance between giving the reader a good enough sense of my position while considering my own personal boundaries.

Methodology

I chose critical narrative analysis as a method. This method was useful for exploring participants’ experiences of the WCA, as located within their ongoing adjustment and rehabilitation following TBI. There is an acknowledgement within the method that the researcher is an inherent part of the construction of meaning and that there is an explicit political focus. As such, the method was congruent with the social constructionist epistemological stance and the research aims.

The method is extremely time-intensive and, in many ways, the ideal sample size is a single case study (Langdridge, 2007). Although the method is still viable if stages of 'critiquing the illusions of the subject' and 'destabilising the narrative' are excluded, I considered these essential for the topic at hand. I was able to locate a study that had used this method to analyse data for 46 participants across seven focus groups, albeit with a larger research team (Stacey et al., 2016). I came to the conclusion that a sample of 8-15 participants was viable, but I would need to monitor the volume and richness of the data carefully to cease recruitment at the right time. Rich data was provided by participants from the outset and the decision to stop recruiting was made in conjunction with the rest of the research team.

A key aspect of the critical narrative analysis process is the notion that we are always telling or listening to a story from 'somewhere'. Since attempts to bracket one's own influence on the data collection and analysis are always imperfect (Langdridge, 2007), it is important to reflect on your position as the researcher and share this with the reader. I engaged in reading critical social and political theory relevant to disability in order to support my reflections and found it a useful process to draw out my own position in a way that allowed it to be communicated to others. Making this process so explicit resulted in my awareness of my own stance being much more at the forefront of my mind than when I have used other methods in the past.

In terms of my own position, I was aware of the significant impact of my clinical work in choosing my research topic. As I have mentioned previously, my experience throughout clinical psychology training has been that difficulties with the benefits system have contributed to clients’ distress. This has been the case across a variety of client groups, including mental health, learning disabilities and neuropsychology. Due to the therapeutic relationships I have developed with clients and my awareness of my duty of care, this has proved to be an emotionally charged topic for me to work on. I have continued to feel frustrated when I see clients’ struggling, although have found it helpful to channel this frustration into giving voice to people through this research. Despite my largely negative experiences, I was able to draw some positive experiences from the data, particularly in regards to certain individual staff members within the benefits system, whom participants experienced as supportive.

Given the time constraints placed on a doctorate in clinical psychology thesis, it was necessary to start analysing existing data as I was still conducting interviews. This was useful in terms of staying familiar with previous interviews and gaining a sense of when an adequate sample had been recruited. This also impacted on the position from which I was interviewing participants. I was becoming increasingly aware of the key themes I was drawing from the interviews and how this might be impacting on the questions I was asking. Keeping a reflective log felt particularly helpful at this point so that I could be aware of any tendency to arrive at interviews with preconceived ideas.

Overall, any shifts in my views have been negligible; I still maintain that the WCA is not suitable for purpose and has the potential to cause distress. Notwithstanding my own position throughout the process, I think that an alternative researcher or different methodology would have resulted in largely similar findings. Wide reading across disciplines suggested that similar experiences had been reported in other WCA research (e.g. Headway, 2015), as well as research exploring the experiences of long-term benefit claimants (e.g. Garthwaite, 2014).

Final Reflections

Exploring the wider context in regards to disability following TBI has strengthened my own resolve to continue advocating for change at societal and political levels. While my personal views on the WCA did not necessarily change, immersing myself in the narratives of people with TBI has given me an enhanced understanding of the lived experience. Participants described their financial struggles and the negative emotional impact of the process. It was evident that this affected their ability to focus on dealing with the life changing consequences of their brain injury.

When considering the experiences of caregivers, this was initially in relation to them being part of the wider system around the individual with TBI. However, as I completed the literature review, and reflected on the lack of available social and material supports, this view changed somewhat. I was struck by how the distress of these individuals deserved attention in its own right, and not merely as an adjunct to the person with TBI.

Both people with TBI and their caregivers are at risk of not having their basic needs met. This may be due to government policy regarding benefits, as well as the availability of services and social support. In the absence of necessary supports, the primary concern lies understandably with survival and installing some sense of stability and security. Individual intervention may be unhelpful if contextual issues are not concurrently addressed. It is my hope that clinical psychology as a profession can continue to draw attention to these important issues.

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Section Four: Ethics Section

Work capability assessments: The experiences of individuals with traumatic brain injury

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Faculty of Health and Medicine Research Ethics Committee (FHMREC)
Lancaster University

Application for Ethical Approval for Research involving direct contact with human participants

Instructions

1. Apply to the committee by submitting:
    a. A **hard copy** of the University's **Stage 1 Self Assessment (part A only)** and **Project Questionnaire**. These are available on the Research Support Office website: LU Ethics
    b. The completed application **FHMREC form**
    c. Your full research proposal (background, literature review, methodology/methods, ethical considerations)
    d. All accompanying research materials such as, but not limited to,
        1) Advertising materials (posters, e-mails)
        2) Letters/emails of invitation to participate
        3) Participant information sheets
        4) Consent forms
        5) Questionnaires, surveys, demographic sheets
        6) Interview schedules, interview question guides, focus group scripts
        7) Debriefing sheets, resource lists

Please note that you DO NOT need to submit pre-existing handbooks or measures which support your work, but which cannot be amended following ethical review. These should simply be referred to in your application form.

2. Submit the FHMREC form and all materials listed under (d) by email as a **SINGLE attachment in PDF format** by the deadline date. **Before converting to PDF ensure all comments are hidden by going into 'Review' in the menu above then choosing *show markup>balloons>show all revisions in line.***

3. Submit one collated and signed paper copy of the full application materials in time for the FHMREC meeting. If the applicant is a student, the paper copy of the application form must be signed by the Academic Supervisor.

4. Committee meeting dates and application submission dates are listed on the FHMREC website. Applications must be submitted by the deadline date, to:

    Dr Diane Hopkins
    B14, Furness College
    Lancaster University,
    LA1 4YG
    d.hopkins@lancaster.ac.uk

5. Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application.

6. Attend the committee meeting on the day that the application is considered, if required to do so.

1. **Title of Project**: Work Capability Assessments: The experiences of individuals with traumatic brain injury

2. **Name of applicant/researcher**: Rebecca Potts

3. **Type of study**

☒ Includes *direct* involvement by human subjects.

☐ Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. Please complete the University Stage 1 Self Assessment part B. This is available on the Research Support Office website: LU Ethics. Submit this, along with all project documentation, to Diane Hopkins.

4. If this is a student project, please indicate what type of project by marking the relevant box/deleting as appropriate: (please note that UG and taught PG projects should complete **FHMREC form UG-tPG**, following the procedures set out on the FHMREC website

PG Diploma ☐ Masters dissertation ☐ PhD Thesis ☐ PhD Pall. Care ☐

PhD Pub. Health ☐ PhD Org. Health & Well Being ☐ PhD Mental Health ☐ MD ☐

DClinPsy SRP ☐ [if SRP Service Evaluation, please also indicate here: ☐] DClinPsy Thesis ☒

Applicant Information

5. **Appointment/position held by applicant and Division within FHM** Student of the Doctorate in Clinical Psychology Programme

6. **Contact information for applicant**:
E-mail: r.potts1@lancaster.ac.uk **Telephone**: [redacted]

Address: Clinical Psychology, Faculty of Health and Medicine, Furness Building, Lancaster University, Lancaster, LA1 4YG

7. **Project supervisor(s), if different from applicant**: Prof Bill Sellwood, Dr Stephen Weatherhead and Dr Andy Tyerman

8. **Appointment held by supervisor(s) and institution(s) where based (if applicable)**:
Prof Bill Sellwood: Research and programme director – Lancaster DClinPsy
Dr Stephen Weatherhead: Clinical tutor – Lancaster DClinPsy
Dr Andy Tyerman: Consultant Clinical Neuropsychologist [redacted]

9. **Names and appointments of all members of the research team (including degree where applicable)**
Rebecca Potts – Trainee Clinical Psychologist – Lancaster DClinPsy
Prof Bill Sellwood: Research and programme director – Lancaster DClinPsy
Dr Stephen Weatherhead: Clinical tutor – Lancaster DClinPsy
Dr Andy Tyerman: Consultant Clinical Neuropsychologist [redacted]

The Project

NOTE: In addition to completing this form you must submit a detailed research protocol and all supporting materials.

