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Doctoral Thesis:

The experience of adjusting to Acquired Brain Injuries

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Word Count Statement

Thesis section	Text	Tables, figures, references and appendices	Total
Abstract	295	0	295
Literature Review	7978	8943	16921
Research Paper	7975	10634	18609
Critical Appraisal	3981	1359	5340
Ethics Section	4799	11316	16115
Total	**25020**	**28839**	**56985**

Abstract

This thesis comprises of a literature review, a research paper and a critical appraisal of the research process.

In the literature review, a meta-synthesis methodology was utilised to identify and synthesise 25 studies that explored the experiences of coping and adjusting to a Traumatic Brain Injury (TBI). Four themes emerged; Immediate impact of injury: "I didn't know what one should do as a human being"; Extrinsic factors that influenced recovery process; "Without him, I'm not sure I would have managed to live anymore"; Intrinsic factors that influenced recovery process: "Come on, snap out of it and do what you've got to do" and Post-injury growth: "I am glad I had my accident because it's made me into a better person". Findings are discussed in terms of the impact of loss experienced because of the injury, the impact on the participants' identity, and the intrinsic and extrinsic factors that supported coping and adjustment.

The research paper utilised interpretative phenomenological analysis, whereby six participants who had received a diagnosis of encephalitis were interviewed, to explore how they had made sense of the diagnostic process, experiences of receiving the diagnosis and the impact it had on their coping and adjustment to the illness. Three themes emerged 'Being on a wild goose chase- challenges with getting the diagnosis', 'The emotional rollercoaster experience and 'significance of information and others'. Findings suggest that encephalitis is a complex condition and the diagnostic journey is filled with many uncertainties fuelled by inadequate knowledge and understanding. Certain factors facilitate and hinder adjustment to the condition. The clinical implications of these findings are discussed.

The critical appraisal discusses the comparisons between the findings of the literature review and research paper. Reflections about epistemology are discussed, alongside reflections on the research process as a whole.

Declaration

This thesis records work undertaken for the Doctorate in Clinical Psychology at Lancaster University's Division of Health Research between October 2017 and November 2018. The work presented here is the author's own, except where due reference is made. The work has not been submitted for the award of a higher degree elsewhere.

Name: Jeri Tikare

Signature:

Date: 16th November 2018.

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To the librarians at Lancaster University and more specifically at the NHS library who relentlessly supported me with my literature review, I am very grateful for all your help.

To my friends and family, thank you for your patience, your prayers and support throughout this journey. To my wife who epitomised the beauty and blessing of marriage supporting me through thick and thin. I appreciate all the sacrifice and pain you have had to endure and I appreciate you with all of my heart. To my parents who gave everything so that I could have a future. I will forever be grateful.

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The experience of adjusting to life after a traumatic brain injury in adults: A metasynthesis.

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Prepared for submission to *Journal of Neuropsychology* [1]

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[1] Please note this manuscript was prepared in line with author guidelines for *Journal of Neuropsychology (*See Appendix 4A). The word count is in line with University guidelines rather than journal guidelines **Abstract**

Traumatic Brain Injury (TBI) is a condition that has the potential to suddenly change a person's life, sometimes leaving them with lifelong impairments that could reduce their range of functioning, quality of life and require a period of rehabilitation and adjustment. This metasynthesis aims to bring together the qualitative literature on adjustment in TBI and offer an over-arching interpretation of current findings to contribute to the knowledge of the subjective experience of these individuals. A systematic search of qualitative articles was conducted using four databases which identified 25 studies that met the inclusion criteria. These were subsequently synthesised using Noblit and Hare's (1988) guidance for meta-ethnography. Four themes emerged from the metasynthesis; Early impact of injury: "I didn't know what one should do as a human being"; Extrinsic factors that influenced recovery process: "Without him, I'm not sure I would have managed to live anymore"; Intrinsic factors that influenced recovery process: "Come on, snap out of it and do what you've got to do"; Post-injury growth: "I am glad I had my accident because it's made me into a better person". Important clinical implications are drawn from the findings and future research suggestions are discussed.

Declaration of Interests: None.

The experience of adjusting to life after a traumatic brain injury in adults: A meta-synthesis.

An acquired brain injury (ABI) is described as an injury to the brain that has happened as a result of an event that occurred after birth (Byrne, Coetzer, & Addy, 2017; Headway, 2015). ABI is the umbrella term that incorporates such injuries that occur through a variety of mechanisms including tumours, infection and strokes as well as those that occur as a result of trauma. Thurman et al. (1999) define a traumatic brain injury (TBI) as:

> a craniocerebral trauma, specifically, an occurrence of injury to the head (arising from blunt or penetrating trauma or from acceleration-deceleration forces) that is associated with any of these occurrences attributable to the injury; decreased level of consciousness, amnesia, other neurologic or neuropsychological abnormalities, skull fracture, diagnosed intracranial lesions, or death (p.603).

Several studies have highlighted TBIs as a key area for public health and social care need as it is seen as the foremost cause of mortality and morbidity worldwide in individuals under 45 (Huang, 2013; Tabish & Nabil, 2014; Werner & Engelhard, 2007). It is estimated that 1 million and 1.7 million people in the United Kingdom and the United States respectively are treated in hospitals each year for TBIs of all severities (Huang, 2013; Tennett, 2005). Because of the high incidence of TBIs, they are associated with a significant economic burden, costing the economy in Europe and the United Stated 33 billion Euros and up to 48.3 billion dollars annually respectively (Tagliaferri et al., 2006; Tabish & Nabil, 2014).

In addition to the economic burden, Tabish and Nabil (2014) assert that approximately 10 million people suffer TBIs which are severe enough to result in death or hospitalisation around the world each year. Survivors of the injury also have to deal with significant

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enduring secondary consequences and complex impairments spanning their physical,

cognitive, emotional, behavioural and social functioning, all which can affect their quality of

life (QOL) (Stocchetti & Zanier, 2016; Tabish & Nabil, 2014).

Several studies have highlighted the fact that these enduring consequences make

adjustment and long-term recovery difficult and contribute to maintaining the disability status

of the patient (Humphreys, Woods, Phillips & Macy, 2013; Mathias & Coats, 1999; Tate &

Broe, 1999). However, successful TBI rehabilitation can have positive impacts on these

secondary consequences (Faul et al., 2007; Humphreys et al., 2013; Kayani, Homan, Yun &

Zhu, 2009) and can facilitate adjustment.

Adjustment after a TBI is a term that refers to the patient's responses to the impact of

the injury and it is described as a reflection of how an individual progressively makes

changes to return to a state of equilibrium after the state of distress or disequilibrium resulting

from the injury (Dekker & de Groot, 2018; Moss-Morris, 2013). Assessment of outcomes

and adjustment following TBI is crucial as it facilitates a review of the economic burden it

poses, informs policies, and facilitates the evaluation of intervention and rehabilitation

effectiveness (Humphreys et al., 2013). Assessing adjustment after the injury has proven to

be a challenge for researchers because of some of the distinctive characteristics and

difficulties associated with the injury (Berger, Leven, Pirente, Bouillon & Neugebauer, 1999;

Stocchetti & Zanier, 2016).

Studies that have informed policies and rehabilitation programs for TBIs have been

founded based on quantitative studies that utilise psychometric outcome measures of QOL

and adjustment (Bagiella et al., 2010, Cicerone, et al., 2011; Wilde et al., 2010). Some of

these studies have highlighted the importance of psycho-cognitive, somatic, social, spiritual,

and cultural factors, and engagement in work activities (Azouvi et al., 2016; Cnossen et al,

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2017; Gould & Ponsford, 2015). However, despite the progression in the designs of these outcome measures, several authors have suggested that they lack content validity, show significant differences in outcomes in different trials, and are not representative of all the factors of adjustment or QOL after a TBI (Bragge et al., 2016; Tulsky et al. 2016; Stocchetti & Zanier, 2016). Further, they fail to identify an individual's subjective perspective of adjustment, view of the future and other experiences following the injury (Polinder et al. 2015; Stocchetti & Zanier, 2016). In an attempt to offer a more holistic outcome measure more specific to TBIs, the QOL after TBI (QLIBRI) and the TBIQOL were developed (von Steinbuchel et al., 2010; Tulsky et al., 2016). However the QLIBRI was put together based on literature reviews (von Steinbuchel et al., 2010), while the development of the TBIQOL utilised qualitative research methods using focus groups (Carlozzi, Tulsky, Pamela & Kisala, 2011; Tulsky et al., 2016). The qualitative phase highlighted an impact of the injury in five domains – emotional, physical, cognitive health, social participation and personality change (Carlozzi et al., 2011; Tulsky et al., 2016). This holistic measure highlights the vital contribution of qualitative studies in the creation of credible outcome measurements of QOL and adjustment after TBI and this forms the fulcrum of the relevance of this review.

Over the last few decades, there have been many studies focused on the health outcomes of people with TBIs using qualitative methodology (Conneeley, 2012; Levack et al., 2014; McPherson et al., 2018). This method of research has been recognised as a valuable way to obtain new knowledge as it enables an exploration of a phenomenon by focusing on the participants' lived experience and their interpretation of the experience, which facilitates an understanding in a way that is not accessible by quantitative measures (Anzules, Haennl & Golay, 2007; Espindola & Blay, 2009). Therefore, in order to identify outcomes to reflect experiences of people with TBIs, this study presents a qualitative metasynthesis of all empirical research focused on individuals' experiences of TBIs.

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A qualitative metasynthesis is a systematic and elaborate process of interpretive analysis that generates new knowledge by focusing on selecting qualitative studies on a particular phenomenon, then analysing, and interpreting findings across the studies (Sandelowski, Voils & Barrosso, 2006). The aims of this method of analysis is to give a representation of the increasing volume of qualitative literature and by amalgamating them, increasing the usefulness which in turn would help inform clinical practice, inform outcome measurements design, and improve health care in general (Hannes, Booth, Harris, Noyes, 2013; Toye et al., 2014).

A review of qualitative literature similar to the one proposed in this study was carried out by Levack, Kayes and Fadyl in 2010. In their study, they investigated the lived experience of recovery following TBI. However, no specific method of approach to the meta-synthesis was reported and it did not reflect participants' views of barriers and facilitators of adjustment, limiting its clinical utility. In addition to this, the study included papers with unclear methodologies. Finally, there have been several other studies done since Levack, Kayes and Fadyl's metasynthesis in 2010. Therefore, the current review will also take into consideration several papers from around the world that have been published since the previous review in 2010, employing the meta-ethnographic method as described by Noblit and Hare (1988).

The aim is to produce a synthesised understanding of the lived experience of adjustment in the life of adults who have suffered a TBI, to gain a better understanding of factors that hinder or facilitate adjustment, and to offer ideas for good practice in the rehabilitation of these individuals.

Method

Review design

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This review aimed to combine the findings from qualitative work about the experiences of adjusting to a TBI, utilising the principles of meta-ethnography published by Noblit and Hare (1988) (See appendix 1B). The process of meta-ethnography accomplishes the creation of higher order interpretations by constant comparisons, enabling commonalities and divergences in the meaning and interpretations across the individual studies to be extracted and explored, while at the same time maintaining original participants' accounts and experiences (Britten et al., 2002; Noblit & Hare, 1988). The purpose behind this is to reach novel interpretations beyond those reached by the original authors (Noblit & Hare, 1988).

Step 1: Systematic search and selection of studies

A systemic search of four electronic databases (Medline, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO and Embase) was done and completed in 17th February 2018. Search terms included words and phrases such as TBI, adjustment, experience, and qualitative research. A complete table of the search strategy can be found in Table 1. The search terms were then combined using Boolean terms 'and' and 'or'. Two librarians, who are classed as specialist in the subject (one from the University and one from a National Health Service Trust), were consulted on the search strategy.

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The final search returned 2042 studies across all databases. Limits of 'peer-reviewed academic journal articles' as well as 'English language' were then applied to the results. Thereafter, studies identified from other bibliographies were included, duplicates were removed, and the inclusion and exclusion criteria were then applied to all the abstracts, and full text in some instances. Figure 1 shows a flowchart of article selection.

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Step 2: Inclusion/exclusion criteria

The studies selected were screened using the following criteria: the papers must (a) be classified as what constitutes qualitative research as described by Sandelowski and Barroso (2003), (b) be published in a peer-reviewed journal as a baseline indication of quality, (c) be published in English, (d) have explored the lived experiences of adjusting to a TBI, (e) have only recruited adult participants (over 18 years of age). Also, studies using a mixed method, but where the qualitative data met these criteria were included in the metasynthesis. In addition to this, studies were excluded using the following criteria: if the paper (a) focused on issues outside the experience of solely adjusting to a TBI (for example usefulness of a particular intervention or rehabilitation service), (b) interviewed people who were children when they sustained their injury, (c) lacked specificity regarding the type of ABI (d) recruited family members, caregivers or health professionals (HP), except in papers in which the data and themes from the participants with TBI were clearly distinguishable, (e) reviewed other studies as opposed to reporting their own findings, (f) explored participants' experience of adjusting to a TBI but exploring it based on the evaluation of an intervention, diagnostic tool or a rehabilitation service,(g) editorials and (h) studies not available in full text.

Characteristics of studies

After the application of the inclusion and exclusion criteria, 27 papers of 25 studies published between 1997 and 2018 were included in the review, which all shared the common

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broad aim of qualitatively investigating the experience of adjusting to a TBI. The papers from

Jumisko, Lexell and Soderberg (2005; 2009) as well as Nochi (1998; 2000) are from the same

study. A more comprehensive summary of the features of the studies is available in Table 2.

Across all the studies, there were 392 participants with sample sizes ranging from two to 60;

and the age range from 18 to 81. The studies reported different types of qualitative analysis

for their results (see Table 2).

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Step 3: Evaluating the quality of the studies.

The quality of each of the studies selected was assessed using the Critical Appraisal

Skills Programme (CASP) and qualitative checklist (Public Health Resource Unit, 2006).

The CASP was used to appraise the ethical procedures, research context of the studies

selected, and the methods used (see appendix 1C for the CASP scores).

The CASP was used with a four-point rating scale as adapted from that used by

Duggleby et al. (2010), Murray, and Forshaw (2013) and an overall numeric score for

assessing the quality of the studies retrieved. The first two items on the CASP checklist are

screening questions relating to the lucidity of the research questions and the appropriateness

of the qualitative approach. All studies selected met this criterion. Subsequently, the studies

selected were then assessed using the other eight criteria, which were related to issues around

the design, reflexivity, ethical consideration and the designs of the study.

Subsequently, the scores across the eight domains of the CASP were calculated. The

CASP scores ranged from 21-30. In order to improve the reliability and validity of the

appraisal, as recommended by NHS Quality Improvement Scotland (2011), 10 of the studies

were randomly selected and subjected to an audit by a colleague and any disagreements regarding scores were discussed, with a consensus reached after further scrutiny.

The scores were used as a medium for reflection, as suggested by Barbour (2001), to guide the order in which they are prioritised with the higher scoring studies being read and reviewed before the lower scoring ones (Campbell et al., 2003). Sandelowski and Barroso (2002) assert that regardless of the shortfalls in any studies, exclusion of these studies could amount to significant contributions being overlooked. Therefore, to facilitate inclusion and ensure that relevant data was not missed (Bondas & Hall, 2007) no study was excluded based on the CASP scores.

Step 4: Analysis and synthesis of studies

Studies included in the review were synthesised using Noblit and Hare's (1988), interpretative meta-ethnographic approach.

After the search, the selected articles were read and reread, and concepts and themes were highlighted in order to identify how they were related. Subsequently, relevant information such as sample size, age range, and the number of years post injury were extracted into a table (Table 2).

The concepts and themes identified from each study were then translated into one another. This involves comparing within and between articles' interpretations, concepts, themes or subthemes identified in order to build what Britten et al. (2002) using Schutz's (1962) terminology describe as second-order constructs (derived from the authors of the studies' interpretations of the participants' interpretation of the subject). The participants' interpretations are the first order constructs. The final stage involved synthesising themes into higher order themes or what Britten et al. (2002) describe as third order constructs which

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preserve and epitomise the meaning of the individual studies. Noblit and Hare (1988) assert

that synthesis is an "interpretation of interpretations of interpretations" (*p.35*).

Appendix 1E shows which papers contributed to each of the themes derived from this

meta-synthesis.

Findings

Synthesising the findings of the 25 studies revealed four themes, each with

subthemes. The findings represented participants' journeys from the point of having the

injury to a point where they had either come to terms with living with the injury or not.

Participants' quotations from the original papers are provided to illustrate the findings and

ensure interpretations remain close to the original participants' meanings (Noblit & Hare,

1998). The articles are referred to by the numbers that have been allocated to them (see table

2).