10. **Summary of research protocol in lay terms (indicative maximum length 150 words**):
The Work Capability Assessment (WCA) is a checklist introduced in by the government in 2008 to assess the functional ability of an individual to hold employment, thereby also deciding upon benefits received. People with Traumatic Brain Injury (TBI) experience a range of physical, cognitive, emotional, social, and behavioural difficulties which often fluctuate; the way in which this translates into functional disability is complex. The WCA may not be sensitive enough to take all of these difficulties into account. In addition, patients and their families tend to focus on returning to their previous level of functioning, as a way of coping. They may unintentionally minimise or underestimate their difficulties and so a full and accurate portrayal of their functioning may not be communicated. A survey by Headway found that 53% of people with brain injury placed in a work-related activity group as a result of the WCA, felt that they should have been in the higher level support group.

Low return to work rates for people with TBI indicate that clinical psychologists and other professionals working within this field are likely to have a majority of clients who have claimed benefits after becoming disabled by their brain injury. Questions arising for these professionals include how they might best mitigate the impact of the WCA on their clients, as well as how they might advise administrators of the benefits system in terms of minimising the emotional demands placed upon those assessed and meaningfully assessing the functional impact of TBI.

The aim of the proposed qualitative study is to explore the views and experiences of working age adults regarding the WCA. Individual interviews will be conducted and a critical narrative approach will be used to analyse the data. Langdridge (2007) outlines six stages as a framework for carrying out narrative analysis: (1) A critique of the illusions of subjectivity (2) Identifying narratives, narrative tone, and rhetorical function (3) Identities and identity work (4) Thematic priorities and relationships (5) Destabalising the narrative (6) Synthesis.

The research questions are:
(1) How do working age adults with a traumatic brain injury experience the work capability assessment?
(2) What are their views regarding how disability might best be assessed in the context of brain injury?

11. **Anticipated project dates (month and year only**)
Ethics submission: June 2016 for July 2016 review Start date: August 2016 End date: July 2017
Recruitment is intended to take place Aug – Oct 2016. If ethical approval is received during August 2016, then the project will start immediately following receipt of the approval letter. If further changes are required, the start date will be September 2016. The thesis is due to be handed submitted in May 2017.

12. **Please describe the sample of participants to be studied (including maximum & minimum number, age, gender**):
Participants will be working age adults with a diagnosed Traumatic Brain Injury (TBI). The study will aim to recruit 8-15 participants. This will be a convenience sample based on those who respond to advertising. As qualitative research aims for a logical, rather than statistical, generalisation of findings (Yardley, 2015) there is no specific sample size which can be seen as ensuring that the study is viable in advance. While some literature on qualitative research suggests that data saturation may be reached at a certain sample size, the definitions of data saturation are not always compatible with the epistemology of critical narrative analysis. Critical narrative analysis is not only concerned with identifying themes within the stories told by individuals to convey their experience of their own

lifeworld, but also considers how these narratives are constructed and influenced within the social and societal context. When conducting the narrative interviews, the richness and depth of the stories may vary, as may the extent of opportunity to use critical social theory to interpret the findings. It has been suggested that "case study work from this perspective is, in many ways, ideal" as the method is very labour intensive (Langdridge, 2007, p.132). However, a study with a large research team which used focus groups successfully analysed data from 46 participants using Langdridge's (2007) guidelines for critical narrative analysis (Stacey et al., 2015). Therefore a decision will need to be made in discussion with supervisors regarding when to cease recruiting, based on the quality of the data collected as well as the time constraints associated with a DClinPsy thesis research project.

Participants will need to meet the following inclusion criteria: (1) A diagnosis of TBI; (2) Working age adults (defined as aged 16-65 years); (3) Taken part in a WCA (at minimum, have completed an ESA-50 form) following their TBI; (4) Most recent contact with the WCA process within the last 36 months.

In addition, the following exclusion criteria will be applied: (1) Individuals with degenerative brain conditions; (2) Individuals whose brain injury, or first of multiple brain injuries, occurred during childhood (under the age of 16 years); (3) Non-English speaking individuals. Individuals with a language barrier in addition to their brain injury may be at a double disadvantage in terms of taking part in the WCA process. This is considered to be an important area that warrants specific future research. This issue will be covered within the literature review in the final write up of the project and recommendations will be made in regards to future research with this particular client group.

Once the researcher has determined whether respondents meet the inclusion and exclusion criteria, participants will be selected on a "first come, first served" basis. Should the volume of responses exceed the target sample size of 8-15 participants, then recruitment in the North West of England will initially be prioritised due to the time and expense associated with extensive travel. There will be no additional selection criteria.

13. **How will participants be recruited and from where? Be as specific as possible**.
The research project will be advertised via charities such as the United Kingdom Acquired Brain Injury Forum (UKABIF) and Headway. Recruitment will also take place through social media, and relevant professional networks including the British Association of Brain Injury Case Managers. Charities and networks will be contacted by the lead researcher using email (university email account) and provided with a copy of the participant information sheet., along with any other information they may wish to review before making a decision about advertising the study. If the organisation agrees to assist with recruitment, they will be provided with electronic copies of advertising materials and participant information sheets. They will be asked to advertise the study through available channels including: webpages; online forums; associated social media (including Facebook pages and Twitter accounts); newsletters; and noticeboards in waiting rooms (if applicable). Charities and networks will also be offered the opportunity to have the researcher visit them in person to explain the research and answer any questions. The lead researcher, or another member of the research team, will carry out these visits. It will be made clear during any such visit that participation is entirely voluntary and there is no obligation to take part.
The researcher (Rebecca Potts) will "tweet/re-tweet" adverts from charities and networks using their personal (professional use only) twitter account in order to further share the advert.

Posters and information sheets will contain the contact information for the researcher. Participants will then contact the researcher by email or telephone if they are interested in taking part. The researcher will answer any questions they might have and arrange a suitable interview time if they wish to participate.

14. **What procedure is proposed for obtaining consent**?

When potential participants initiate contact with the researcher, the researcher will ask if they have seen an information sheet, as they may be responding to a poster. If they haven't already accessed an information sheet, then a copy will be provided to them via post or email. This will ensure that all participants will have had the opportunity to review the information sheet at least 24 hours prior to interview. A copy of the information sheet will also be taken along to scheduled interviews and a hard copy given to the participant. There is a standard and "easy read" version of the information sheet, in order to accommodate cognitive difficulties with language and comprehension. Further adjustments to the delivery of the information sheet will be made as needed (e.g. reading it aloud).

The information sheet states that by consenting to take part, participants are agreeing to the interview being audio recorded and transcribed. This will also be communicated verbally. Participants will be asked to sign a consent form prior to taking part in the interview, with assistance from a family member or carer if needed. Verbal consent will also be asked for (and audio recorded) at the start of the interview. The information sheet states that participants are free to withdraw from the study at any time up to the completion of data analysis, and that this will not result in any negative consequences. This will also be communicated verbally before the interview and repeated as appropriate during the interview.

The researcher will be aware of potential issues relating to the capacity of individuals to consent to take part in the study, as set out by the Mental Capacity Act (2005). Participants with a brain injury are more likely than the general population to experience difficulties with the cognitive functions required for decision making. In line with the Mental Capacity Act (2005), there will be an assumption of capacity at the outset. If the researcher subsequently sees reason to doubt whether the participant has capacity to consent, then they will not go ahead with the interview. The capacity of a participant with a brain injury to consent would not be expected to decrease following the interview, unless this was due to an additional cause (such as a degenerative brain condition which is part of the exclusion criteria).

15. **What discomfort (including psychological eg distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks. State the timescales within which participants may withdraw from the study, noting your reasons.**

The focus of this research is the experience of WCA from the point of view of people with a TBI. Irrespective of the research, people who have sustained a brain injury often experience a level of distress as they adjust to the event and the consequences. In terms of the WCA, there is evidence that some people with a range of disabilities have found the WCA process distressing in itself. Therefore, it is possible that asking participants to share their experiences has the potential to cause or exacerbate distress. The researcher will inform and remind participants that they can ask for the interview to stop at any time and will remain alert to any signs of distress. As a trainee clinical psychologist, the researcher has some experience of working with people who have sustained a brain injury and has developed skills to contain difficult emotions. Participants will be sign posted to other services where appropriate and the information sheet directs participants towards services that can help. Participants will be able to withdraw from the study following the interview by contacting the researcher. It is stated within the information sheet that if the data have already been incorporated into themes, it might not be possible to withdraw an individual contribution. However, every effort will be made to do so, up to the point of submission of the assignment in May 2017.

16. **What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take**).

It will be necessary for the lead researcher to go to participants' homes or a community location in order to conduct the interviews. To ensure the safety of the researcher, Lancashire Care Foundation Trust (LCFT) lone working policy and Lancaster University safety in fieldwork policy will be followed. This will include the use of a 'buddy' system to ensure the safety of the researcher and participants. The researcher will ensure that a colleague is available to perform the 'buddy' role for each scheduled interview. This will involve leaving the time of the interview and a sealed envelope containing the location. If the researcher has not contacted the buddy by a pre-arranged time, the buddy will try to contact the researcher. If they do not manage to contact them, then they will open the envelope and inform the police of the situation. If the researcher feels unsafe at any time, they will leave the location immediately. Participants will only be able to contact the researcher via a dedicated research phone number or Lancaster University email address.

17. **Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study**.
There are no direct benefits to taking part in this study, although some participants may appreciate having the opportunity to share their experience.

18. **Details of any incentives/payments (including out-of-pocket expenses) made to participants**:
There are no payments or incentives available for taking part in the study. If the interview takes place at a location other than the participants home, then travel expenses to and from the interview will be reimbursed, up to a total of £20 per participant. The cost of travel expenses is covered by the DClinPsy programme.

19. **Briefly describe your data collection and analysis methods, and the rationale for their use. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality**.
The research is qualitative in design and will use narrative methods. Data will be collected via unstructured interviews, as narrative methods intend for individuals to have space to share their own story. The participants will be oriented to the context of the WCA and then invited to share their story. The researcher will ask questions for clarification purposes as needed. Where possible, participants will be interviewed alone. However, if participants' need or want the support of a family member or carer to take part then this will be acceptable. The interviews will be audio recorded and transcribed by the lead researcher (Rebecca Potts). The study will use critical narrative analysis to interpret the data collected. This approach has been chosen as it provides a framework for analysing personal narratives while considering the broader context and the position from which they are being created.

Participants will be asked whether they would like the write-up of the study to contain their real name, a pseudonym of their choosing, or a pseudonym of the researcher's choosing. This will ensure anonymity if the participants wishes. Participants will be informed that any personal information will be transported and stored securely. It will be explained within the information sheet that direct quotes from participants may be used in the write up. However, their name will not be assigned to these unless they want it to be. Participants will also be made aware that if the researcher has concerns about their safety, or the safety of anyone else, then the appropriate authorities will need to be informed. This includes, but is not limited to, the police and social services. Wherever possible, the researcher will inform the participant before they break confidentiality. The only exception to this would be if the researcher believed the risk would be increased by doing so.

20. **If relevant, describe the involvement of your target participant group in the *design and conduct* of your research**.

The target participation group has not been involved in the specifics of the design and conduct of the research. However, the topic of the study was chosen by the research team based on clinical experience and feedback from service users with brain injury regarding the WCA.

21. **What plan is in place for the storage of data (electronic, digital, paper, etc.)? Please ensure that your plans comply with the Data Protection Act 1998**.
The typed interview transcripts will be stored on Lancaster secure server for 10 years following submission of the thesis. The research director (currently Bill Sellwood) or a member of staff at Lancaster University assigned by the research director will be responsible for deleting the transcripts as scheduled.
Hard copies of demographic information and consent forms will be locked away until the researcher is able to scan them and store an electronic copy on the Lancaster server for 10 years (as per the same procedure outlined for transcripts). The paper copies will be destroyed as soon as they have been scanned. Identifying details for participants will be kept electronically in a separate file on the password encrypted Lancaster University server. These identifying details will be deleted by the researcher once the project has been assessed and participants wishing to receive a summary of findings have done so.

22. Will audio or video recording take place? ☐ no ☒ audio ☐ video
If yes, what arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?
Interviews will be audio recorded. Since it is not possible to encrypt the portable audio recording device, the audio files will be uploaded to Box immediately for secure storage and sharing with supervisors where necessary. The audio files will then be deleted from the audio recorder. Where immediate transfer to Box is not possible, the audio recorder will be locked away until the researcher can access a computer to transfer the file to Box. All files will be saved to Lancaster University server as soon as possible. Audio files will be kept on the university server until the project has been marked and will then be deleted.

23. **What are the plans for dissemination of findings from the research? If you are a student, include here your thesis**.
This research will be written up as a thesis assignment for the Doctorate in Clinical Psychology. The research team will also attempt to publish the research in an academic journal. Participants will have the option of receiving a summary of the results. The research team may present the research at conferences if the opportunity were to arise. Participants will be informed about plans for dissemination.

24. **What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek guidance from the FHMREC**?
Given that this research is related to government policy, it will be important to fully inform participants about the capacity for influencing change to the system. It will be made clear within the information sheet that the lead researcher is associated with Lancaster University and that the study is not connected to parties who make decisions in regards to the WCA. Participants will be informed that there is an intent to disseminate the findings from the study to contribute to the evidence base regarding the WCA. However, the researcher does not have the ability to make direct changes to the system.

Signatures: Applicant: ………………………………………………………………………………

Date: …………………………………………………….......................................

*Project Supervisor (if applicable): ………………………………….................

Date: …………………………………………………….......................................

*I have reviewed this application, and discussed it with the applicant. I confirm that the project methodology is appropriate. I am happy for this application to proceed to ethical review.

Lancaster University

Applicant: Rebecca Potts
Supervisor: Bill Sellwood and Stephen Weatherhead
Department: Health Research
FHMREC Reference: FHMREC150xx

26 September 2016

Dear Rebecca,

Re: Work Capability Assessments: The experiences of individuals with traumatic brain injury

Thank you for submitting your research ethics application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

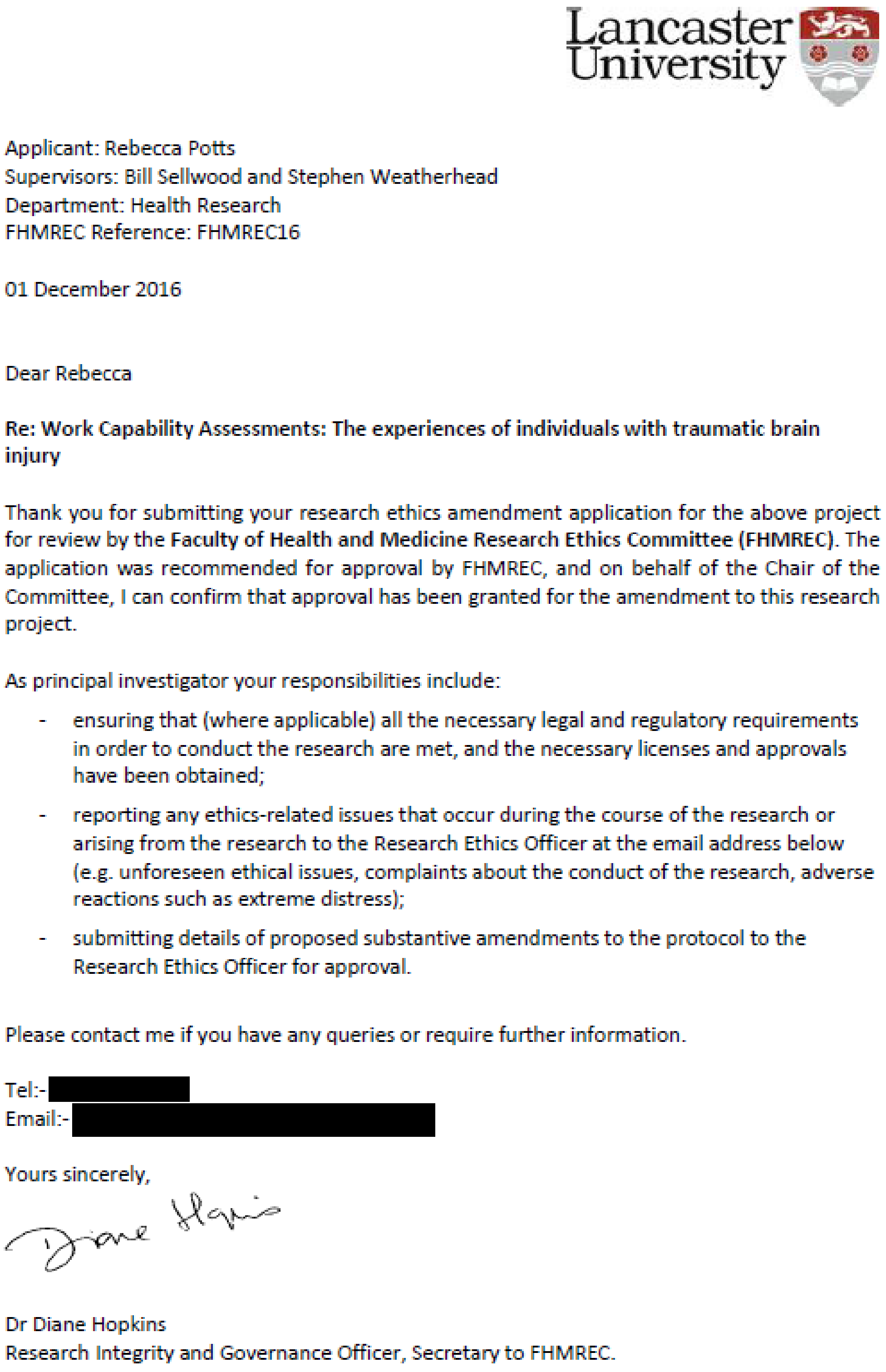
Please contact me if you have any queries or require further information.