**Early impact of injury: "I didn't know what one should do as a human being" (paper
11b).**

Participants reported experiencing waking after the injury and trying to make sense of

what had happened to them. They described the challenges associated with a perceived

dissociation from reality because of the shocking experience of loss and the difficulties with

understanding what was going on. As a result, they were presented with the challenge of

filling in the gaps and understanding the meaning the injury posed to their sense of self.

Experience of loss. An early impact resulting from the injury was the sense of loss,

which was prevalent across all studies. Some participants reflected on the life-changing

impairments that occurred due to the injury, which deprived them of the person they were;

"before my crash, I used to have many friends, but now I have hardly got any…I have lost things, my friends, normal way of everyday life...'(paper 22, p.233).

The majority of participants discussed the grieving process resulting from the loss and the difficulties with coming to terms with it; "well I still haven't come to terms with being different to what I used to be…whenever I try to talk about it, I end up like this (tearful) …I was still sort of grieving for myself then, what I have lost..." (paper 16, p.5).

Filling in the gaps. The psychological impact of returning to a state of consciousness and not understating what was going on in their surroundings afterwards left some participants disorientated; "I was looking around, and I was like what is happening? Where am I? I don't know it didn't seem real" (paper 18, p.862). Some of the difficulties resulting from a state of confusion include memory loss, which participants struggled to fill; "I can't remember clearly, you know…It's like a void or black hole. It's like…my memory is like a chalkboard where some part is erased" (paper 25a, 871).

While some of the participants discussed the difficulties associated with a lack of understanding, others attempted to breach the gap in their memory and increase their understanding of their injury by seeking information; "I think it's very important to hear the story about what has happened to you, as it is the only way to piece the puzzle together" (paper 4. p.127).

Conflict between old and new self. In addition to dealing with the sense of loss, confusion and a lack of understanding following the injury, participants tried to navigate coming to terms with the changes from former to new capabilities; "I used to be very active, active at work and at doing sports…I went from that to suddenly not being able to get dressed,…So this is just a completely new me" (paper 22, p.2299). Participants discussed how alienated they felt from the old 'self' and the confusion associated with understanding

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new aspects of their current self; "I struggle daily…to be the person I used to be. I…am

trying to redefine myself. I don't know this person anymore" (paper 25a, p. 872).

For some participants, managing these frustrations involved a denial of the injuries

and an attempt at being normal; "if I can do the same things as everybody else then that's all

that matters…. I was in so much denial over my injuries and consequences I just wanted to be

normal". Some participants were able to reflect on the negative impact their coping styles had

on their recovery, while other participants described a realisation of the need for acceptance;

"straight after it happened, I was thinking, I want to get back to that level where I was at. But

that didn't happen. I have had to come to terms with that" (paper 17, p.5).

Extrinsic factors that influenced the recovery process; **"Without him, I'm not sure I**
would have managed to live anymore".

The impact of external factors on the adjustment process was prevalent across all of

the studies. This theme reflects how these factors, which include friends, family, pets, paid

carers and HP, either facilitated or impeded the recovery process.

Health professionals (HP). The interaction with HP was significant for many

participants especially due to the intensive role they played in helping them make sense of the

injury. Some participants discussed positives of HP input; "…occupational therapist, never

knew they existed until I came here…people like W.F. were terrific. The whole place has

opened my eyes to what rehabilitation is…" (paper 22, p.235). Some participants described

the active role HP played in dealing with the distress of a lack of understanding of the injury

by the provision of credible information that could be understood by the participants:

A lady called (AF) was able to sit me down and say "look, the symptoms line up with a head injury that you would have received to this part of the head". And it all started to fit into place then. But up until then, I was absolutely terrified (paper 5, p.1972).

However, others reflected on negative experiences in their encounters with HPs, which impeded their recovery. Some participants described that while seeking an understanding of their diagnosis they felt accused of malingering, being fraudulent, or not applying themselves enough in their recovery; "I was thinking about medical people…are patronising…what that does to your sense of self is incredible…I don't get depressed easily, but I've been suicidal a couple of times because of that (paper 1, p.6). Some participants described the distress associated with a dismissing response from professionals; "when I try to ask for advice…I get the "you were only in hospital for a few days" comment all the time. I wish I knew what was wrong and what would help" (paper 10, p.412).

Also, the degree of post-injury support was variable, with some participants reporting that they felt they were left to cope with the uncertainties like duration of physical and cognitive symptoms following the injury; "I would have liked some sort of check-up. Or they could have given me some written information and told me not to panic" (paper 6, p.931). One participant reflected on how this lack of support affected different areas of life; "I went home after a week, and the doctors thought I would be back to normal. I couldn't think clearly, and I would leave food burning on the stove. I forgot to feed my dog…" (paper 10, 413). In contrast, one participant was able to use the lack of the support to build resilience and drive himself to recovery: "being one's own therapist- this is a challenge" (paper 3, p. 427).

The role of significant others. Some participants reported that relationships with people who were of great importance to them was vital and contributed to their recovery

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process; "Yes without him (father) I'm not sure I would have managed to live anymore and survive, overall, because he was a great support" (paper 18, p.286). Participants described different forms of support, for example, practical support; "they pick me up because I don't have a car" (paper 13, p.649), and social support; "I have my sisters who have kept up with the rehabilitation services...not all people have a social network like mine (paper 6, p.930). Significant others helped participants maintain perspectives, move forward, promoting self-efficacy and self-belief:

> …my friend David, he felt I had the ability [to pursue psychology studies] and was very instrumental in not making me believe anything else …getting back confidence was a challenge...the thing at the back of my mind was always the doctor, ' she can't, she won't. She's not good enough'…and it was a friend who convinced me that I was intelligent enough to do a university degree (paper 20, p.987).

Despite the positive impact of the support from significant others, participants discussed difficulties brought about by these relationships. Some participants reported feeling like they had become a burden; "people are really like concerned initially and then… don't want to know" (paper 5, p.1971). Many of them dreaded the thought of having to rely on people and the impact it would have on their sense of self; "you need to beg for help almost for everything you have to do, then people help you, of course, but it takes its toll naturally on the self-esteem, that you can't do what you might have done earlier" (paper 19, p.286).

Intrinsic factors that influenced recovery process: "Come on, snap out of it and do what you've got to do."

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This theme reflects how participants found the strength to regain control over the injury and the impact it had on their everyday life by utilising resources that came from within.

Active engagement. Participants appeared to struggle with the dependence on others; "I don't want to rely on the Government. I don't want to just get by…I want to do well" (paper 9, p. 82). They craved for normalcy and highlighted the importance of independence:

I can't live like this for the rest of my life. That's why I rolled out of bed in the hospital because I couldn't…I am not used to it. I like to be independent and not to depend on other people (paper 7, p.597).

This desire for independence drove participants to take an active approach to engage with their recovery; "but then my old self came in and said 'come on, snap out of it and do what you've got to do'. So I did, I got on with it…I just made that decision and moved on" (paper 25, p. 246). Participants highlighted an internal drive that helped them with this; "That was just something that I did on my own. I've become more determined as well, since the accident…It makes me strive to be something (paper 17, p.863).

Looking for new ways of doing things enabled participants to engage in activities and establish routines, which they stated were factors important in their adjustment as it also had an added benefit of managing secondary consequences of the injury: "The one thing that has been good for me was to be physically active…I read something about a symptom after my injury could be depression…the best pill against depression is to get out of the house…this kept depression away" (paper 22, p.2302).

Acceptance: Several participants highlighted how acceptance was key to moving on; "whatever happened to me happened to me. Nothing I can do about that now is there? But

there is something I can do about what I have got left. So got on with it" (paper 25, p.247).

One participant described how coming to a place of realisation that they cannot do things as well as before helped their adjustment; "I realised at that time…I couldn't perform my job properly any more. I pretended I could, but I couldn't…not everything needs to change back" (paper 4, p. 126). Another participant discussed the need for an acknowledgement of the old self and the acceptance of the new self; "I have become just like a straight line and have to acknowledge that this is life number two. I had the first before the injury; now I have a new one (paper 22, p.2300).

In addition to this, acceptance of the new self-enabled participants to see that their adjustment takes time, which also helped put less pressure on them; "it [recovery] was up and down…and although it was slow and arduous at times, I learnt a lot of myself" (paper 5, p. 1973). Several participants highlighted how this insight and acceptance enabled them to be more conscious of their limitations, learn to focus on the now and enjoy living a day at a time;

> Every day I live for today. I do everything for today because, to me, the past never comes back…If I look at life from that respect, it gives me respect. It gives me hope that's how I can make today, like, better than yesterday, and I don't worry about tomorrow (paper 24b, p.1799).

Emotional engagement. Several participants mentioned experiencing both negative and positive emotions, but managing to navigate them was vital in the recovery process; "I have felt so, in dark moments, almost as an eloquent need…the emotions are difficult to manage, and that is also an effect of the injury, although I am much, much more affected than I have ever been before;" (paper 18, p.288). One participant discussed initially managing his difficulties with fear and how this got easier over time; "…afraid of getting lost, afraid of

being harassed to ask…I find the more I go out and experience this, the easier it gets" (paper 15, p.855). Another participant managed the stresses resulting from the injury by challenging their thoughts; "…I have to grab my thoughts and say: get hold of yourself, don't sit like this…and after a round of this, it can go well…as far as feelings are concerned" (paper 3, p.428). Other participants described adopting a hopeful and forward-looking approach; "however bad things are with people around me, I do know now I will improve. I know that I'm going to make more of a recovery to be able to relate to that person." (paper 25, p.288). Some participants manage their grief by comparing themselves to others who might be in worse situations than they were;

> I was older. He was a younger man when he got injured. I was 37. So, I already lived pretty much….my you know, not much was going to be changed for me. I didn't miss anything…you know, I have pretty much life experienced by 37…I feel bad for them [younger people with TBI] because they're never going to have, have girlfriends (paper 25b, p. 1798).

Post-injury growth: "I am glad I had my accident because it's made me into a better person."

This theme involved reflecting on life before the injury and subsequently making plans for the future. Some participants reflected that they had adopted new values and a new appreciation of life; "you put things into perspective…you appreciate things that were not important before. "There is a new ruling my house, which is that we don't go to bed without saying good night. You never know what tomorrow brings" (paper 6, p.929).

In addition, some participants reflected on positive impacts such as changes in attitudes and behaviours; "I think in a lot of ways, I'm a better person now than I was before the accident…have a lot more tolerance and a lot more appreciation for somebody who looks

a little different; what they might have been through" (paper 19, p.12). The reframing of the experience of the injury as a positive occurrence was evident for many of the participants, with some of them appreciating their benevolent and public-spirited selves post injury; "I am glad I had my accident because it's made me into a better person. It's made me help people. If I see a lady across the road with shopping, I will run over and help her" (paper 2, p.68). Also, several participants highlighted how the injury had given them a new clarity regarding what is most important in life; "the most important things in life…I think the head injury has made me realise what they are…the life that I have now, you know it's very precious. It's more precious than what I ever had before" (paper 25, p.250).

Some participants focused on the positive consequences and benefits resulting from the injury; "time I spent with my daughter is a real bonus, there's no way I would have spent that time with her before the injury" (paper 17, p. 864). Whilst for others the experience of the injury and the acceptance of the 'new self' represented an opportunity to be given a second chance at life; "I think after having the accident you know, it's like if I died right now, I have got to know that everything I do is good…I must be here for a reason" (paper 20, p 986). One participant, in particular, was very grateful to the person who hit him stating that the person saved his life; "if she didn't do what she did, I probably would be dead by now if I lived the same way I was" (paper 24b, p. 1798).

Discussion

This meta-synthesis amalgamates qualitative literature on the experience of adjusting to a TBI. The synthesis of the findings of 25 studies resulted in four themes, which suggest that in adjusting to TBIs people experience an early impact of the injury comprising loss and grief, a lack of clarity and understanding about their condition and difficulties with managing

identity conflicts. External support and internal coping skills determine the ability to adjust to the injury with successful navigation possibly leading to post-traumatic growth (PTG).

The impact of loss and grief is significant. In a review of the literature to identify common aspects of loss in diverse situations, Murray (2001) explored Bowlby's (1961) and George's (1993) description of adjustment to loss and grief both of which are pertinent to this study. Murray (2001) describes Bowlby's (1961) perception as being centred around internal processes encompassing stages such as shock and numbness, whilst George's (1993) perspective emphasises the importance of external factors and social context as a medium through which adjustment occurs. Participants in this metasynthesis highlighted subjects around internal and external factors, describing some critical physical, social and psychological consequences of the injury, which catalysed their experience of loss and influenced the process of adjustment.

Several studies have attempted to explicate the impact of chronic illness, which has been described as 'non-death' loss, on adjustment (Ahlstrom, 2007; Charmaz, 1983; Jacoby, Ring, Whitehead, Marson & Baker, 2014). In addition, some studies highlight the impact of the uniqueness of TBIs on the grieving process (Coetzer, 2004; Salas & Coetzer, 2015). These studies suggest that whilst a complete physical recovery is often made, people have to contend with navigating a variety of other changes because of the injury, which makes grieving challenging, as evident in this metasynthesis. Davis and Nolen-Hoeksema (2001), drawing from social-cognitive models of adjustment (Epstein, 1973, 1994; Janoff- Bulman, 1992), assert that the ability to define what has been lost and subsequently discover meaning facilitates adjustment, reducing distress associated with grief. However, this meta-synthesis highlights the difficulties participants' experienced in understanding their TBI and defining what had been lost, as well as difficulties communicating this to HPs.

Several studies have highlighted the negative impact of the lack of understanding on the recovery process more widely, citing it as a source of uncertainty, frustration and anxiety (Dirette & Plaisier, 2007; Turner et al., 2007). In a literature review of the experiences of people with brain injuries after discharge, Sinnakaruppan and Williams (2001) highlighted patients and families reporting unmet needs that revolved around the need for more information. Several other studies have echoed this inadequate information from HPs or lower perceived knowledge (Biester et al., 2016; Kivunja, River & Gullick, 2018; Mueller et al., 2017). Some of these studies suggest that they occur because of a wide range of misconceptions about TBIs such as time of recovery, prognosis and secondary impact of the injury, impacting on the information delivered (Bradford, 2015; Block, West & Goldin, 2016), which can also misinform support networks.

The role and the impact of support networks especially the family unit in the recovery process of TBIs has been well researched (Foster et al., 2012; Kreutzer et al., 2009; Vangel, Rapport & Hanks, 2011). Some studies have shown better outcomes in the recovery process of patients with TBIs when significant others are engaged with the process (Chua, Ng, Yap & Bok, 2007; Kreutzer et al., 2009). The family and significant others as a support system providing practical and emotional support in facilitating adjustment was evident throughout this metasynthesis. However, participants were mindful of becoming a burden on their family members. Several studies have highlighted the negative impact on carers when caring for people with brain injuries (Damianakis, Tough, Marziali & Dawson, 2016; Kitter & Sharman, 2015) with some studies stating that depression among family caregivers occurs four times as much as in the general population (Malec, Van Houtven, Tanielian, Atizado & Dorn, 2017). This highlights a need for the support of caregivers in the improvement of outcomes in the rehabilitation process as recommended by the UK NICE (2014) guidelines.

Despite the positive impact of significant others on adjustment, participants also had to navigate the impact of the injury on their self-concept. Davis and Nolen-Hoeksema (2001) suggest that making sense of the impact of the injury through understanding, facilitates the maintenance of two aspects of the self that are typically threatened by the injury (Davis and Nolen-Hoeksema, 2001), the sense of self-worth and our assumptions about how the world works. Several participants struggled to accept the loss of capabilities associated with their 'old self' and accept some of the incapabilities associated with their 'new self'. Charmaz (1983) asserts that a notable occurrence in the chronically ill is the loss of self, which transpires as people lose aspects of their old selves without growth and replacement of new valid selves. This metasynthesis highlighted the importance of understanding the transition in identity following the injury. Individuals who had come to terms with the loss of their 'old self' were able to utilise external and internal factors to facilitate their recovery process and develop a new identity, a 'new self'. An inability to navigate the challenges posed to identity can contribute to poor rehabilitation outcomes and mental health difficulties (Cantor et al., 2005; Ylvisaker, Mcpherson, Kayes, & Pellet, 2008).

Some models that facilitate our understanding of this pathway to a new definition of 'self' have been suggested (Park, 2010a; Thomas, Levack & Taylor, 2014). However, the meaning-making model (Park, 2010a) appears to represent the processes highlighted in this metasynthesis. Baumeister (1991) describes meaning making as a "mental representation of possible relationships among things, events, and relationships. Thus, meaning connects things" (p.15). According to Park (2010a), this model considers two levels of meaning (global and situational), which influence the way people appraise events and cope. Global meaning refers to "a person's fundamental beliefs/values, goals and subjective sense of purpose which function together to infuse life security and significance" (Holland, Marlott & Currier, 2014. p. 231). Situation meaning refers to a person's appraisal of a particular situation (Park,

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2010a). Park (2010a) suggests that distress occurs when there is a discrepancy between an individual's 'global meaning' and the appraised 'situation meaning' with difficulties in re-addressing this balance possibly resulting in health difficulties (see figure 2).