Tel:- [redacted]
Email:- [redacted]

Yours sincerely,

Diane Hopkins

Dr Diane Hopkins
Research Integrity and Governance Officer, Secretary to FHMREC.



Lancaster University

Applicant: Rebecca Potts
Supervisors: Bill Sellwood and Stephen Weatherhead
Department: Health Research
FHMREC Reference: FHMREC16

01 December 2016

Dear Rebecca

Re: Work Capability Assessments: The experiences of individuals with traumatic brain injury

Thank you for submitting your research ethics amendment application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for the amendment to this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Tel:- [redacted]
Email:- [redacted]

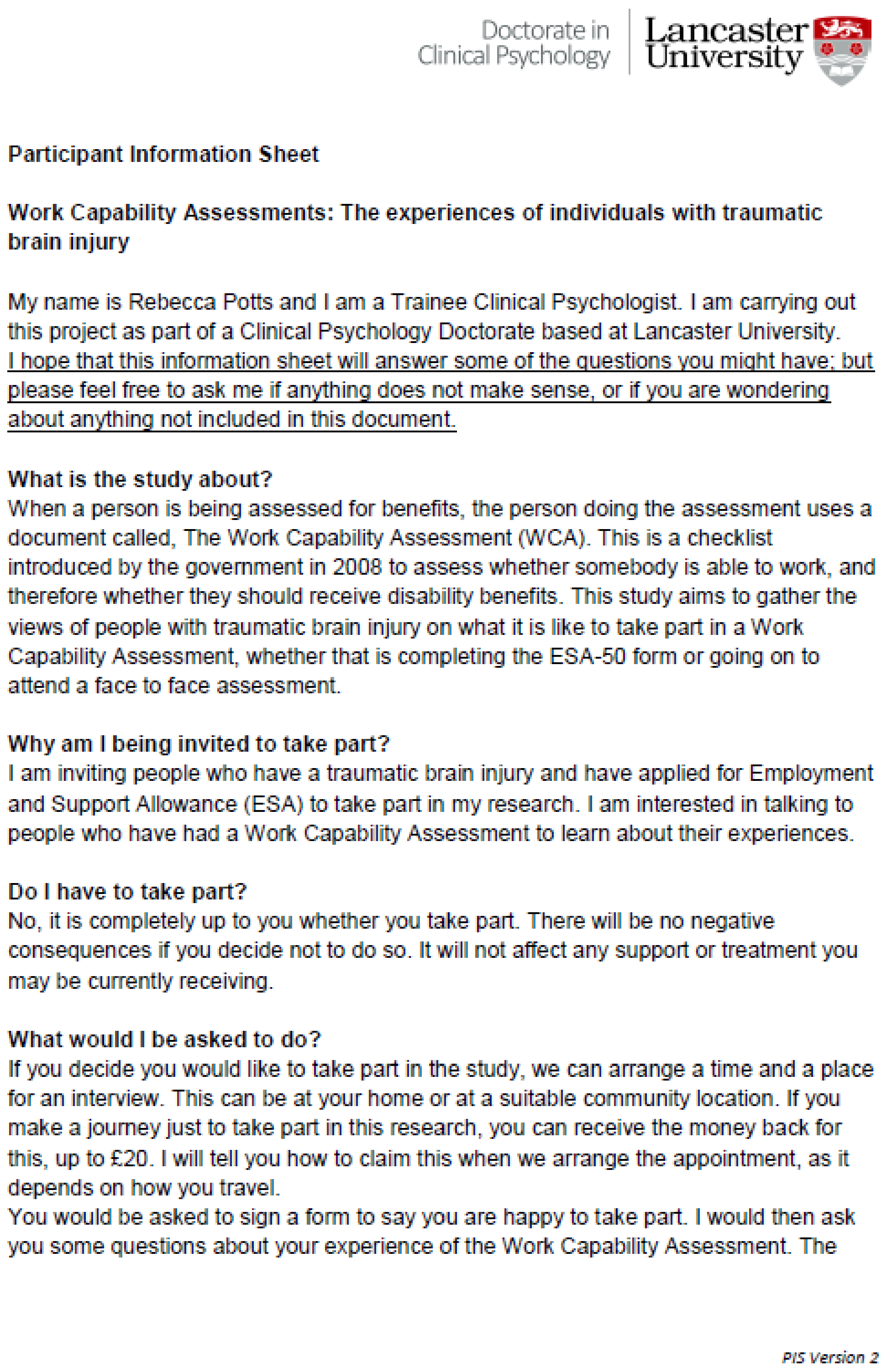
Yours sincerely,

Diane Hopkins

Dr Diane Hopkins
Research Integrity and Governance Officer, Secretary to FHMREC.

Appendix 4-A

Participant Information Sheet



Doctorate in Clinical Psychology

Lancaster University

Participant Information Sheet

Work Capability Assessments: The experiences of individuals with traumatic brain injury

My name is Rebecca Potts and I am a Trainee Clinical Psychologist. I am carrying out this project as part of a Clinical Psychology Doctorate based at Lancaster University. I hope that this information sheet will answer some of the questions you might have; but please feel free to ask me if anything does not make sense, or if you are wondering about anything not included in this document.

What is the study about?

When a person is being assessed for benefits, the person doing the assessment uses a document called, The Work Capability Assessment (WCA). This is a checklist introduced by the government in 2008 to assess whether somebody is able to work, and therefore whether they should receive disability benefits. This study aims to gather the views of people with traumatic brain injury on what it is like to take part in a Work Capability Assessment, whether that is completing the ESA-50 form or going on to attend a face to face assessment.

Why am I being invited to take part?

I am inviting people who have a traumatic brain injury and have applied for Employment and Support Allowance (ESA) to take part in my research. I am interested in talking to people who have had a Work Capability Assessment to learn about their experiences.

Do I have to take part?

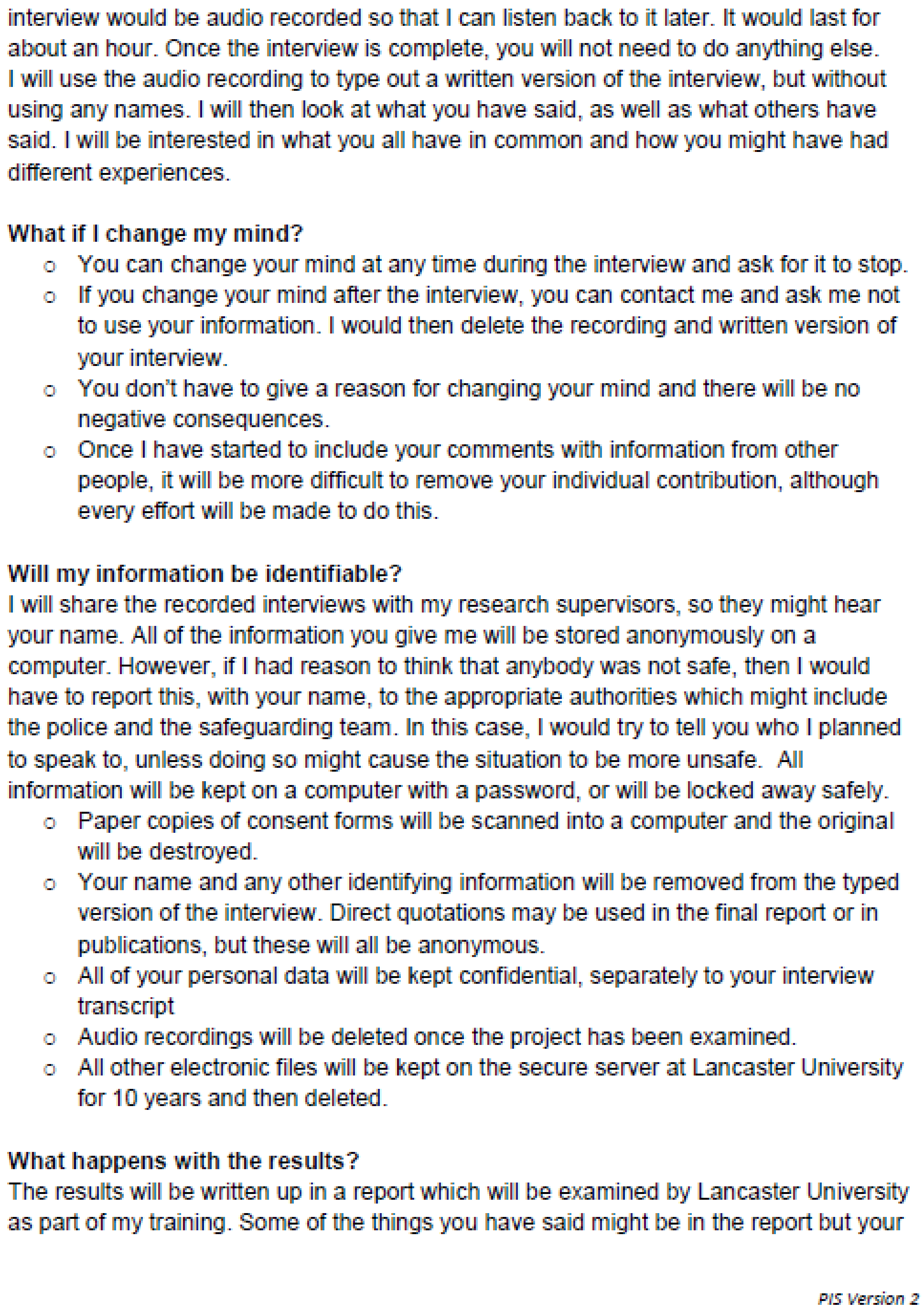
No, it is completely up to you whether you take part. There will be no negative consequences if you decide not to do so. It will not affect any support or treatment you may be currently receiving.

What would I be asked to do?

If you decide you would like to take part in the study, we can arrange a time and a place for an interview. This can be at your home or at a suitable community location. If you make a journey just to take part in this research, you can receive the money back for this, up to £20. I will tell you how to claim this when we arrange the appointment, as it depends on how you travel.

You would be asked to sign a form to say you are happy to take part. I would then ask you some questions about your experience of the Work Capability Assessment. The

PIS Version 2



interview would be audio recorded so that I can listen back to it later. It would last for about an hour. Once the interview is complete, you will not need to do anything else.
I will use the audio recording to type out a written version of the interview, but without using any names. I will then look at what you have said, as well as what others have said. I will be interested in what you all have in common and how you might have had different experiences.

What if I change my mind?

- You can change your mind at any time during the interview and ask for it to stop.
- If you change your mind after the interview, you can contact me and ask me not to use your information. I would then delete the recording and written version of your interview.
- You don't have to give a reason for changing your mind and there will be no negative consequences.
- Once I have started to include your comments with information from other people, it will be more difficult to remove your individual contribution, although every effort will be made to do this.

Will my information be identifiable?

I will share the recorded interviews with my research supervisors, so they might hear your name. All of the information you give me will be stored anonymously on a computer. However, if I had reason to think that anybody was not safe, then I would have to report this, with your name, to the appropriate authorities which might include the police and the safeguarding team. In this case, I would try to tell you who I planned to speak to, unless doing so might cause the situation to be more unsafe. All information will be kept on a computer with a password, or will be locked away safely.

- Paper copies of consent forms will be scanned into a computer and the original will be destroyed.
- Your name and any other identifying information will be removed from the typed version of the interview. Direct quotations may be used in the final report or in publications, but these will all be anonymous.
- All of your personal data will be kept confidential, separately to your interview transcript
- Audio recordings will be deleted once the project has been examined.
- All other electronic files will be kept on the secure server at Lancaster University for 10 years and then deleted.

What happens with the results?

The results will be written up in a report which will be examined by Lancaster University as part of my training. Some of the things you have said might be in the report but your

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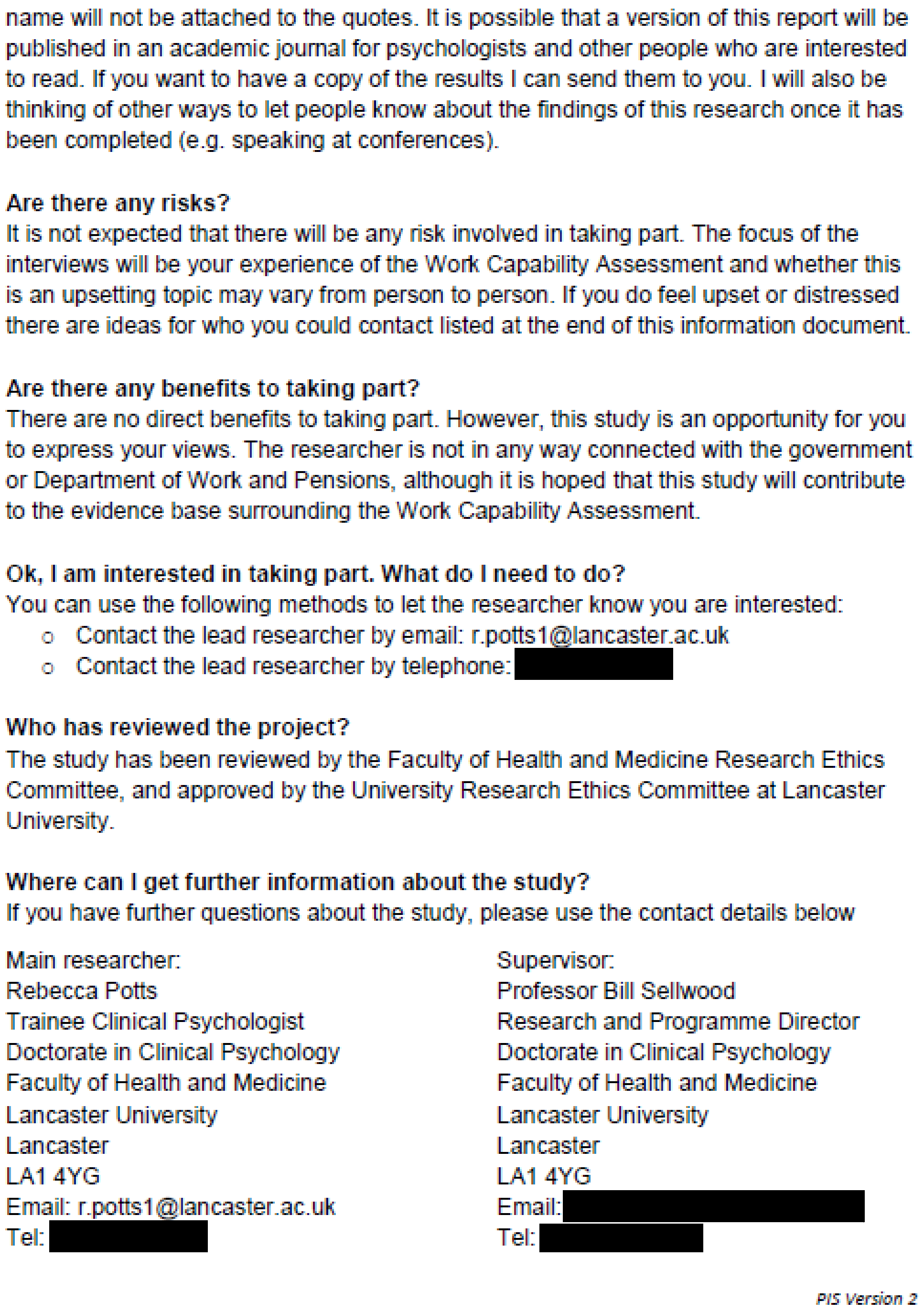


name will not be attached to the quotes. It is possible that a version of this report will be published in an academic journal for psychologists and other people who are interested to read. If you want to have a copy of the results I can send them to you. I will also be thinking of other ways to let people know about the findings of this research once it has been completed (e.g. speaking at conferences).