In the case of an illness, loss, or more specifically in this case a TBI, Park (2010b) asserts that appraisal of the situation determines the extent of the distress and this appraisal is associated with the individual's global beliefs, which is related to aspects of their 'old self'. In addition, Park (2010b) suggests that the distress associated with the discrepancy incites a coping response, which include problem-focused coping, emotion-focused coping (Lazarus and Folkman, 1984) and meaning-making strategies. Park (2010b) suggest that if these strategies are successfully utilised they reduce the discrepancy and subsequently, the distress (see figure 2).

……………

INSERT FIGURE 2

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Some of these coping strategies were represented in this metasynthesis as they form the foundation of the third theme, which describes internal factors derived from the participants that influenced their adjustment. Participants appeared to utilise problem-focused coping strategies to manage the distress resulting from the conflict between dependence and independence. Participants engaged in active efforts to challenge themselves cognitively and engaged in direct actions to resolve the challenges created by the injury, reducing the discrepancy in the process (Park, 2010a). Several studies have highlighted the benefits of utilising this coping strategy in people with TBIs (Anson & Ponsford, 2006; Wolters, Stapert, Brands & Van Heugten, 2010).

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In addition to this, participants utilised emotion- focused coping strategies. It has been argued that the use of emotion- focused strategies; such as distraction, venting emotions, denial and others can be maladaptive and lead to more distress and adverse outcomes (Aldwin, 2007; Anson & Ponsford, 2006; Wood & Doughty, 2012). Even though aspects of this were evident in this metasynthesis, this assertion has been disputed by Stanton, Parsa and Austenfeld (2002) who suggest that the reason behind this is the nature in which emotion-focused coping is measured and analysed. Participants in the metasynthesis engaged with their emotions and were able to make sense of some of the situations they were in and as a result, make progress. This supports Stanton et al.'s (2002) assertion about the usefulness of emotion-focused coping strategies especially when it involves actively engaging emotions as some participants in this meta-synthesis did.

The final strategy suggested by Park (2010a; 2010b) is the meaning making coping strategy. This strategy aims to restore congruency between an individual's situation and global meaning (Park & George, 2102). Several studies using this model have reported good outcomes on the role of meaning making in adjusting to a range of traumatic experiences, hence the importance of this being taken into account during rehabilitation especially with supporting identity issues as highlighted by this metasynthesis (Nikčević & Nicolaides, 2013; Park, Edmondson, Fenster & Blank, 2008; Zeligman, Varney, Grad, & Huffstead, 2018). To add credence to Park's (2010b) assertion, several participants in this review were able to come to a place of acceptance, which can be likened to elements of the 'meaning making' strategy. Several participants highlighted how accepting that they cannot do things as they used to before helped them to adjust, which is a process described by Park (2010b) as assimilation. Some other participants reflected on how changing their perspectives and beliefs about their 'self' facilitated their recovery process, which is a process described by Park (2010b) as accommodation.

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A successful utilisation of the coping strategies resulted in what could be described as Post-Traumatic Growth. According to Linley and Joseph (2004), research focusing on the outcomes of trauma and adversity has focused on the negatives, consequently giving a one-sided view of the outcomes. Regarding positive outcomes, several participants reflected their lives have more meaning after the injury. Theorists have suggested that some people who have experienced a considerable amount of affliction and trauma may not only get better and cope but can even exceed their pre-trauma level of functioning (Linley & Joseph, 2004; Widows, Jacobsen, Booth-Jones, Stone & Fields, 2005). Research into PTG and life-threatening illnesses suggest that patients report having a better life because of the injury, which was also reflected in this metasynthesis (Pakenham, 2007; Powell, Ekin-Wood & Collin, 2007). However, despite the growth and outcomes resulting from injury, several studies have highlighted the importance of engagement in coping strategies, as they are a powerful determinant of the PTG discussed and recovery after TBI (Powell et al., 2007; 2012).

Clinical Implications

The findings of this review suggest that individuals with TBIs struggle with several consequences because of the early impact of the injury, one of which is a lack of understanding. As suggested by Charmaz (1983), the culture in which the chronically ill are only treated from an acute perspective needs to be challenged. This culture is evident in the UK for example, as the British Psychological Society (2011) comments that the UK National Institute for Health and Clinical Excellence (NICE, 2007) guidelines on brain injuries focused on the acute care of brain injury patients. It is pertinent the communication between HPs and individuals with brain injury needs to be improved to enhance outcomes. This could be facilitated by allowing patients an opportunity to go through early medical notes, accounts from relatives and others if there is a sense that it is essential for people to fill these gaps in.

In addition to this, UK NICE (2012) guidelines on improving the experiences of care using the National Health Service suggests that a platform between HPs and patients is created in which discussions that meet their needs of care can occur at a pace they feel comfortable with and ensuring that their understanding of the conversation is reviewed from time to time.

In addition to this, the findings of this study reiterate the importance of family and other social support systems in adjusting to a TBI. Also, the subject of the challenges and long-term strain faced by family members caring for someone with a brain injury has been widely studied as well as the need to support them as a result (Rietdijk, Togher, & Power, 2012; Stevens et al., 2015).

Finally, in addition to the importance of HPs highlighted, the study sheds light on the importance of the role of clinical psychology in not only working with clients with TBIs but ensuring that all the systems that contribute to recovery and good outcomes are working together seamlessly. The role of clinical psychologists in influencing policy and becoming advocates at the social and national level has been increasingly discussed (Rhodes, 2015). This study highlights the need for a paradigm shift in the manner in which some HPs acutely treat people with brain injuries without thinking about the long-term consequences of recovery.

As well as working systemically with all the systems involved, this study highlights the vital role of the clinical psychologist in working one-to-one with clients, especially within the framework of coping strategies, meaning making, acceptance, and the transition from the old self to the new self. Several studies have shown the effectiveness of therapies such as cognitive behavioural therapy, mindfulness and others in improving recovery for people with TBI and their families (Gallagher, Mcleod & Mcmillan, 2016; Ponsford et al., 2016; Bedard et al., 2014). More specifically, some other therapies have been suggested to facilitate identity

reconstruction such as narrative therapy (D'Cruz, Douglas & Serry, 2017; Gibson, 2015) and acceptance such as acceptance and commitment therapy (Whiting, Simpson, Mcleod, Deane & Ciarrochi, 2012;2018) constructs which have both been shown in this metasynthesis as salient in the adjustment to TBIs.

Strengths and limitations of the study

An important aspect of the meta-synthesis, which could be perceived as a limitation, involved ensuring that only studies that met the inclusion criteria were included. Hence, studies which focused on the experiences of people with TBIs but included voices of caregivers, were excluded. Adherence to the inclusion criteria also meant separating the construct of adjustment from others concepts such as coping, recovery and rehabilitation as there is ambiguity within literature about the definition of adjustment (Hank, Temkin, Machamer, & Dikmen, 1999; Moss-Morris, 2013). This meant that only studies that represented the definition of adjustment given in this review were included and studies that included these other constructs were read and reread to ensure that they captured this (Dekker & de Groot, 2018; Moss-Morris, 2013). Consequently, some studies that focused on other constructs such as the impact of gender, rehabilitation models and physical illness were excluded. Therefore, there is the possibility that valuable insights into the experience of adjusting to a TBI generally were missed.

In addition to this, the majority of the studies were from a Western population. This approach limits the geographical applications of the findings of this study. Another limitation of the study is that some of the studies had low CASP scores, which brings into question the rigour, credibility and relevance of the studies included. However, while synthesising, more weight was given to studies with higher CASP scores.

Conclusion

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This synthesis explored the lived experience of adjusting to a TBI using a meta-ethnographic approach. The process of adjustment following an injury was associated with participants experiencing the early impact of the injury; such as loss, a lack of understanding, and conflict in identity as they struggled to transition between the 'old self' and their 'new self'. Navigating the process of adjustment was supported by both internal and external factors. On one hand, HPs were supportive especially with practical support; however, they contributed to some of the distress suffered by the participants. The role of the family and caregivers was well-discussed and highlighted as key to adjustment.

This research focused on people with TBIs who could support themselves to take part in an interview, excluding studies, which included caregivers. Therefore, future research could explore the experience of people with TBI in conjunction with families or caregivers.

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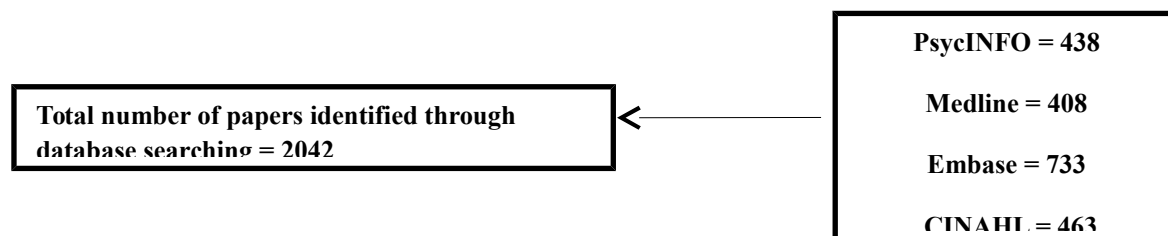*Neuropsychological Rehabilitation,* 18(5-6), 713-741. doi:

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Zeligman, M., Varney, M., Grad, R., & Huffstead, M. (2018). Posttraumatic Growth in

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Database	Free Text Plus MESH- **TBI** (S1)	Free Text – Methodology (S2)	Free Text- Adjustment (S3)
PsycINFO	""acquired brain injur*"" OR ""traumatic brain injur*"" OR "Craniocerebral trauma" OR "exp "TRAUMATIC BRAIN INJURY"" OR "exp "ACQUIRED BRAIN INJURY""	"qualitative" OR "interview" OR "thematic analysis" OR "phenomenol*" OR ""phenomenological analysis" OR "narrative analysis" OR "focused groups" OR "focus group" OR "discourse analysis" OR "grounded theor*" OR "action research" OR "content analysis" OR "ethnograph*" OR "hermeneutic*" OR "heuristic*" OR "semioticsX" OR "cluster sample*" OR "field stud*" OR "ethnomethodology*" OR "exp "QUALITATIVE RESEARCH" OR "exp "QUALITATIVE STUDIES"	"recover*" OR "adjust* "adapt*" OR "accept*" "coming to terms" OR "making sense of" OR "making sense" OR "rehabilitation" OR "restoration" OR "readju OR "exp CONVALESCENCE/"
Medline	As above	As above	As above
Embase	As above	As above	As above
CINAHL	As above	As above	As above

Table 1: Details of Searches Relating to Database Specific Indexing Systems

Total number of papers identified through database searching = 2042	←	PsycINFO = 438 Medline = 408 Embase = 733 CINAHL = 463

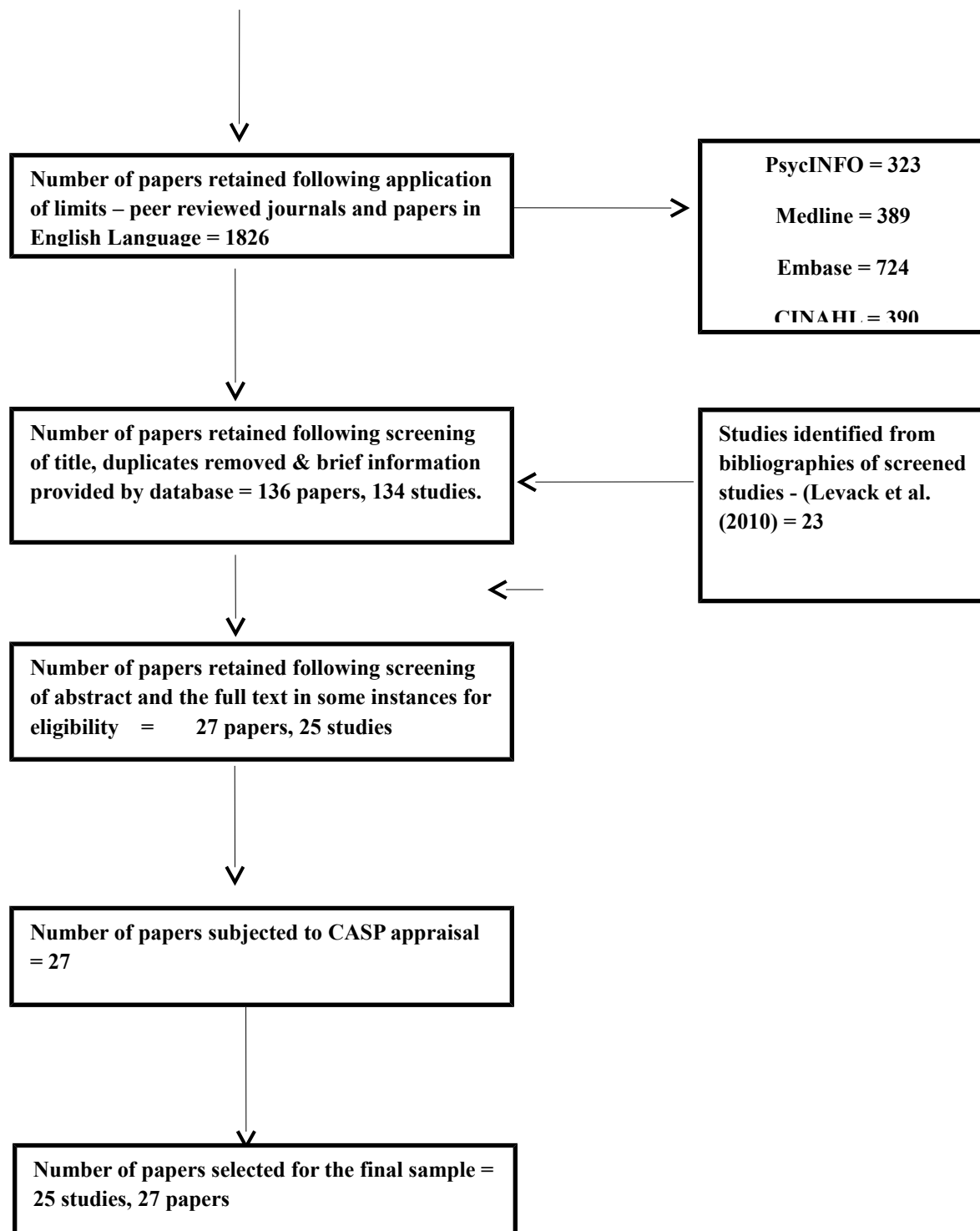EXPERIENCE OF ADJUSTING TO A TBI.