Are there any risks?

It is not expected that there will be any risk involved in taking part. The focus of the interviews will be your experience of the Work Capability Assessment and whether this is an upsetting topic may vary from person to person. If you do feel upset or distressed there are ideas for who you could contact listed at the end of this information document.

Are there any benefits to taking part?

There are no direct benefits to taking part. However, this study is an opportunity for you to express your views. The researcher is not in any way connected with the government or Department of Work and Pensions, although it is hoped that this study will contribute to the evidence base surrounding the Work Capability Assessment.

Ok, I am interested in taking part. What do I need to do?

You can use the following methods to let the researcher know you are interested:

- Contact the lead researcher by email: r.potts1@lancaster.ac.uk
- Contact the lead researcher by telephone: [redacted]

Who has reviewed the project?

The study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee, and approved by the University Research Ethics Committee at Lancaster University.

Where can I get further information about the study?

If you have further questions about the study, please use the contact details below

Main researcher:	Supervisor:
Rebecca Potts	Professor Bill Sellwood
Trainee Clinical Psychologist	Research and Programme Director
Doctorate in Clinical Psychology	Doctorate in Clinical Psychology
Faculty of Health and Medicine	Faculty of Health and Medicine
Lancaster University	Lancaster University
Lancaster	Lancaster
LA1 4YG	LA1 4YG
Email: r.potts1@lancaster.ac.uk	Email: [redacted]
Tel: [redacted]	Tel: [redacted]

PIS Version 2

Complaints
If you want to raise a concern or make a complaint and you do not want to report this to the researcher, please contact:

Professor Roger Pickup
Associate Dean for Research
Faculty of Health and Medicine
Lancaster University
Lancaster
LA1 4YG

Email: [redacted]
Tel: [redacted]

What if I feel worried or upset afterwards?
If you feel worried or upset after the interview, you may wish to talk to a professional you trust such as a GP or counsellor. You could also contact one of the telephone numbers below.

To talk about how you are feeling:	For issues relating to brain injury:
The Samaritans	Headway
Tel: 08457 90 90 90 (24-hour helpline)	Tel: 0808 800 2244 (Mon-Fri, 9am-5pm)
Website: www.samaritans.org.uk	E-mail: helpline@headway.org.uk

Thank you for reading this information.

Appendix 4-B

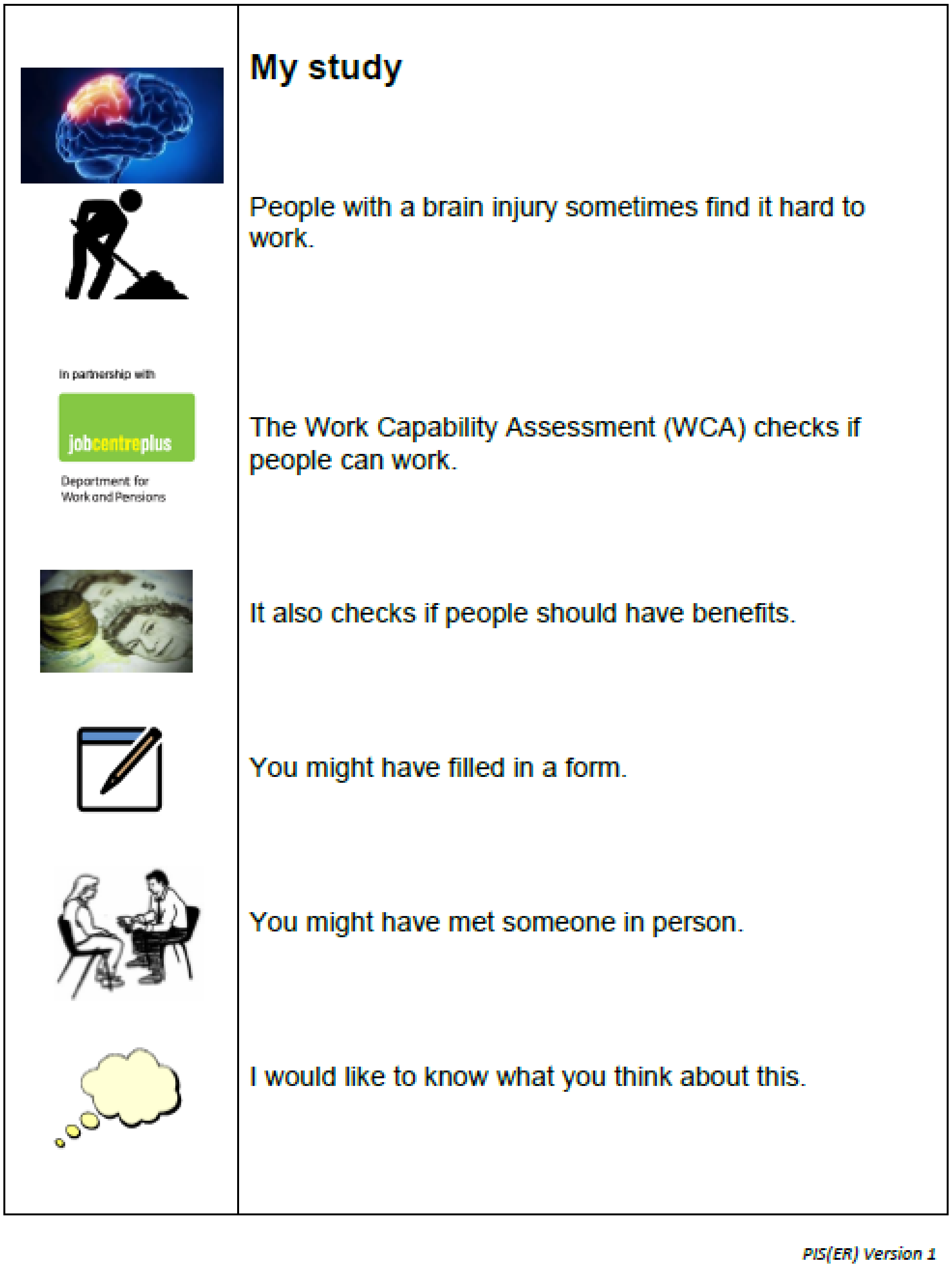
Participant Information Sheet – Easy Read

Doctorate in Clinical Psychology | Lancaster University

Participant Information Sheet – Easy Read

Work Capability Assessments: The experiences of individuals with traumatic brain injury

	Hello
[redacted]	My name is Rebecca Potts.
Lancaster University	I am studying a Doctorate in Clinical Psychology at Lancaster University.
	If you have a question, please ask me.



My study

People with a brain injury sometimes find it hard to work.

In partnership with
jobcentreplus
Department for Work and Pensions

The Work Capability Assessment (WCA) checks if people can work.

It also checks if people should have benefits.

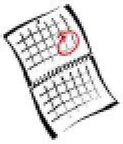
You might have filled in a form.

You might have met someone in person.

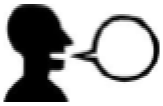
I would like to know what you think about this.

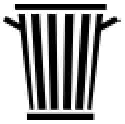
PIS(ER) Version 1

	Taking part
	I am asking people who have had a traumatic brain injury to join in my study.
	You will need to have done a Work Capability Assessment.
	It is up to you if you want to talk to me.

	What will happen
	I will ask you for a date and time I can talk to you.
	You can meet me at your home.

PIS(ER) Version 1

	I will ask you to sign a form to say you are happy to talk to me.
	I will then ask you what it was like to have a Work Capability Assessment.
	I will use a tape recorder to record what you say.
	I will type what you say onto a computer.
	I will not use your name.

	Changing your mind
	You can decide to stop talking to me at any time.
	You can ask me to delete the recording.

	What happens next
	I will keep what you have said on my computer.
	I might show it to my team at university.
	I will not tell them your name.

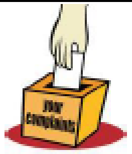
	I will write a report about what you and other people have said.
	I will not use your name in my report.
✉	I can send you the results if you would like to see them.

	Is it safe?
Lancaster University ✓	Lancaster University has said it is ok for me to do this study.
	Some people can feel upset when they talk about things that are hard.

☑ Yes ☐ No	**If you want to take part**
☎	You can phone me: [redacted]
@	You can email me: r.potts1@lancaster.ac.uk

?	**If you want to know more**
☎ @	You can talk to me Rebecca Potts Trainee Clinical Psychologist Doctorate in Clinical Psychology Faculty of Health and Medicine Lancaster University Lancaster LA1 4YG Email: r.potts1@lancaster.ac.uk Tel: [redacted]

☎	You can talk to Bill, who is my supervisor Dr Bill Sellwood Research and Programme Director Doctorate in Clinical Psychology Faculty of Health and Medicine Lancaster University Lancaster LA1 4YG Email: [redacted] Tel: [redacted]

	**Complaints**
☎	If you want to complain about the study, you can talk to Roger. Roger is in charge of studies at Lancaster University. Professor Roger Pickup Associate Dean for Research Faculty of Health and Medicine Lancaster University Lancaster LA1 4YG Email: [redacted] Tel: [redacted]

If you feel upset

If you feel upset you can talk to someone:

The Samaritans
Tel: 08457 90 90 90 (24-hour helpline)
Website: www.samaritans.org.uk

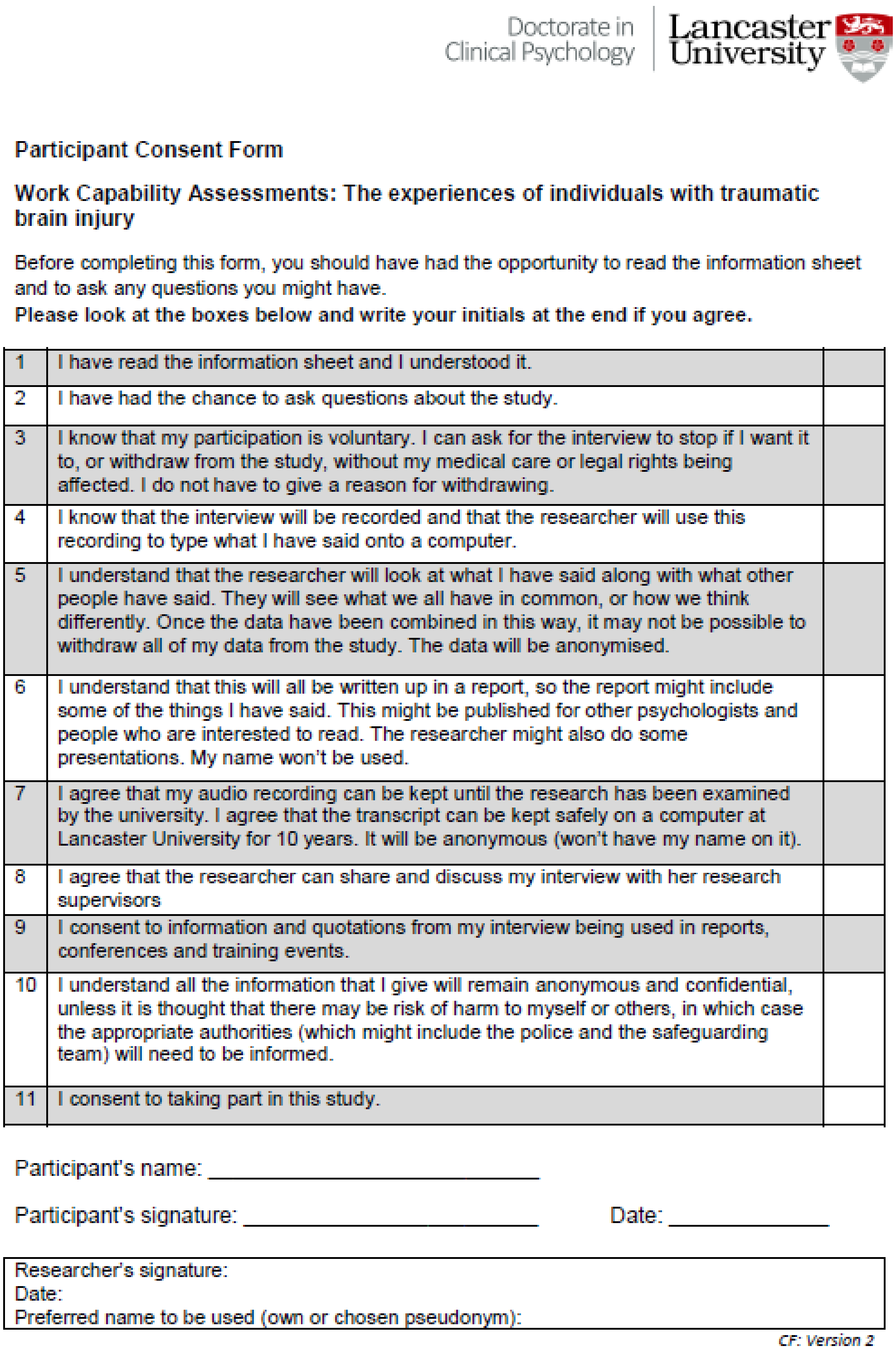
If you want to know more about brain injury:

Headway
Tel: 0808 800 2244 (Mon-Fri, 9am-5pm)
E-mail: helpline@headway.org.uk

Thank you

Appendix 4-C

Consent Form



Doctorate in Clinical Psychology | Lancaster University

Participant Consent Form

Work Capability Assessments: The experiences of individuals with traumatic brain injury

Before completing this form, you should have had the opportunity to read the information sheet and to ask any questions you might have.
Please look at the boxes below and write your initials at the end if you agree.

1	I have read the information sheet and I understood it.	
2	I have had the chance to ask questions about the study.	
3	I know that my participation is voluntary. I can ask for the interview to stop if I want it to, or withdraw from the study, without my medical care or legal rights being affected. I do not have to give a reason for withdrawing.	
4	I know that the interview will be recorded and that the researcher will use this recording to type what I have said onto a computer.	
5	I understand that the researcher will look at what I have said along with what other people have said. They will see what we all have in common, or how we think differently. Once the data have been combined in this way, it may not be possible to withdraw all of my data from the study. The data will be anonymised.	
6	I understand that this will all be written up in a report, so the report might include some of the things I have said. This might be published for other psychologists and people who are interested to read. The researcher might also do some presentations. My name won't be used.	
7	I agree that my audio recording can be kept until the research has been examined by the university. I agree that the transcript can be kept safely on a computer at Lancaster University for 10 years. It will be anonymous (won't have my name on it).	
8	I agree that the researcher can share and discuss my interview with her research supervisors	
9	I consent to information and quotations from my interview being used in reports, conferences and training events.	
10	I understand all the information that I give will remain anonymous and confidential, unless it is thought that there may be risk of harm to myself or others, in which case the appropriate authorities (which might include the police and the safeguarding team) will need to be informed.	
11	I consent to taking part in this study.	