Figure 1. Flowchart of included studies.
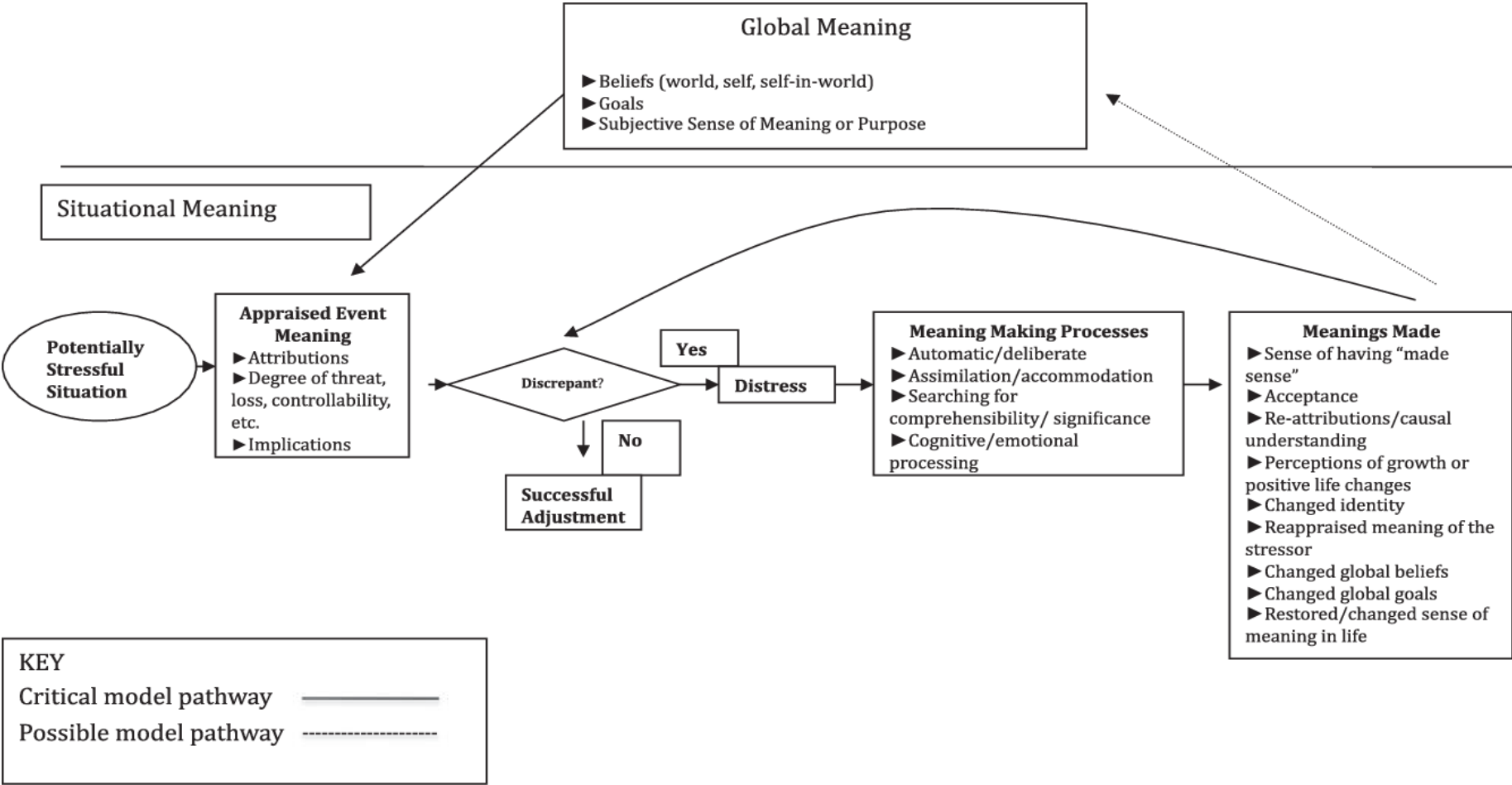
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Figure 2: The meaning making model from Park (2010a)

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Paper	Author	Date	Research Aim	Sample size	Age range	Country	Data collection and analysis
1	Levack, Boland Taylor, Siegert, Kayes, Fadyl & Mcpherson	2014	Exploring the recovery experiences of people with TBI regarding change in self-identity.	49 (34 men & 15 women)	21-79	New Zealand	Focus group interviews Grounded theory
2	Douglas.	2013	To explore the way in which adults who have sustained severe injuries conceptualise themselves after the injury.	20 (16 men & 4 Women).	21-54	Australia	Open ended in-depth interviews. Grounded theory.
3	Johansson, Haugstad, Berg & Johansson.	2016	To explore peoples experience in developing a mastery of day-to-day activities and roles after TBI with the expectation of going back to work.	8 (All men)	30-60	Norway	Semi-structured interviews. Grounded theory.
4	Hoogerdijk, Runge, & Haugboelle.	2011	Exploring how individuals with a TBI make sense of their process of adaptation to the injury with special focus on the role engagement in activities plays in the process.	4 (3 men & 1 woman)	33-61	Netherlands	Structured and semi-structured interviews. Narrative analysis.
5	Snell, Martin, Surgenor,	2017	**Quantitative element-** Examining neuroimaging,	10 (4men & 6	26-67	New Zealand	Semi-structured interviews

	Siegart & Hay-Smith.		neuro-cognitive and psychological factors in people with TBIs. **Qualitative element –** Exploring people with TBIs experiences of the symptoms, treatment and recovery from the injury.	women)			Thematic analysis.
6	Heidi, Christensen, Poulsen & Egerod.	2018	Provide an understating of lived experience of recovery in adults with a TBI.	20 (12 men & 8 women)	25-63	Denmark.	Semi-structured in-depth interviews. Qualitative thematic analysis.
7	Soeker, Van Rensburg & Travil	2012	Exploring lived experience of having a TBI with regards to resuming work.	10 (9men and 1 woman)	31-64	South Africa.	In-depth interviews. Phenomenological approach.
8	Nalder, Fleming, Cornwel, Shields & Foster.	2013	Exploring people with TBIs experience of transition from hospital to home.	16 (15men & 1 woman)	18-55	Canada	Semi-structured in-depth interviews. Qualitative data thematic analysis using the framework approach.

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9	Mcrae, Hallab & Simpson	2016	Exploring the vocational rehabilitation pathways of people with TBIs.	29 (18 men & 11 women)	19-66	Australia	Semi-structured interviews. Thematic analysis
10	Chamberlain	2005	Exploring the experience of surviving a TBI.	60(40 men & 20 women)	18-81	Australia	Opened question interviews. Narrative analysis.
11	Jumisko, Lexell & Soderberg.	2009 2005	A. Exploring the meaning of feeling well in people with TBIs B. Exploring the meaning of living with a TBI	8 (6 men & 2 women) 12(10m en & 2 women)	23 - 50 29 – 53	Sweden	Semi-structured interviews Phenomenological hermeneutic approach
12	Callaghan, Powell & Oyebode.	2006	Exploring the experience of gain awareness of deficits after a TBI.	10(7 men and 3 women)	21-60	United Kingdom	Semi-structured interviews. Interprétative Phenomenological anaylsis (IPA).
13	Petrella, McColl, Krupa & Johnston.	2005	Exploring the factors that facilitated the return to productive activities for people with TBI.	6 (4 men & 2 women)	33-78	Canada	Semi-structured interviews. Grounded theory.
14	Levack, McPherson & McNaughton	2004	Exploring people with TBIs experience of attempting to return to work after the injury.	7 (4 men & 3 women)	26-51	New- Zealand	Open ended interviews. Phenomenological approach.

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15	Karlovits & McColl.	1999	Identifying the stresses experienced face by people with TBI during recovery and how they adjusted to these stresses.	11 (10 men & 1 woman)	19-39	Canada.	Semi-structured interviews. Phenomenological approach.
16	Morris, Prior, Deb, Lewis, Mayle, Burrow & Bryant.	2005	Exploring people with TBIs views of outcome following the injury.	32 (24men and 8 women)	31-64	United Kingdom.	Semi-structured interviews. Grounded theory.
17	Shotton, Simpson, & Smith	2007	Exploring people with TBIs experience appraisal, coping and adjustment to their injuries.	9(7men & 2 women)	21 -59	United Kingdom	Semi-structured interviews. IPA.
18	Strandberg	2009	Exploring the changeover process in people with TBI from the experience of the trauma to the impact in everyday life and then recovery.	15 (10 men & 5 women)	28-56	Sweden	Semi-structured interviews. Qualitative latent-content analysis.
19.	Klinger.	2005	To explore occupational adjustment after a TBI.	7 (6 men & 1 Woman).	29-45	Canada	Semi-structured interviews. Grounded theory.
20.	Muenchberger, Kendall &	2008	To explore peoples experience of identity,	6 (4men & 2	22- 42	Norway	Semi-structured interviews.

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	Neal.		change following TBI.	women)			Phenomenological approach.
21.	Sveen, Soberg, & Ostensjo.	2016	Exploring how individuals with reconstruct everyday occupations and work following the injury.	20 (8 men & 12 women)	22- 60	Norway	Focus group interview. Qualitative content analysis.
22	Parsons & Stanley.	2008	Exploring the experiences of occupational adaptation following TBI.	2 (All men)	30 - 44	Australia	Semi-structured, open and in-depth interviews. Phenomenological approach.
23.	Gelech & Desjardins.	2011	To explore the way in which people with a TBI reconstruct the self-following the injury.	4 (3 men & 1 woman).	37-55	Canada	Life history and semi-structured interviews. Qualitative analysis.
24.	Nochi.	1998 2000	To explore the loss of self and the reconstruction of the self in people with TBI after the injury.	10 (6 men & 4 women)	24-49	Japan	In-depth, semi-structured interviews, observation and open-ended questions. Grounded theory.
25	Roundhill, Williams &	2007	Exploring how individuals with a TBI experience the	7 (6 men & 1	32-60	United Kingdom	Semi-structured interviews.

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Hughes	sense of loss and their views of adjustment over time.	woman)	IPA.

Table 2. Summary of studies that were included in the review

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Appendix 1A

Author guidelines for *Journal of Neuropsychology*

Author Guidelines

The Journal of Neuropsychology publishes theory-driven patient studies and Registered Reports. The central brief is to learn more from patients with brain dysfunctions to gain a better understanding of brain-behaviour relationships and to help future patients. Important developments in neuropsychology will follow from a multidisciplinary approach embracing neighbouring fields such as developmental psychology, neurology, psychiatry, physiology, endocrinology, pharmacology and imaging science. The journal publishes group and case studies addressing fundamental issues concerning the cognitive architecture of the brain. In addition, the journal includes theory-driven studies regarding the epidemiology of specific deficits, new assessment tools, and the evaluation of treatment regimes.

The journal is committed to a fast and efficient turn-around of papers, aiming to complete reviewing in under 90 days. Submissions are processed via a web-based system and reviewers are required to complete their referee report within 28 days.

Papers will be evaluated by the Editorial Board and referees in terms of scientific merit, readability, and interest to a general readership.

All papers published in The Journal of Neuropsychology are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

1. Quality Control

The content, format, quality and ambition of the JNP as a major outlet for theory-driven neuropsychological studies is under constant review by the Consulting Editors:

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The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

3. Paper formats and length

Research papers are full-length reports of original scientific investigations. Papers should normally be no more than 6000 words excluding abstract (maximum 250 words) and references. Multiple citations for a single point are usually duplicative and authors are urged to cite the best reference. The Editor retains discretion to publish longer papers.

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Theoretical or review articles are full-length reviews of, or opinion statements regarding, the literature in a specific scientific area. They need not be exhaustive but should give an interpretation of the state of research in a given field. They should normally be no more than 4000 words excluding abstract (maximum is 250 words) and references. The number of references should not exceed 40-45. Multiple citations for a single point are usually duplicative and authors are urged to cite the best reference. The Editor retains discretion to publish longer papers.

Brief communications are short reports of original research or case reports. They contain no more than 1500 words excluding abstract (maximum is 80 words), references, a total of up to three tables or figures, and no more than 10 references.

Fast-track papers are timely and relevant reports that, to the discretion of the Editor, are included in the issue following acceptance. Authors may ask that their submitted manuscripts are considered for fast-track.

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• The main document must be anonymous. Please do not mention the authors' names or affiliations (including in the Method section) and refer to any previous work in the third person.

• Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript but they must be mentioned in the text.

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• Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi. All figures must be mentioned in the text.

• All articles should be preceded by an Abstract (see point 3 for guidelines), giving a concise statement of the intention, results or conclusions of the article.

• For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide DOI numbers where possible for journal articles.

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• In normal circumstances, effect size should be incorporated.

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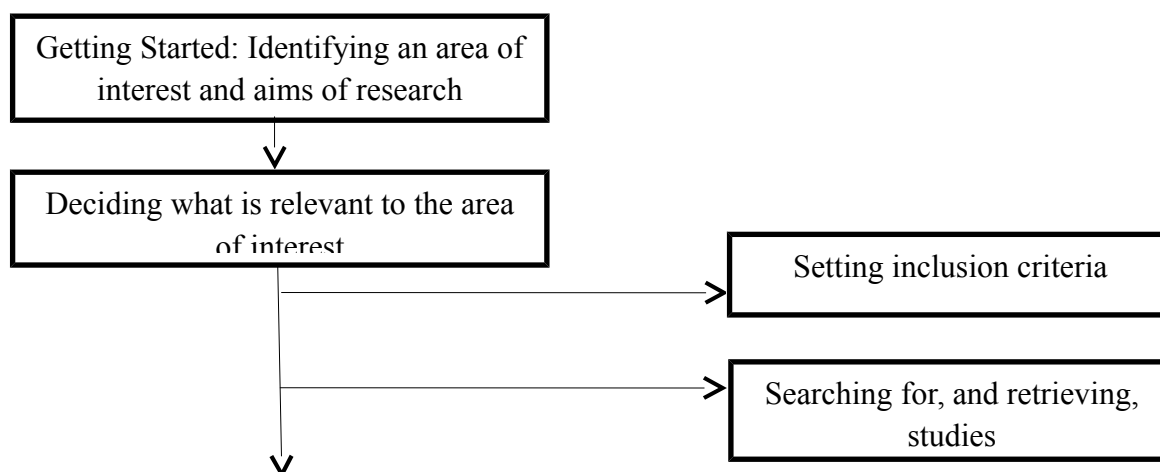
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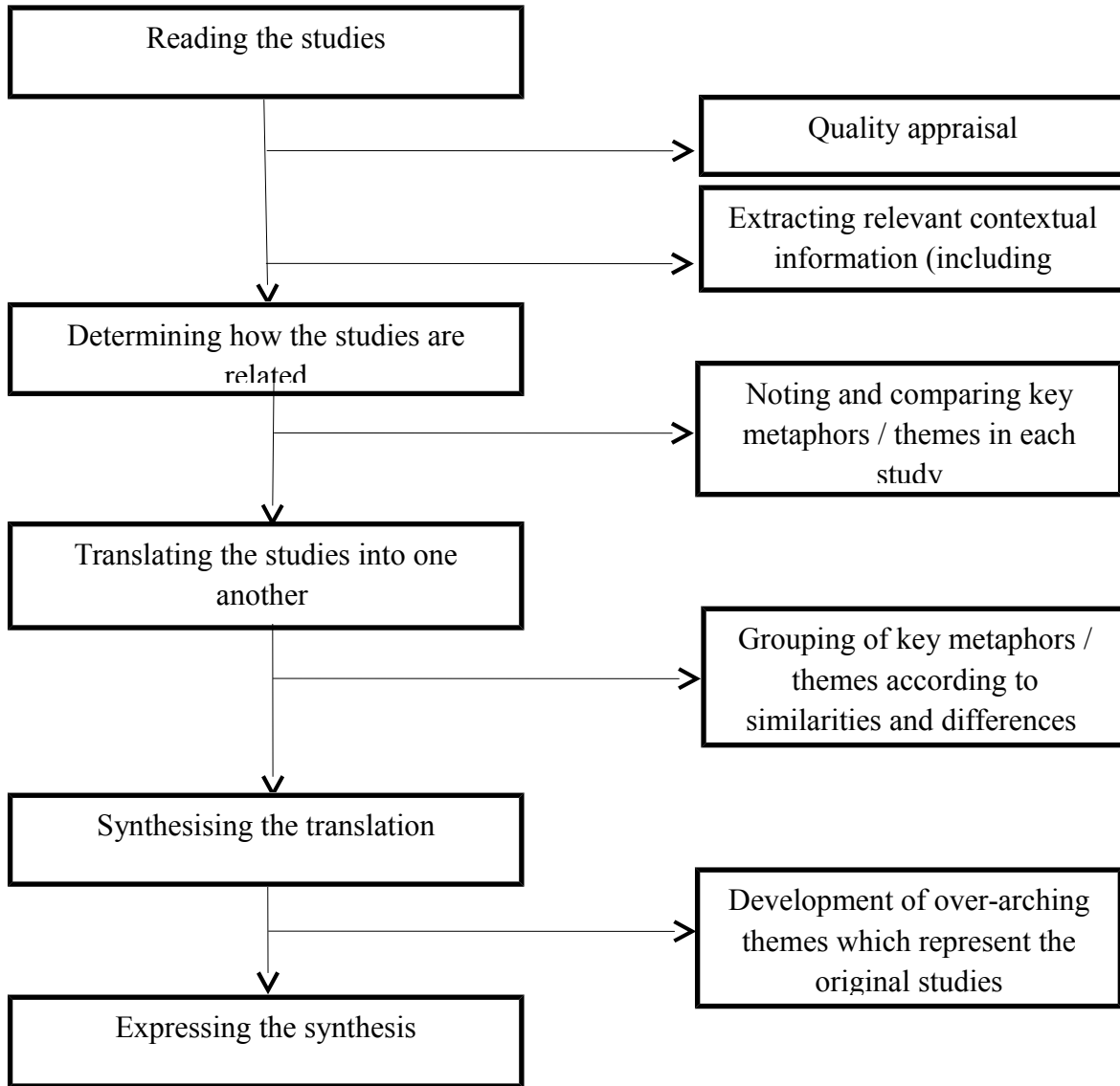
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Appendix 1B

Figure showing stages of meta-synthesis in accordance to guidance provided by Noblit and Hare (1988).

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Reading the studies

Quality appraisal

Extracting relevant contextual information (including

Determining how the studies are related

Noting and comparing key metaphors / themes in each study

Translating the studies into one another

Grouping of key metaphors / themes according to similarities and differences

Synthesising the translation

Development of over-arching themes which represent the original studies

Expressing the synthesis

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Appendix 1C

CASP scores for the included studies

Study	Clear statement of aims	Qualitative methodology appropriate	Research Design	Sampling	Data collection	Reflexivity	Ethical issues	Data analysis	Findings	Value of research	Total
1	3	3	3	3	3	1	3	3	3	3	28
2	3	3	3	3	3	3	3	3	3	3	30
3	3	3	3	3	3	1	1	3	3	3	26
4	3	3	2	3	3	3	1	3	3	3	27
5	3	3	3	3	3	1	1	3	3	3	26
6	3	3	3	3	3	3	3	3	3	3	30
7	3	3	2	3	3	2	3	3	3	3	28
8	3	3	3	3	3	1	1	3	3	3	26
9	3	3	2	3	3	1	3	3	3	3	27
10	3	3	2	2	2	2	3	3	3	3	26
11a	3	3	3	2	3	3	2	3	2	3	27
11b	3	3	3	3	3	2	3	3	3	3	29
12	3	3	3	3	3	1	1	3	3	3	26
13	3	3	3	3	3	1	1	3	3	3	26
14	3	3	3	2	3	3	2	3	3	3	28
15	3	3	3	2	3	1	1	3	3	2	24
16	3	3	3	3	3	2	3	2	3	3	28
17	3	3	3	3	3	2	3	3	3	2	28

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18	3	3	3	3	3	3	3	3	3	3	30
19	3	3	2	2	2	1	1	3	3	3	23
20	3	3	3	2	3	1	1	3	2	2	23
21	3	3	2	1	3	1	1	3	3	3	23
22	3	3	2	2	2	1	2	2	2	1	20
23	3	3	1	1	3	1	1	3	3	3	22
24a	3	3	3	1	3	1	1	2	3	3	23
24b	2	3	1	2	1	1	1	3	2	2	18
25	3	3	3	2	2	1	1	3	3	2	23

Appendix 1D

Table demonstrating how the themes and quotations from each study contribute to Theme One: Immediate impact of the injury

Paper	Original Themes	Supporting quotations
1	Having a coherent, satisfying and complete sense of oneself.	"I mean who the hell am I, you know? Really, I'm a writer, you know, I'm semi-retired so could you know, write, and I have a book I've been writing from – for years, and now I can't write. So now, who am I?"
4	A necessary struggle to gain a new identity.	"I am not normal: it will never be like I was before. I think differently and I feel different"
5	What the heck is going on?	"...I don't remember the injury but then I have no reason for … I keep thinking "Why do I feel like this...? because I don't remember getting hit or anything its hard for your brain to sort of think, "Right that's why you feel like crap" It's hard to describe really"
6	A new beginning	"You miss a lot after the accident, among other things going to work where you exchange experiences and spend time with your colleagues, I was not prepared because I wanted to work till I was 70. I was not prepared for the third life stage where I landed".
7	A sense of loss of former self	"I could run from here to Cape Town without losing my breath and I don't have to jog everyday that's just the way my body was. Like sitting here , all the things that you know are all incredibly debilitating. A young 65 that expected to do all of the things I used to be able to do, till dooms day"
8	Wanting normality	It's always been but I can't do it right now. I'm not working. I'm not fit to do this. I can't do this. I really can't do this. So it's sad a bit, but I give it time and everything.

9	Adjustment		" I expected that I would be able to do what I couldn't do"
10	Grief and regret within self		"I used to be proud of my job and I earned a good wage. I'll never be able to work in that [executive] job again. Now I have a fraction of that money to live on…. I have lost my identity, who will respect me now? No respect, no income and that which I value so much- my mind- it doesn't work like it used to"
			"she read where the salmon came from. Suddenly she started to cry, tears falling down her cheeks, yet no words…"
11b	Losing one's way		"I don't remember anything about my life before the accident …When I woke I couldn't identify my mother, my brother, and sisters and I couldn't identify anything…. I didn't know that I was almost an 18year old girl…I didn't know what one should do as a human being".
	Missing relationships		"It's rather a big thing when so many friends leave"
	Searching for an explanation		"I was injured on some hotel stairs, I slipped down, I don't remember …after coming home from the hospital, I wanted to go there and have a look what it was like…I felt it over the whole body, I don't understand how I could have fallen"
			"I think that you have to believe that there is damage there, so that damage is why I

12	Explanations	can't do certain things. that red splodge is why I can't read…. when I actually saw the damage, that's when I realised that I was different because I saw it with my own eyes"
	Fear and loss	"why am I still here? …. Everything I can do has been taken away from me. What use am I?
13	Intrinsic factors- Experimenting	"…my perception of what I can do and my knowledge of what I can do. There is always a constant war between the two of them. I think I can do much better than I actually can and then I try to achieve that and I don't make it"
16	Loss	"apparently when you are close to death you go through a tunnel and that where I feel I still am, in the tunnel. Horrible feeling terrible. I haven't gone on and died, and yet I haven't gone back, just sort of left."
		"I feel that was my life, that was my future. I had everything planned; finish my course training to be an architect, get my qualification, go off get a decent job and start life. Meet a girl, have a family, everything you know. And that was like stopped"
		"I started thinking about what would have happened if I hadn't been knocked over and what life would have been like"
17	Waking! Understanding	"I was looking around and I was like what's happening? Where am I? … I don't know it just didn't seem real, it's hard to like (pause) when I was here it just seemed like I was in like a sort of a dream. It seemed like a long type of dream."
		"It was really weird ... I didn't actually know why I was there. I couldn't

		understand. I just saw all of these people in wheelchairs and I thought what am I doing with all of these disabled people."
18	Theme of changes	"Yes, according to my opinion, identity crisis is a quite good word, because when you are pulled from your own safety surroundings- if I say surrounding – I mean your established environment at home and work"
19	I am who I am, but I am not who I was before.	"After the accident I couldn't do this and I couldn't do that ... I used to run the business in my head, I used to look after the house. I used to look after the cars. I used to go out all the time. I was just on the go"
20	Contraction of identity	"…all you want to go and do is be the person you can…. Cause you're brought up with the 'self' you know, you dealt with everything and it doesn't matter how old you are, the history you've had gets you to the point that you're at now and then to become something totally different"
21	Changes in perception of self	"I used to be very active, active at work, active doing sports, well, active in general. I went form that to suddenly not bearing getting dressed, …so this is a completely new me, I do not recognise myself"
		"yes, you are not the same (as before the injury), you do not react in the same way anymore, my emotional life is levelled off, and this is so frustrating…"
22	Things are different now	"…even the f…. way I talk – it's so slow and I sound like I'm drunk or angry, it just makes me feel so small…Before my crash I used to have a lot of friends – but now

		I've hardly got any...I have lost things, my friends, normal way of everyday life, all these things that I can't do which are so easy and basic for other people to do."
23	Public aspects of the self: The great fall and aspects of loss.	"Well it [my injury] ended a relationship with a woman that I was engaged to. I don't know why. I have had no explanation. She ditched me" "I'm no longer Miss M. the teacher. I'm Barb the resident"
24A	Loss of clear self-knowledge- Uncertainty of where I come from	"I can't remember clearly, you know. I remember driving to a throughway, but that's all. I can recall. It's like a void, or a black hole. It'sxxxx like… my memory is like a chalkboard where some part is erased".

Appendix 1E

Contribution of each study to the meta-synthesis themes

STUDY

Meta-synthesis Theme	1	2	3	4	5	6	7	8	9	10	11 A	11 B	12	13	14	15	16	17	18	19	20	21	22	23	24 A	24 B	25

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Theme																								
1. Immediate impact of the injury.	X			X	X	X	X	X	X	X		X	X	X		X	X	X	X	X	X	X	X	X
2. Extrinsic factors that influenced the recovery process	X	X	X		X	X			X			X			X	X	X		X					X
3. Intrinsic factors that influenced the recovery process.		X	X	X		X	X	X		X			X		X	X			X			X	X
4. Post traumatic growth		X		X		X		X		X		X			X		X	X			X	X

Section Two: Research Paper

An exploration of the experience of adjusting to a diagnosis of encephalitis in adults

of working age: A qualitative investigation.

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Prepared for submission to *Journal of Neuropsychology.* [1]

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[1] Please note this manuscript was prepared in line with author guidelines for *Journal of Neuropsychology* (See appendix 2-A). The word count is in line with Lancaster University guidelines rather than journal guidelines.

Abstract

The complex nature of the symptoms and presentations of encephalitis means that it can pose a challenge for clinicians, patients, and their families. The aim of this study is to gain more insight into how people with a diagnosis of encephalitis experienced receiving the diagnosis and exploring the impact this experience had on their adjustment to life.

Six participants took part in the study. Interviews were analysed using Interpretative phenomenological analysis (IPA). Three themes emerged from the analysis: (i) Being on a wild goose chase- challenges with getting the diagnosis: "my blood test came back negative that time but my symptoms were definitely there", (ii) The emotional rollercoaster experience: "that was a kind of shock…I had never cried so much in my life" and (iii) The significance of information and others: "I was emailing her [neurologist] clinical papers saying that just because the blood test is negative doesn't mean- false negative". Clinical implications are drawn, and suggestions for future research discussed.

Introduction

Encephalitis is characterised by the inflammation of the brain parenchyma, which is associated with clinical evidence of neurological dysfunction (Tunkel et al., 2008; Venkatesan et al., 2013). It affects essential functions in both the brain and body (Sutter et al., 2015), leading to cognitive, physical and psychological difficulties (Easton, 2016). Some of these difficulties include emotional and behavioural changes such as low mood, anxiety, cognitive and physical changes (Dewar, 2016; Dewar, 2017; Ellerington, 2015). These changes affect the everyday existence of the individuals, potentially having long-term effects on quality of life (Easton, 2016; Ramanuj et al. 2014). Encephalitis is complex (George, Schneider, & Venkatesan, 2014; Venkatesan et al., 2013) with one challenge posed being the estimation of prevalence rates, which vary from region to region across the world. Estimates of encephalitis in the United States of America within the general population have been suggested to be 25.3 per 100,000 people (Dubey et al. 2018) while that of Australia has been suggested to be 5.2 per 100,000 people (Britton et al, 2015) and England 5.2 per 100,000. However, Boucher et al. (2017) suggests that because of the frequency of the discovery of new causative agents, the epidemiology of encephalitis is in a constant state of flux.

Granerod, Cousens, Davies, Crowcroft and Thomas (2013) assert that encephalitis is associated with a high rate of illnesses and loss of life, which costs the National Health Service (NHS) approximately £40 million a year. In the USA, encephalitis has been described by George et al. (2014) as a significant disease burden with the mortality rate of roughly one in 20, costing the economy about $2 billion a year, with patients who survive having undergone various rigorous diagnostic tests (Britton et al., 2015; Dubey et al., 2018).

Another factor that contributes to the complexity of the illness is the fact that there is a wide variety of presentations and a multitude of possible causes, generally categorised into infectious and non-infectious, that have been linked to the illness (Britton et al., 2015; Dubey

et al., 2018). The ability to characterise these causal factors demonstrates that there has been

some advancement and progress made in research into encephalitis (Wilken et al., 2017).

However, several authors have highlighted the fact that up to 50% of the causes of

encephalitis remain unidentifiable (George et al. 2014; Wilken et al. 2017).

A diagnosis of encephalitis is commonly made by exclusion, which means that

clinicians rely on clinical features and investigations, including blood and cerebral spinal

fluid analysis and brain imaging techniques, to exclude causes of presenting symptoms,

before eventually arriving at a diagnosis (Dubey et al., 2018; Vogrig, Brigo, Valente, & Gigli

2018). Despite the efforts to distinguish between infectious and non-infectious forms of the

illness, complexities with diagnosing this illness occur because some subtypes of non-

infectious encephalitis mimic clinical presentations of infectious forms (Boucher et al., 2017;

Dubey et al., 2018). This can result in delayed diagnosis, delivery of an incorrect diagnosis

and hence the commencement of improper treatment, leading to a higher chance of

neurological damage, deterioration in health, and death (Boucher et al., 2017; Dubey et al.,

2018).

The treatment of encephalitis is dependent on the nature of the causative factor;

however, the timing of commencement of the treatment is an essential factor in successful

outcomes of both treatment and mortality (Fillatre et al., 2017; Poissy et al., 2009). This also

suggests the importance of early diagnosis; however, despite the advances in the

understanding of this illness over the past two decades, several authors have highlighted the

challenges with diagnosing this illness (Britton et al. 2015; George et al. 2014; Wilken et al.,

2017).

Extensive diagnostic testing has already been established as salient in clinical

decision-making regarding the diagnosis and the treatment of encephalitis. However, several

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studies looking at the effects of diagnostic testing on patients have reported both benefits and negative psychological impacts as they contribute to the patient's perception of the illness, affecting medical outcomes (Devcich, Ellis, Broadbent, Gamble & Petrie, 2012; Vis et al., 2013). Vis et al. (2013) suggest that regardless of the outcomes of the tests, there is potential for testing to distress patients, which can be detrimental to adjusting to the condition. To mitigate this, Vis et al. (2013) accentuate the importance of the patient-clinician relationship, especially in the diagnostic delivery process. Other studies have highlighted the importance of the doctor-patient relationship in the diagnostic process and delivery of the diagnosis (Ong, De Haes, Hoos & Lammes, 1995; Munoz Sastre, Sorum, & Mullet, 2011). These studies suggest that verbal and non-verbal messages from doctor to patient can facilitate the patient's understanding and build trust, which in turn can have an impact on adjustment and adherence to treatment (Ong et al.,1995; Polonsky et al., 2017).

Several studies have also highlighted the impact the way a diagnosis of an illness is delivered has on patient outcomes (Palmer & Thain, 2010; Mulligan, Macculloch, Good & Nicholas, 2012; Jutel, 2016). The studies again highlight the importance of communication, but also emphasise the fact that the way patients appraise and respond to the information given to them affects the illness trajectory. Jutel (2016) states that the "moment at which a diagnosis is delivered to a patient, particularly when it is serious, is an important social moment…not only dictates the clinical pathway…also rewrites the patient's narrative, shifts their identity, predicts potential outcomes, and foregrounds mortality" (p.92.)

However, despite the strong evidence available regarding the importance of communication during the diagnostic journey and delivery, encephalitis presents particular problems, some of which have been discussed above. These include the often-protracted process of investigation, the non-specific nature of the symptom profile and unclear

aetiology. Therefore, this clinical group present potential challenges that clinicians need to understand thoroughly when discussing the diagnosis with patients.

Considering the diagnostic process of a complicated condition such as encephalitis, there is a clear need to know how patients appraise their experiences of investigations and final diagnosis of encephalitis. Having their understanding of this process should aid when clinicians discuss these investigations and diagnosis, together with its implications in a way that optimises retention of the information and minimises distress. This in turn may aid in patients' long-term rehabilitation. This study attempts to use interpretative phenomenological analysis (IPA) to explore survivors' lived experience of the journey to receiving the diagnosis from a psychological perspective, with an attempt to view the meaning given to the experience and understand the impact that might otherwise not be obvious (Giorgi & Giorgi, 2003).

Previous studies have explored people's experiences of having a diagnosis of encephalitis (Atkin, Stapley & Easton, 2010; Cooper et al., 2016). Atkin et al.'s (2010) study focused on using the context of broader family and social relationships as a foundation to understand how people with a diagnosis of encephalitis made sense of the condition. Cooper et al.'s (2016) study, on the other hand, using narrative analysis, focused on people in the general population's accounts of their diagnosis and treatment of herpes simplex encephalitis.

This study aims to contribute a unique perspective to this field by focusing on the experiences of the diagnostic process and the impact of this on adjustment. Balogh, Miller, and Ball (2015) assert that the diagnosis is both a method of classification as well as a process. They describe the diagnostic process as "a complex, patient centred, collaborative activity that involves information gathering and clinical reasoning with the goal of determining patient's health problem" (Balogh, Miller, & Ball, 2015, p. 33). The process

begins from when the patient starts to struggle with the symptoms and seeks help from a

healthcare professional, comprises of all the processes involved to reach a diagnosis, and

ends when the diagnosis is delivered (Balogh, Miller, & Ball, 2015).

This study aims to make a unique contribution to this field by focusing on the

experience of individuals who are at a working age at the time of receiving the diagnosis of

encephalitis using IPA.

Method

Design

To facilitate the exploration of the differences and commonalities between and within

the participants' experiences, a qualitative, inductive and ideographic approach was utilised.

This method was deemed the most appropriate given that there are no current studies

focusing on the unique element of people with encephalitis gaining meaning and perspective

of the diagnostic journey (Frankfort-Nachmias & Nachmias, 1996).