Participant's name: ____________________________

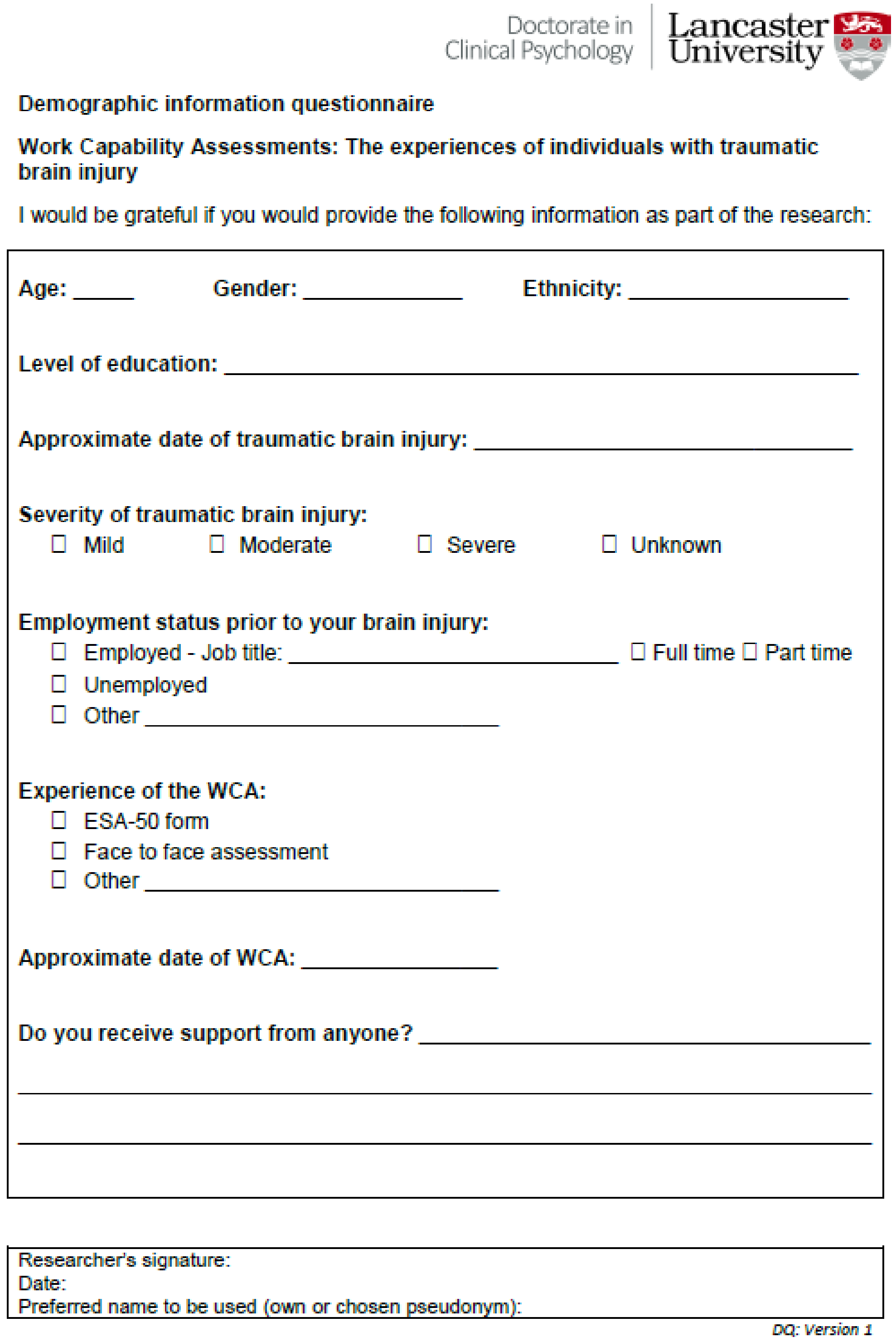
Participant's signature: _________________________ Date: _____________

Researcher's signature:
Date:
Preferred name to be used (own or chosen pseudonym):

CF: Version 2

Appendix 4-D

Demographic Questionnaire



Doctorate in
Clinical Psychology

Lancaster
University

Demographic information questionnaire

Work Capability Assessments: The experiences of individuals with traumatic brain injury

I would be grateful if you would provide the following information as part of the research:

Age: _____ **Gender:** _____________ **Ethnicity:** __________________

Level of education: ____

Approximate date of traumatic brain injury: _______________________________

Severity of traumatic brain injury:
☐ Mild ☐ Moderate ☐ Severe ☐ Unknown

Employment status prior to your brain injury:
☐ Employed - Job title: ___________________________ ☐ Full time ☐ Part time
☐ Unemployed
☐ Other _____________________________

Experience of the WCA:
☐ ESA-50 form
☐ Face to face assessment
☐ Other _____________________________

Approximate date of WCA: ________________

Do you receive support from anyone? _____________________________________

____

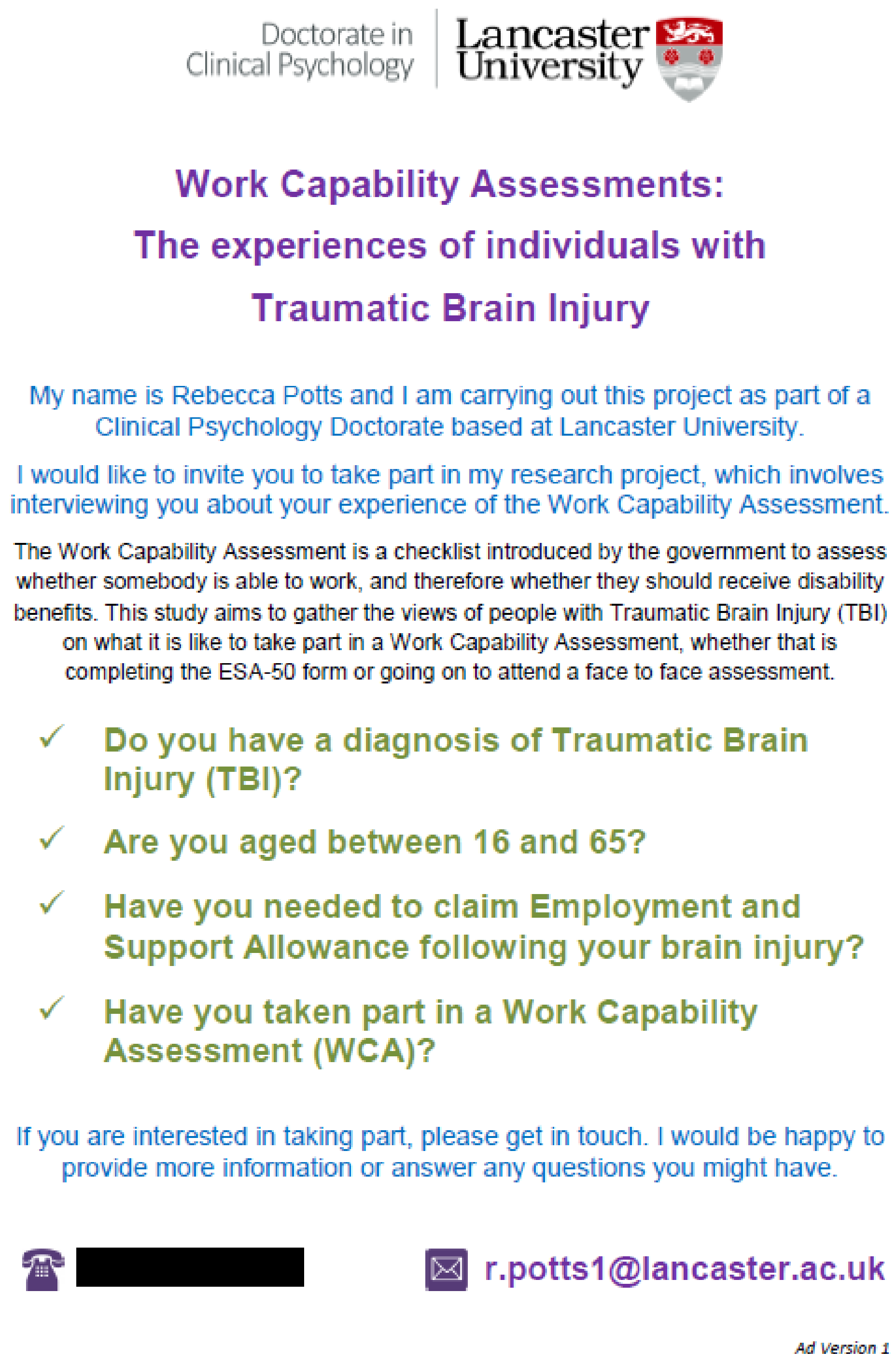
____

Researcher's signature:
Date:
Preferred name to be used (own or chosen pseudonym):

DQ: Version 1

Appendix 4-E

Advertising



Doctorate in Clinical Psychology | Lancaster University

Work Capability Assessments: The experiences of individuals with Traumatic Brain Injury

My name is Rebecca Potts and I am carrying out this project as part of a Clinical Psychology Doctorate based at Lancaster University.

I would like to invite you to take part in my research project, which involves interviewing you about your experience of the Work Capability Assessment.

The Work Capability Assessment is a checklist introduced by the government to assess whether somebody is able to work, and therefore whether they should receive disability benefits. This study aims to gather the views of people with Traumatic Brain Injury (TBI) on what it is like to take part in a Work Capability Assessment, whether that is completing the ESA-50 form or going on to attend a face to face assessment.

- ✓ **Do you have a diagnosis of Traumatic Brain Injury (TBI)?**
- ✓ **Are you aged between 16 and 65?**
- ✓ **Have you needed to claim Employment and Support Allowance following your brain injury?**
- ✓ **Have you taken part in a Work Capability Assessment (WCA)?**

If you are interested in taking part, please get in touch. I would be happy to provide more information or answer any questions you might have.

☎ [redacted] ✉ r.potts1@lancaster.ac.uk

Ad Version 1