Semi-structured interviews were used to gather the views of the participants as they

facilitate the exploration of the subject that is salient to the participants (Denzin & Lincoln,

2008). IPA was used to explore the data as Smith and Osborn (2007) suggest that IPA is

useful for examining complexity, process or novelty. The fundamental aim of IPA as a

methodology is to understand the meaning participants make of their lived experiences

(Smith, Flowers & Larkin, 2009). Smith, Flowers and Larkin (2009) emphasise the dynamic

role of the researcher in making sense of the participants' views, which is consequently an

attempt to make sense of the phenomenon being studied. This is what Smith and Osborn

(2007) depict as a "two-stage interpretation process" or a "double hermeneutic". Pietkiewicz

and Smith (2014) describe this process as an attempt by the researcher to put themselves in

the participant's shoes during interpretation but at the same time continually asking critical

questions about possible things implied within the data but not said during the interpretation process.

Research approvals

Ethical approval was granted after review by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University [FHMREC] (see ethics section for the letter of approval and the other documents [p. 4-47 – p. 4-49).

Protocols to provide guidance, should participants become distressed while reliving some of these experiences, were established and resources for further support were also approved (see ethics section p. 4 – 37).

Participants

The nature of IPA requires a more in-depth and interpretative analysis; therefore, there is a need to focus on a reduced number of participants to not lose the sense of the individual participant's experience as data are aggregated for the group (Smith and Osborn, 2007). A sample size between six to 12 participants was sought for this study.

The participant pool was individuals within the United Kingdom with a diagnosis of encephalitis that had been confirmed by a neurologist. Social media and brain injury charities were utilised as a platform for advertising. However, participants were only recruited via the social media platform. The social media platform was closed Facebook groups; where before joining potential members are screened to ensure that only people that have reported a diagnosis of encephalitis or their family members are permitted to join the group. Individuals were invited to participate if they had been given a diagnosis of encephalitis and were within the working age of between 18 and 65. As at the time of recruitment, the prospective participants must have had their diagnosis for at least two years

to allow time for adjustment and not more than five years to keep the experience of the process of receiving the diagnosis as fresh as possible.

Participants who expressed an interest in taking part in the study were sent participant packs through the post. These participant packs contained an eligibility checklist, participant information sheet, an expression of interest form, two consent forms (one for the participant to keep and one to be returned to the researcher) and a stamped self-addressed envelope (see ethics section p.4 -28 to p.4-36). Participants who remained interested after examining the information pack were requested to opt-in to the study by filling in and signing the consent forms.

Nine people consented to be contacted by the main researcher; however, six participants in total were interviewed as one of the participants did not meet the inclusion criteria, and the other two participants did not consent within the allotted time for recruitment. Six women participated, two of them were employed, one had her own business, and the other three were unemployed. The participants were given pseudonyms (see Table 1 for narrative description of participants) in the transcripts.

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INSERT TABLE 1

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Data collection

The interviews were based on a semi-structured interview schedule, (see appendix 2B) which was developed by the researcher using Smith and Osborn's (2007) guidance on interviewing in phenomenology and informed by previous research that had looked at the experiences of people with encephalitis (Atkin et al., 2010; Cooper et al., 2016). Attempts were made to engage an expert patient (someone with a diagnosis of encephalitis) to facilitate

the development of the interview schedule, however, no volunteer opted in within the allotted period.

The interviews were completed by May 2018 and were conducted in participants' own homes, with the main researcher ensuring that the University lone worker's policy was followed. At the commencement of each interview, the participant information was discussed and participants were made aware that even though the consent form had been signed and returned, they still had the option to withdraw their consent. The interviews lasted for an average of 55 minutes. Each participant was provided with a debriefing sheet at the end of the interview.

Data analysis

Each interview was audio recorded, and subsequently transcribed verbatim. All forms of identifying information were anonymised, and the data were then analysed following the methods devised by Smith et al. (2009). Interpreting the data involved the main researcher first identifying the transcript that was the richest and most comprehensive. The selected transcript was then analysed, and subsequently, other transcripts were analysed on a case-to-case basis (Smith et al. 2009).

Step 1. Reading and re-reading. In order to facilitate familiarisation and engrossment in the data, the transcripts were read and re-read by the researcher. In addition to this, to make sure that the analysis was focused on the participant and to ensure that loss of information due to transcription (Davidson, 2009; Poland, 1995) was minimised, the audio recording was played while analysing the first transcript. All the researcher's thoughts and observations during this stage were noted and recorded in a reflective diary (see appendix 2C).

Step 2. Initial noting. Following familiarisation with the data, initial notations and comments were made on the right-hand margins of the transcript. The initial commentaries and notations were made at a descriptive level which merely described the content of the participant's response, both at a linguistic level, which noted the language used by the participant, and at a conceptual level, which noted the initial interpretation of the participant's experiences (see table 2).

Step 3. Developing emergent themes. This part of the analysis involved the notation and commentaries being read and re-read then consequently clustered into themes by identifying the connections between them, which represented the participant's experiences (see table 2).

Step 4. Searching for connections across emergent themes. The next step involved comparing the developing themes. The themes were all typed up and spread across different screens on the computer to facilitate a smooth transfer from one place to the other. Similar themes were grouped, and colour coded (abstraction) while opposite themes were grouped separately (polarisation) and colour coded. These processes enabled the recognition of superordinate themes (Smith et al. 2009). Figure 1 shows an example of the identification of a superordinate theme for one of the participants.

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INSERT TABLE 2

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INSERT FIGURE 1

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Step 5. Analysis of the next case. After all the phases were carried out with the first participant and the superordinate themes identified, the same process (steps one to four) was implemented on the five other transcripts. The researcher ensured that each transcript was treated as an individual case allowing the themes and superordinate themes to develop for each transcript.

Step 6. Searching for patterns amongst the cases. Finally, all superordinate themes identified in each transcript were typed up and displayed on multiple screens to enable the researcher to compare the cases and make connections between them. This final clustering of themes resulted in the identification of three superordinate themes across the whole dataset (see table 3 for a combination of the super-ordinate themes involving the complete dataset).

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INSERT TABLE 3

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Facilitation of the credibility of the analysis

The issue of quality in qualitative research and whether it can be evaluated appropriately is a widely discussed debate (Sparkes, 2001; Ravenek & Rudman, 2013). However, for this study, guidelines suggested by Elliot, Fischer and Rennie, (1999) were followed to enhance the thoroughness and hence the credibility of the analysis.

Consistent with Yardley's (2008) approach, a reflective diary was kept throughout the process (see appendix 2C). An example of the usefulness of this includes when the researcher realised that, after the first interview, his preconceived ideas about the experience of receiving the diagnosis influenced the flexibility that is meant to be allowed for participants when responding to questions. Discussion of diary entries such as this was helpful in supervision (a clinical psychologist working with the target population) as it

enabled the acknowledgement of possible bias and framed the nature of the subsequent interviews (Elliot et al., 1999; Smith et al., 2009).

In addition to this, methodological rigour was enabled by ensuring that the emerging themes were grounded in the data and the analysis of the themes was done with supervisors who are experienced in both IPA and encephalitis (Elliot et al., 1999; Smith et al., 2009). Doing this ensured that, as suggested by Yardley (2000), the interpretations of the transcripts were not fixed to one perspective and were understandable to other people.

Results

The IPA generated three superordinate themes (i) Being on a wild goose chase-challenges with getting the diagnosis: "my blood test came back negative that time but my symptoms were definitely there …", (ii) The emotional rollercoaster experience: "that was a kind of shock…I had never cried so much my life", and (iii) The significance of information and others: "I was emailing her [neurologist] clinical papers saying that just because the blood test is negative doesn't mean- false negative". The themes represent experiences of the journey to receiving the diagnosis and the impact these had on adjustment (see figure 2).

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INSERT FIGURE 2

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Being on a wild goose chase- challenges with getting the diagnosis: "my blood test came back negative that time, but my symptoms were definitely there."

This theme represents participants' experiences of the journey from initial symptoms up until delivery of diagnosis, with the feeling of a prolonged search for something that was complicated and difficult to find.

All participants, apart from Isla, expressed the view that encephalitis was a diagnosis that was poorly understood by themselves, health professionals (HP), and the public. However, of particular relevance to them was the perceived inadequate level of understanding they experienced with HPs while struggling with their symptoms. Most of the participants highlighted the experience of having to undergo a variety of tests and the considerable amount of time it took for them to wait for some of these results while struggling with their symptoms.

Several participants highlighted the distress associated with long waits for test results (Olivia, Grace, Elsie, Phoebe, and Aiofe). Participants discussed the difficulties associated with waiting so long for test results but then being told that they were clear, even though they were convinced that there was something wrong; "my blood test came back negative that time but my symptoms were definitely there…I have done more research that shows that you can have a negative result…but she (neurologist) didn't understand" (Elsie).

The inadequacies in the understanding of the condition were prevalent throughout Elsie's narratives. Elsie described how un-containing her GP was, stating, "he was rubbish", and therefore she excluded him from her treatment; "I didn't feel my GP has been great and I didn't involve him much because their knowledge is very limited". Some of the participants highlighted the confusing experience of the HPs referring them to a psychiatrist. Grace stated that "they thought I was insane" and that she was threatened with being sectioned; "this psychiatrist came in to interview me, and he said oh they are going to lock you up". Aiofe described the horrifying experience of actually being put in an institution, wrongly diagnosed with psychosis despite vehemently opposing this view; "I'd be locked in the room and they will stand over me when I took a bath or shower, and that wasn't very nice... I was pregnant, and they thought I was crazy".

In addition to this, the majority of the participants highlighted being moved from hospital to hospital and from one professional to the next. One participant, highlighting the challenges with diagnosing her symptoms, stated that after being moved so many times, they gave up on her; "…and it was difficult to diagnose…after two weeks they said there's nothing more we can do for you so prepare to die" (Phoebe). In addition to this, the complexities associated with searching for a diagnosis are evident as some participants describe the confusion surrounding their diagnosis. One participant stated, "they thought I had HIV" (Grace) while others highlighted the distresses associated with changes in their diagnosis:

> So they have an MDT, all the neurologists and the radiologist…and then they decided that maybe I actually had a brain tumour because the swelling was so large they couldn't identify what it was…that was a completely different diagnosis...but they were not all completely agreeing in on this (Elsie).

As participants journeyed with HPs in circumnavigating a diagnosis, several of them discussed trying to facilitate the process of diagnosis or trying to discourage the professionals from investigating specific pathways that they felt were wrong, but they felt they were not listened to. Phoebe felt she was being mocked and all attempts to refute these claims were not heard; "It was more like mocking me…as much as I tried to explain that I had never had genital herpes ever in my life…they didn't believe me". Isla, who had a good experience of receiving the diagnosis, described herself as lucky when compared to the people she had met; "I was lucky that I was very seriously ill quickly and that the medical team had the experience of encephalitis...other people have said that they were told to stop making a fuss, go home and get on with it". Elsie who commented on the frustrating experience of not being believed and its impact on herself and her family shared this reflection:

Knowing there was something wrong with me and not having people really believe that something was wrong with me…and people saying it was stress and anxiety...trying to get people to believe you was really frustrating…more stressful than actually being unwell.

Isla had a different experience despite being moved from place to place; she described her hospital experience as positive as testing procedures were quick and effort was made to facilitate her understanding of the diagnosis; "He was ever so nice... He was the one that kept saying what I had". However, in addition to the difficult experience of not being believed during the journey to receiving the diagnosis, Elsie described an experience of inadequate containment during the diagnostic delivery process because of insufficient knowledge:

…GP had got to me first, but he didn't understand what it meant. So he was reading out a report saying that I had a swelling in my hippocampus and I'm like 'so what does it mean' and he went 'I don't know'. So he is giving me this bad news but doesn't know what it means himself which is quite worrying for me.

As a result of this lack of understanding there appeared to be a consensus that there needs to be more training for HPs; "educate the doctors to think out of the box" (Aiofe). One participant, while echoing the need for more education, felt that there was a gap in the level of knowledge; "although she is a neurologist, and she has the knowledge, she is not an expert like Dr X" (Elsie).

The emotional rollercoaster experience: "that was a kind of shock…I had never cried so much my life".

This theme represents participants' experiences of extreme fluctuations in their emotions on their journey towards receiving and adjusting to the diagnosis.

All participants contributed to this theme, describing their emotional states and reaction to different stages. Participants described the experiences of shock because of the sudden loss of their health when they started to feel unwell; "when I started to feel unwell, it came out of the blue…so it was a bit of shock" (Elsie). In addition, Elsie discussed the experience of having some of the investigations done as anxiety provoking; "it was a scary experience, scarier because I knew the risks factors…what could potentially go wrong". Another participant highlighted the impact of the traumatic experience of some of the investigations; "they were going to insert that into me, and I said no…I've had enough of chemicals in my brain…I don't give a shit about dying I am not having that" (Grace).

Several participants reflected on the emotional impact of the diagnostic journey. Elsie also discussed the overwhelming feeling of worry about what could potentially happen; "...that was quite a worrying time you know thinking what was going to happen in my life, where was I going, was I going to be left disabled". When eventually given the news of the diagnosis, several participants highlighted the range of emotions they experienced receiving it. Elsie stated that she "felt so dizzy and so rotten" and was getting "really anxious" while Olivia highlighted how scary the experience was because it had to do with the brain; "it was scary because you don't understand it… I know that this something that [has] affected your brain which is the most important part of the body". In addition, Isla described the overwhelming emotional experience when the reality of the effects of the illness dawned on her; "I couldn't understand why I couldn't do it, I didn't want to see people - I was terrified of people…that was a kind of shock…I had never cried so much my life because it didn't make any sense". For Isla, the initial state of shock led to a period of low mood which consequently caused her to have suicidal thoughts:

I didn't know what was going on…as we lived on a road that lorries would go past in

the night and I would just think oh I'm just going to have to go in front of a lorry, then

that's it.

However, in addition to the feeling of shock, participants experienced relief when

receiving the diagnosis (Elsie, Phoebe, & Olivia). Phoebe reflected on the fact that this relief

came as a result of knowing what they were fighting; "it was a relief because I was, I finally

knew what I had…because not knowing what it is was scarier than the diagnosis", whilst

Elsie stated that this feeling of relief also came about because of the sense of being believed:

The weight of the world had been lifted off my shoulders it was a huge relief because

firstly I knew there was something wrong with me…I still think there were people

who had a niggling doubt that there wasn't anything wrong with me.

The significance of information and others: "I was emailing her [neurologist] clinical

papers saying that just because the blood test is negative doesn't mean- false negative".

This theme represents participants' experiences of factors that facilitated or hindered

adjustment during their journey to receiving their diagnosis, when the diagnosis was

delivered and after it was delivered.

Despite the highs of the relief felt by some participants after receiving the diagnosis,

some participants reflected on the impact of inadequate information given after that; "…being

told I had viral encephalitis doesn't mean much…it helped because it led me to look for

things myself…he didn't explain it and let me know what was around to help me" (Olivia).

In addition, Olivia who had her diagnosis changed from one form of encephalitis to another,

shared her disappointment at not being given adequate information and likened the

experience to being treated like a child:

I think people need to tell you everything. I would have really appreciated my doctors

coming in and telling me what was going on, but they treated me like a bit of a

child…Still to this day I have not had one doctor say to me you've had acute

disseminated encephalitis that means inflammation of the brain and spinal cord.

Furthermore, all the participants stated that they were not given adequate information

regarding the possible impact of the consequences of the illness. Elsie, reflecting on the

dramatic changes in her life because of the illness, highlighted the lack of information about

encephalitis and its consequences and how helpful having this could be:

I don't think there is enough information for anybody to give me because they are so

limited…I think I was quite naïve if I look back from where I am now and go back to

then, my knowledge and what I have lived through and all the changes because my

life has changed completely…I think there could be a lot of information that could be

given.

Grace reflected on the potential dangers of insufficient information; "was worried

because nobody told me anything about driving and I black out a lot…I popped in my car and

drove…I didn't have a clue where I was". In addition to this Elsie, having already reflected

on the insensitive and uncontained way the diagnosis was delivered, further highlighted the

impact of a lack of information about the secondary consequences of the illness:

Obviously, I got a phone call (given the diagnosis). I was given medication, and that is

really it…But I felt that I didn't know how long it would take to get better and I took

a year, and that was never explained …I wasn't able to drive, and it had a huge impact

on my life, and I don't think people really understand or appreciate what that feels

like.

Some participants suggested things that could help with the challenges of inadequate information; "have written information to give to you that you could take your time and read through. Basic information so it's easy to understand [something] in writing or in pictures you can go back to refer to" (Olivia).

Several participants reflected on the impact of having access to influences of power on their journey towards a diagnosis and subsequent adjustment. Elsie highlighted that having access to the right people expedited investigations; "I managed at work to get somebody to look at me…just not through the proper route…a surgeon…and he ordered an MRI scan...and basically, I got a cancellation the next day...so it showed up the hippocampal swelling". Phoebe reflected on the privilege of access to a specialist; "…you have to find out what this is, and I made it a challenge for him, I also had the support from other professors wanting to help me". This experience of the impact of power in facilitating their journey was also shared by Isla who was able to afford a private neurologist to overcome the long waiting lists, and Aiofe stated that she was only listened to when family and lawyers got involved; "…My mom and my sister came up…They sort of took over …they got a solicitor. I had to fight [along] with the solicitor to get help from the hospital…For him to speak for me and get me help".

In addition, Phoebe highlighted how being a HP and having knowledge saved her life by enabling her to fight her corner; "Being a doctor helped me to fight…because I have access to medical information and medical studies and research and understand them". This experience of imbibing a fighting spirit is one shared by all the participants, illustrated by the resilience shown in the journey towards diagnosis and adjustment. Elsie described this act of resilience, emphasising the need to remain "positive through it all ensuring it doesn't get the better of you and make you depressed".

While Elsie engaged this fighting spirit to ensure dealing with the effects of the illness did not get her down; other participants described engaging their fighting spirit when they were down. Isla described going down a spiral because of the secondary consequences of the illness and needing to push herself by engaging her thoughts "I just remember thinking shit I'm going to have to get up here and move otherwise this could be it". On the other hand, Aiofe described being in a hopeless place because of being deprived of her liberties because of the illness and hence needing to fight; "it was always a fight, you know to fight to get out or fight to say well if I've got a diagnosis why can't I get help with getting out?"

In addition to the active engagement of internal resources to facilitate adjustment, all participants reflected on the use of external resources. Four out of the six participants described the experience of engaging in psychological therapy. Phoebe discussed the experience of pre-emptively enlisting the support of a clinical psychologist to help with the diagnosis process; "…my therapist helps me a lot because I started psychotherapy right from the beginning…I said that I don't want to get depressed...I need[ed] all the help I can get from everywhere". Several participants highlighted the use of psychological therapy for managing the secondary consequences of encephalitis.

In addition to psychology, other external support systems discussed by participants included family, friends, support peer groups, and a particular charity, which helped greatly through the provision of telephone counselling and printed materials. Isla employed the materials as a sense of reassurance; "I would have them with me all the time and keep checking", while Aiofe discussed the experience of using the online forum of the charity to have questions answered and facilitate understanding; "This helped quite a lot - if I have any questions I wrote it on there and they would get back to me…9/10 times [they] have expressed themselves rather than a doctor that doesn't know". In addition to enhancing

understanding, Grace stated that if it were not to be for this charity, she felt she would not be alive; "I would have probably topped myself…but since I've had xxx, I am not depressed..."

Discussion

The purpose of this research was to explore the lived experience of receiving a diagnosis of encephalitis with the aim of reviewing the meaning given to the experience in order to facilitate our understanding of the impact on adjustment. Through the process of IPA, three themes were derived.

Theme one represents the "wild goose chase", a metaphor for the experiences of an enduring pursuit towards getting a diagnosis. This theme confirms the complexity of encephalitis, and despite numerous advances over the last decade (George et al. 2014), the condition continues to pose challenges in prognosis and treatment. These complexities can be understood using Innes, Campion and Griffiths (2005) framework of complex consultations. The authors suggest that consultations are straightforward when both the patient and clinician create an element of certainty. According to Innes, et al. (2005), challenges with complexities and uncertainty regarding consultation and diagnosis occur when symptoms are complicated, posing what it described as medical uncertainty (Innes, et al., 2005).   Bhise et al. (2018) define medical uncertainty as "subjective perception of an inability to provide an accurate explanation of the patient's health problems" (p.103).

Several studies examining the impact of medical uncertainty on clinicians report that it causes distress, which is reduced by seeking to acquire more knowledge (Bhise et al. 2018; Yon, Nettleton, Walters, Lamahewa & Buszewicz, 2015). One way in which knowledge is increased is through medical testing which means that medical uncertainty consequently increases test-ordering behaviour among clinicians (O'Riordan et al., 2011; Sonnenberg, 2001). However, whilst medical testing might be beneficial to the diagnostic process (Epner,

Gans & Graber, 2013; Hofmann & Welch, 2017), several studies have highlighted the detrimental impacts these tests could have on patients. These include the effects of false positives and negatives and the impact of this related to anxiety before, during and after the test (Epner, Gans & Graber, 2013; Hofmann & Welch, 2017). The theme of the negative impact of the testing procedures for encephalitis was prominent in the study. Participants reported experiences of high anxiety and distress due to the frequency and intrusive nature of the tests, for example, the lumbar puncture. This resulted in feelings of trauma for some participants in this study, and resistance to further diagnostic tests.

Hall and Hall (2017) describe this experience as a medical trauma, which is "a trauma that is caused by direct contact with the medical setting and developed through the complex interaction between the patient's medical staff, medical environment and a diagnostic experience" (p.19). Hall and Hall (2017) go on to suggest a need for a paradigm shift in the way trauma is characterised (International Classification of Disease -11 and Diagnostic Statistical Manual of Mental Disorders -V) as they limit our understanding as to how traumatic experiences within the medical setting could impact patient lives. They stress that a fundamental factor in understanding the traumatic experience is based on the meaning the patient makes of the experience (Hall & Hall, 2017). Several participants' experiences of medical testing suggest that it was difficult and distressing. While they experienced these distressing situations, participants stated that at numerous points during the process they voiced their opinions in order to help in giving clarity to what appears to be a chaotic process. However, several participants reported that they felt not listened to, which contributed to several other painful emotions.

Communication difficulties between clinicians and patients can result in dissatisfaction and a negative emotional impact on patients, which was evident in the study (Dures et al., 2017; Raja et al. 2015). The impact of the complexities of encephalitis

highlighted in theme one is a range of emotions experienced by the participants. This

emotional experience on the journey to adjustment, underpin theme two. Hughes and Kerr

(2000), assert that complexities in diagnosis may create a power imbalance between doctor

and patient. Bensing and Verheul (2010) highlight the importance of non-verbal

communication, as an anxious clinician could negatively affect the therapeutic relationship

and emotions of the patient. (Hughes & Kerr, 2000). In addition, research has shown that

sharing bad news (the diagnosis) can be distressing for the clinician and consequently the

patient (Hulsman et al., 2010; Shaw, Brown & Dunn, 2015).

Uncertainty around the diagnosis of encephalitis, complexities of the illness,

emotional reactions of both doctors and patients and the delivery of the diagnosis all had a

role to play in the way participants adjusted. Leventhal's Common-Sense Model (CSM) of

self-regulation is a widely used theoretical framework designed to facilitate understanding of

how these factors influence adjustment (Leventhal, Meyer & Nerenz, 1980; Leventhal,

Nerenz & Steele, 1984). According to the CSM, it is not the nature of the illness that

determines how a patient adjusts but the way they perceive the illness (illness perception) and

the coping strategies employed based on the illness perception (Knowles et al., 2017;

Leventhal, Phillips, & Burns, 2016). Leventhal's model suggest a hierarchical system

comprising of three concepts (see figure 3) (i) the patient's perception of the illness (ii)

engagement in coping strategies (iii) the evaluation of the coping strategies utilised (Knowles

et al, 2017; Leventhal, Phillips, & Burns, 2016).

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INSERT FIGURE 3

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Leventhal suggests that patients' illness perceptions contain five components which

include (i) identity - the label given to the illness and its symptoms, (ii) timeline - the belief

of how long the illness might last, (iii) consequences - the belief about the impact of the illness, (iv) cause - a belief about what caused the illness in the first place, and (v) controllability - belief of the extent to which the illness can be controlled (Benyamimi, 2011; Knowles et al., 2016). Illness perceptions are more valued as predictors of adjustment than the severity of illness (Frostholm et al., 2007; Paddison, Alpass & Stephens, 2010). In addition to the factors impacting illness perception mentioned in theme one, participants experienced other factors which facilitated or hindered adjustment post-diagnosis that can be described using the CSM model. For example, inadequate information given by HPs' pre and post diagnosis impeded adjustment. Participants reflected craving medical information around the diagnosis and psychosocial information about potential emotional and social consequences. Several studies have highlighted the importance of adequate information in the recovery of people with chronic illnesses (Adams, 2010; Halkett, Lobb, Oldham & Nowak, 2010; Robinson, Turner, Levine & Tian, 2011). This is reflected by the Department of Health (1996), "Knowledge about health, illness, symptoms and treatment gives people more control over their circumstances and helps them access and use services effectively. People need good quality information…understand the implications and to take part in decisions about treatment and care". (Cm 3425; "A Well-informed Public").

The salience of information on adjustment using the CSM is reflected in the patient's illness perception as the information the patient has received create mental representations of the illness, which in turn facilitates sense-making and coping strategies (Hagger & Orbell, 2003). Inadequate information impacts most of the components of illness perception, as reflected by the participants, as they found it difficult to identify with the illness, have an understanding regarding the timeline, consequences or the controllability of the illness. In addition to this, within the context of the CSM, the role of information is implicated in the factors that contributed to facilitating their journey to adjustment, reflected in theme three.

One of these factors experienced by the participants is the influence of power, which reflected the importance of their access to knowledge by virtue of their searching or training and the ability to use this to inform the sense-making process. The provision of information, training and support of patients with chronic conditions has been shown by many studies to be empowering for the patients, providing the necessary platform to think autonomously, and engage in managing their illness (McCorkle et al., 2011; Trummer, Mueller, Nowak, Stidl, & Pelikan, 2006).

The importance of information was highlighted by participants' engagement in active coping strategies involving searching for information and engagement with a particular charity which facilitated their journey to adjustment. Numerous studies have highlighted the relationship between adequate social support and related quality of life following brain injuries (Haslam, 2014; Walsh, Muldoon, Gallagher & Fortune, 2014). Participants also described the experience of getting their sense of identity back from groups organised by the charities. Studies have highlighted that following a brain injury, it is common that patients struggle with identity issues, which has been linked with poor adjustment outcomes (Broks, 2003; Thomas, Levack & Taylor, 2014). Haslam, Jetten, Postmes, & Haslam (2009) assert that the ability to actively and consistently identify with a social group and thus replace aspects of the self-identity lost because of the injury has a significant effect on adjustment. It appears that engagement in actively seeking information and utilising support groups involved all the components of the illness perception for participants, which in turn facilitated the adjustment journey.

Clinical Implications

The findings in this study suggest that making sense of the diagnosis of encephalitis is a complicated and difficult process. Graber et al. (2012) suggest that diagnostic uncertainty

contributes to the occurrence of diagnostic errors in most areas of medicine. A unique contribution of this study is that participants reflected on the impact of these uncertainties and the impact an inability to contain them, had on their journey towards adjustment. Several other authors have called for a paradigm shift in the approach to uncertainty within the medical curriculum that emphasises reasoning and enhancing skills dealing with uncertainty, with a possible change from the use of the word 'diagnosis' to 'hypothesis' (O'Riordan et al. 2011; Simpkin & Schwartzstein, 2016).

In addition to the tolerance of uncertainty, this study highlights the importance of the provision of information in different formats, and endeavouring to carry patients along on every step of the way during the journey towards a diagnosis. NICE (2014; 2018) asserts that excellent communication that is contextually and culturally appropriate regarding the diagnosis and its consequences is essential for patients with head injuries. Several resources have been studied and found to improve communication in people with cognitive difficulties Houts, Doak, Doak, & Loscalzo, 2006; Ascari, Pereira, & Silva, 2018). The study also highlights the importance and relevance of support groups.

Finally, the study raises the issue of the admission of brain-injured patients in a mental health wards with a diagnosis of a physical health condition. Studies have shown that people recovering from a head injury require specific types of adjustments, which include adjustments to their living environment, and support from people who are trained and have a good understanding of the damage and its consequences (Cameron, Pirozzo & Tooth, 2001; Colantonio et al. 2010).

Limitation and future research

One of the limitations of this study was the fact that it was solely based on the experiences of women. Several studies have highlighted the importance of considering sex and gender-related factors within research as it results in better quality evidence to inform the healthcare of both men and women (Clayton, 2016; Tannenbaum, Greaves & Graham, 2016). However, bearing the inevitability of circumstances like this occurring in research, this study focused on ensuring that the investigation was ethically sound without any unfair bias in the recruitment of a particular sex (Allmark, 2004). It could also be argued that this limitation is also a strength as this study contributes to the literature around acquired brain injury (ABI)'s in women, an area often overlooked in ABI research (Harris et al., 2012; Haag et al., 2016). In addition, exploration of the experiences of male participants in a similar study could represent a future area of research.

Another possible limitation includes the fact that recruitment into the study occurred via brain injury charities and social media and not via the NHS with confirmation of a diagnosis by a neurologist, which could raise questions about the validity of the diagnosis. However, both the charities and closed social media groups utilised have strict criteria for joining.

Finally, another possible limitation is the recruitment of people with different variants of encephalitis as their presentation and experience may be distinct. This was considered, and it was decided that because the focus of the research was on the experience of receiving the diagnosis, a common ground existed. An area of future research could be the exploration of the experiences of people with particular subtypes of encephalitis.

The clinician's experience of dealing with the uncertainties surrounding the diagnosis of encephalitis also merits further exploration. Several studies resonate with this study regarding anxieties around uncertainty (Hautamaki, 2018; Stivers & Timmermans, 2016).

Such a study could provide a platform of acknowledgement of the complexities of the condition, which in turn could put clinicians under less pressure and give them space to deal with the uncertainty the illness poses.

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Table 1: Summary of participants' demographics and narrative description.

Participant	Gender	Age	Diagnosis	Time post injury	Occupation.
Olivia	F	38 years	Unsure- Acute Disseminated Encephalomyelitis/ Viral Encephalitis	4 years	Unemployed
Isla	F	47 years	Viral encephalitis	2 years	Business owner
Grace	F	57 years	Viral encephalitis	4 years	Student/Model
Elsie	F	49 years	Anti-N-methyl-D-aspartate receptor (NMDAR) encephalitis.	3 years	Specialist Nurse
Phoebe	F	38 years	Anti-N-methyl-D-aspartate receptor (NMDAR) encephalitis.	4 years	Medical Doctor

Aiofe	F	26 years	Anti-N-methyl-D-aspartate receptor (NMDAR) encephalitis.	4 years	Unemployed.

The first participant Olivia described having a great life before experiencing the symptoms and remains unsure of the exact type of encephalitis she has because it has changed a few times. The second participant Isla was diagnosed in another country and was the only person that had a positive experience of aspects of the diagnostic process and delivery. Grace – the third participant is still coming to terms with the physical difficulties resulting from the testing procedures. Elsie and Phoebe – participant four and five respectively, are health professionals (HP) that reported benefits they derived because of their profession. Finally, participant six – Aoife whose life changed dramatically because of the trauma of being admitted into a mental-health ward despite having a physical health condition.

Table 2: showing examples of exploratory comments (developed in step two of analysis) and emergent themes (developed in step three of analysis) for sections taken from the transcript of the interview with P4

Emergent Themes	Transcript	Exploratory Comments
	P:…….I the girls did an ECG on me when I was having more	**Clear EEG test results still not right.**
Searching and but no answer.	palpitation and feeling dizzy and we couldn't find anything	
	wrong and I felt there is something not right and things	**Searching and looking for answers –**
Not understanding/hard to understand	progressed quite quickly to cut all the long story short. I went to	**Even the GP does not know.**
	my GP didn't have any joy, you know they thought that maybe it	
Incongruence between prognosis and symptoms	was stress palpitation. Being in my mid-late forties, hormonal,	
	menopausal, and I actually thought that it could be it at the	Trying to make sense of the symptoms
	beginning, then things started to (inaudible) and I had a funny	but highlighted probable causes still did
	feeling down my arm, and then I was a bit vague at times and all	not fit with experience of symptoms.
	these things happened, and I managed at work to get somebody,	
Not understanding/hard to		

understand

a physician to look at me just not through the proper route, because I work in the hospital and he thought it was stress and he

Privileged position- quicker results

didn't want to send me for tests or anything like scans but looked at a few blood tests and different things and then one of my colleagues, when I told her about the (inaudible) and her husband's actually a surgeon but he said he'd have a look at me although he's a surgeon and not a physician, umm and he ordered a MRI scan and basically I got a cancellation the next day if I could be at the hospital within an hour and it's only 5 minutes up the road so I said yeah and umm it showed up the

Seeking but not finding.

hippocampal swelling, so I had quite a large swelling in my hippocampus which even the radiologist in our hospital wasn't familiar with it and had to send it to the neuro centre to say what is this so I got a phone call to come into hospital. And that happened within 3 weeks which I believe when I hear other peoples stories is remarkably quick cos things tend to be quite

Physician thought it was stress- health professionals' suggestion still does not fit with the symptoms.

Despite assertions by health professionals, she is still searching looking for answers.

More testing to facilitate clarity and diagnosis.

Radiologist not familiar with symptoms-

insidious and quite long and protracted but I think me being me, knowing my body and having access to the right people I got the, I got umm into hospital pretty quickly.

She was mindful that despite waiting for three weeks, this was a privilege position to be in by virtue of her job, as other people had to wait longer.

I: XXX before you go on, sorry to interrupt you, what was it like not knowing, like so you going to this place and not knowing.

Suggestions do not fit symptoms- unanswered questions.

P: Well that was huge, yeah that was really difficult for me because I knew there was something wrong with me and I will talk a bit more about that when we go on to talking about getting the phone call umm about my diagnosis, but umm but knowing there was something wrong with me and not having people really believe that I was, I knew there was something physically wrong with me, and people saying it was stress and anxious, now I didn't feel remotely stressed in life, like what I said to you at the very beginning, you know life was good, I was happy, I had lots

Not believed.

Going from professional to professional but still not knowing.

Obvious but not obvious.

of things to look forward to, there had been a little bit of stress at work umm but nothing major and nothing like a critical centre, we had decanted, we had been getting refurbished and had moved to another area of the hospital which I didn't feel great about and I didn't feel it was the safest place to be but I think I had actually, I think I was already unwell at this point and that was more subtle around what was wrong with me rather than I was like acutely stressed. So I knew I didn't have acute anxiety or stress and trying to get people to believe you was really frustrating and I found that, that was actually more stressful than actually umm being unwell but I knew the mottling in particular and the tingling down my arm, that was not normal, that was not stress and anxiety, but it was, it was quite hard and quite frustrating I think and for my family as well because they could see, cos my husband could see this mottling down the right side of my face, I believe it's called facial brachial dystonic seizures,

Complexities of condition.

Feeling unheard-

Providing validation to support diagnosis.

Difficulties with knowing that something was wrong with her but no one believed.

Wrongful assertions by the health professionals – they cannot be right.

She is attempting to align what the professional have said with the symptoms she is experiencing but they do not fit.

nobody medically ever saw them because they're quite transient to catch, I wish XXX had actually videoed it, it would have been great because we could have had evidence of it, and he could actually say to me you're having one of those, we called them moments, seizures, at the time I didn't know they were seizures….. Because I could just be sitting on the couch watching television and it would come on, I didn't always count how many I had but I had quite a few of them, umm I would've liked somebody to be able to see that because I think there would have been more validity in, in them taking me more seriously and I found that quite hard and I think I've changed my approach to patients as a response to what's happened to me, to be honest.

Challenges experienced with getting people to believe you.

Everybody else can see but the health professionals. She is feeling the need to seek evidence to provide validation for the symptoms experienced.

Inadequate knowledge and

understanding.

I: Thanks for sharing that. Going back, because I cut you off, so you talked about the MRI scan, they saw the swelling, then they sent you home.

The need to provide evidence to be

P: No they didn't see the swelling, I had the scan but it wasn't   taken seriously.

reported that day it was maybe about 2 days later when the scan

was reported, I got called to come into hospital.

I: Okay, then what happened?

P: I actually was, I actually had an appointment with my GP that

morning and I went there and he actually, he saw the report but

my friend's husband who was the surgeon who asked for the

Health professional distrust.   scan had just had a call from the radiologist and was about to

phone me to say what had happened but my GP had got to me

first but he didn't understand what it meant. So he was reading

out a report saying that I had a swelling in my hippocampus and

I'm like 'so what does this mean' and he went 'I don't know'. So

he's giving me this bad news but he doesn't know what it means

himself which is quite, it's a bit worrying for me shall we say. He said 'oh I don't know I will find out and I will get back to you' and I was like kind of flummoxed, luckily I had my Mum with me because I wasn't driving and I, because I felt so dizzy and so rotten my parents had been very very good and my Mum ran me to the GP surgery and came in with me, because I was getting, I was getting anxious at this point about you know how things were going and my GP was rubbish, lets face it he was rubbish

I: Did you know about encephalitis before?

P: Well I'd had nursed patients with viral encephalitis and in ICU you get patients who had seizures and maybe don't come out of seizures and require a lot of sedation and then had to be incubated and on a breathing machine, so yes I've looked after patients and actually maybe only about 3 months before we had

Initial diagnosis helpful- still did not make sense

Attempts at sense making.

Despite initial diagnosis-need for further test for validation.

Lack of understanding of the condition by the health professional (GP).

Challenges of receiving a communication of 'bad news' without a level of knowledge of what the bad news means.

Emotional distress associated with still not knowing.

a young girl with viral encephalitis who was very very agitated and I had a difficult day with her one day because she was climbing out of bed and she was all over the place and they can be very hard to manage but because their brains swollen you know, but she made a good recovery so yeah I'd nursed patients and I knew the treatment and I knew that side of things pretty well. Although I knew I didn't feel like that because I didn't have that agitated and irritation although I felt anxious through the palpitations and things, I didn't feel that way but I thought maybe it's early you know so, so we went and I went into hospital, got admitted and they started me on encephalir prophylactic umm and then I was to have a lumber puncture and like you described I was like 'okay'.

.... so a neurology registrar was down visiting another patient and they asked him to come and see me because when When I explained about the symptoms and this, they were taking

Need for proof to be heard.

Demonstration of control and expertise.

More confusion regarding diagnosis.

Family support helpful in managing distress

Lack of faith in competence of health professional.

me seriously now because I had a swelling in my brain, and my symptoms were now deemed a bit different because it was, I was explaining more about having tingling and different things and umm what not and the fact that I felt vague at times and I was dizzy, and things so the neurology reg came and saw me and he knew straight away it wasn't viral and he said I need to take this patient to XXX, she needs to come up and we need to assess her up there, this is not the place for her, as in a district general hospital, which is hugely a relief to me because it meant that I knew that I was going to the place where they had more knowledge and expertise, so I continued with the antiviral and I was then the next day transferred up to XXX where I was under the care of a neurologist by this time.

Lack of clarity

Attempting to make sense of her illness based on her experience of encephalitis in the past- the thought that it could be viral encephalitis gave her a sense of understanding and reassurance that even though it was challenging it was treatable.

Test and more test.

I: So going back to where you were transferred to XXX, so you were having your antiviral medication

Even though it did not feel right treatment was started and more tests

P: Yes so they basically stopped that when I got to XXX because were ordered.

Lack of clarity- Brain tumour/Autoimmune argument.

I think they were pretty, well the lumbar puncture came back negative by this, because this, because I'd had that one day and I went to XXX the next so the results came back when I was being transferred so they knew it wasn't viral, or there was nothing in my lumbar puncture and it was clear, and then I had another one up there, obviously they wanted to do their own and do other tests and things and my bloods were umm sent to XXX to to test for antibodies for the autoimmune encephalitis, which is what they were thinking by this time, at this point, I'd had another MRI scan when I got to XXX, and then on a Friday in XXX the neurologists all meet together, they have what they call the grand rounds so they have a MDT, all the neurologists and the radiologists and then they decided that maybe I actually had a brain tumour because the fact that the swelling was so large and they couldn't actually identify what it was, if it wasn't

The need for physical evidence of a problem for them to take me seriously .

Complexities of diagnosis.

Health professionals taking control and demonstrating a sense of knowledge fostered hope and belief.

Biopsy versus lumbar puncture-

more testing.

autoimmune could it be a brain tumour so then that all came about, could I have a brain tumour, oh that just threw me completely that I could potentially, you know that was a completely different diagnosis, but they weren't all agreeing on this as neurologists don't, so this was thrown into the mix along with everything else, which just sent my brain even more wild because then I go oh a brain tumour that's a whole different ball

Difficulties with testing.

game altogether, umm and then so to diagnose that there was a discussion about having a take a biopsy of my hippocampus which absolutely, if I thought a lumbar puncture was worrying and terrifying the thought of somebody going deep into my brain into my hippocampus to take a little bit of tissue out frightened me even more, there was a lot of tears, there was a lot of worry both for my husband and I and that was quite upsetting umm also

Challenges of testing

my neurologist didn't want to start me on steroids, which she

procedures.

thought probably was the right treatment if it was autoimmune,

Treatment stopped. Deeper state of confusion – It is not anti-viral- lack of clarity of what it is or could be.

More time in hospital-challenges of diagnosis.

because it would shrink potentially a tumour and sample, so she was caught between what was the right thing to do, so there was a discussion about whether I should have a biopsy and they were waiting on this blood tests from XXX, and it took four weeks for this blood test to come back from XXX, which is a long long period of time, umm we were waiting.

I: What was that like for you, were you kept abreast about what was going on? What was your interaction like with the health professionals at that point in time?

But umm yeah being potentially having a biopsy of your hippocampus was an extremely scary time while I was waiting and the waiting was hard. You know I was in hospital for nearly 4 weeks and if you told me I was going to be in hospital for 4 weeks I would never have believed that, and nowadays people don't tend to be in hospital, especially as I was up and walking about and I put my clothes on and things and…it didn't seem

Uncertainty regarding diagnoses impacting treatment.

Still searching and looking, which might have given her a sense of relief as the initial reassurance she got from the initial diagnosis, did not fit with her symptoms based on her previous experience of working with people with viral encephalitis.

Fear associated with another possible diagnosis especially a brain tumour. Lack of clarity and agreement among health professionals.

like a long day and I think maybe part of the day I would be vague and I was having seizures and different things. Umm but the waiting was really difficult.

Distressing impact of the confused state of health professionals – lack of clarity regarding diagnosis.

Distressing diagnostic testing.

I: So you waited for four weeks for the results to come back from XXX? What happened then?

P: I did. So I was allowed home on pass because I'd all my tests, I'd had all my scans, I'd been started on the antiepileptic medication, you know heavy duty stuff, and they basically didn't know what to do with regards to what treatment so I was basically going to have a biopsy of my hippocampus and we were waiting on the bloods from XXX. And so I was allowed home on pass because I was going to see the neurosurgeon on the Monday morning with, to speak to him the risk factors of having and book in an appointment to have it done and of course

More testing – biopsy emotional reactions to the thought of this.

Lack of clarity as to diagnosis impacting on possible treatment

options.

Feeling unheard.

I had a million questions for him and I was very very anxious….I was allowed home on pass I think until the Tuesday and then my Mum had come round to sit with me because they said look you've got to, in case I had a full seizure umm my husband was trying to go to work and not be off work so mum came round and she sat and I got a phonecall umm and it was my neurologist Dr XXX and she phoned to tell me that she had the blood results from XXX. So my diagnosis was given, my first one was given over the phone, so it wasn't an appointment

Challenges with testing procedures – time.

I: What was that like?

P: I'll never, never forget it, when she phoned me and she told me that it was, I'll probably get upset when I tell you this, umm when she told me it was positive it was as if the weight of the world had been lifted off my shoulders, it was a huge relief because firstly I knew there was something wrong with me, definitely something wrong with me because I still, still think

Emotional distress associated with testing procedures and having to wait

there was people who had a niggling doubt who thought that there wasn't actually anything wrong with me and the fact that

Privilege of having knowledge.

we had identified the antibody and I knew what the treatment was and it was quite straightforward….

I: So you were given that diagnosis and there was no kind of like follow up as to this is what it is, this is the consequences of it

P: None at all, because there's no specialist nurses, there's an epilepsy nurse and I actually had to ask to see the epilepsy nurse because obviously there's a lot of issues around having seizures

Inadequate knowledge and understanding.

because even though I didn't have tonic clonic seizures I still got issues around like I can't drive and things like that at the moment umm so I had to ask to see the epilepsy nurse nobody offered that to me but I was in the position that I could ask. I do feel for other people who don't know these things, that don't actually have that option to ask so they don't get it, well I'd hope maybe

for test results.

Seriousness of condition and the impact of the challenges of diagnosis meaning that she has to say in hospital for quite a long period.

Need for more education.

More knowledge about illness

they would or maybe I ask too early, maybe they do see somebody further down the line but I thought I was in the hospital and in the ward so I wanted to see somebody while I was a captive audience, I say a captive audience. But no I didn't have a lot of support and I still don't to this day think the nursing staff in that ward fully understand what those types, the autoimmune encephalitis the impact it has on people and the advice that could be given. I think they are better at the viral kind, you know I think they are better at dealing with that than the autoimmune because when I chat anytime I've been in the ward, because I've been in the ward 3 times now, umm with my relapses and then that treatment I had recently, umm and obviously I chat to them about different things I mean my knowledge is much higher than theirs. I sometimes think I should be doing education with them, you know

I: you think that would be helpful?

Multiple tests done still a lack of clarity as to what the right treatment should be- more testing to give more clarity.

Distress resulting from the need for more testing to be done.

Support from family helpful.

P: I think it would be really helpful, I think they could help other people because I know I'm not the only person who's had that condition, I know it's very rare, Dr XXX was my neurologist, she doesn't , she doesn't breach confidentiality but she will tell me oh I had this patient who didn't fit the picture who had it, so I know there are a couple of other people and through the encephalitis society I know there's been another couple of people been on that ward I was in particularly recently, so I think there is definitely a need for education around it without a doubt…

Impact of being believed.

Diagnosis given over the phone and not in an appointment.

She experienced a sense of validation despite being given a difficult diagnosis. Overwhelming feeling of relief as she had proved the doubters wrong.

I: So what was it like to.. So did you receive another diagnosis again or was it just its come back.

P: When I got .. Basically when I phone the GP and they said just come up to xxxxx just bring yourself up the next day and I sat

False negatives.

and spoke to xxxx a good fellow who was a registrar. I have got

a good relationship with him and I explained my symptoms and

one thing and then another and he basically took the blood off

me and he handed me 40mgs of prednisolone and I said you

think its back too don't you and he went the blood test will

confirm it. But the fact that he had given me the treatment just

from my symptoms I knew he knew that it was back. But it was

False negative and not being   the next day that he actually came back and told me. So there

believed.   was no waiting and that was great because he had already given   Not support for possible symptoms of

me the treatment so much much quicker. ..The second time my   the condition, however having a bit of

Inadequate understanding.   brain scan didn't show swelling s I did get a scan the second   knowledge and understanding about

time… so the MRI the second time didn't show the swelling in   these symptoms and support required

Privilege of patient having a   the hippocampus like it did but then I didn't have all that time of   helpful.

level of knowledge.   feeling unwell trying to get someone to listen to me. I didn't get

in to those sort of things. So I don't think we got to that acute

phase because I had recognised my symptoms so much quicker.

Levels of knowledge and

expertise.

Complexities of the condition-

need of expert experts.

Complexities and uncertainties

of the condition – battle to be

believed.

… since that day my consultant was on call luckily so I got into the ward and she saw me and my blood test actually came back negative that time but my symptoms were definitely there I mean the nausea and the dizziness was horrific but she wasn't convinced because my blood test was negative and I have not even done more research that shows that you can have a negative result but still symptom but she did not understand. Although she is a neurologist and she has knowledge, she is not an expert like Dr xxxxxxx and she didn't seem to think that this was right so I was emailing her clinical papers saying that just because the blood test is negative doesn't mean- false negative … because the symptoms were.. I mean the dizziness was much worse that the first time erm so it was awful.. And the nausea she was thinking it could be something else and I am like I know my

Mindful of her privilege of knowing which fostered her ability to ask for support. Concerned for people that are less aware.

Sounds like she feels that nursing staff do not have an understanding of the different types of encephalitis and struggle to support people with other types apart from viral.

own body. I am a very big believer of that now that if you have got a reliable person.. and she does see that she relies on me to tell her about my symptoms and I think because I am acutely aware of them I am maybe telling them earlier that other people would maybe.. telling them and maybe that why my test hadn't come back positive at that point. I should have said in September when I left the ward, the tested me and it was negative so from the beginning of September in the space of a week I had gone from positive to negative quite quickly cos I was trying to say that I went from a positive to a negative and I am still on steroids in January when they tested me.

Knowledge through experience and reading much more than that of the professionals.

Acknowledgement from health professionals about the challenges and complexities of diagnosing the illness and the need for more knowledge.

Less distress associated with getting the diagnosis quicker. Treatment commenced without waiting for the

results of the test.

Unwell and trying to get people to listen to you.

False –Negatives.

Using experience from the past to support the health professional in the diagnosis. Having to display a level of knowledge about the condition to be believed and facilitate treatment.

Despite the fact that she is an expert, she is not expert enough.

Distress associated with having to deal with the uncertainties surrounding the diagnosis again. Lack of trust in the clinician- patient relationship.

Drawing on resources from the past for validation.

Table 3: Demonstration of how individual super-ordinate themes for each transcript contribute to the development of the super-ordinate themes for the entire dataset (step six of analysis)

Super-ordinate Themes for Entire Dataset	Participant	Individual Super-ordinate Themes Contributing to Super-ordinate Themes for the Entire Dataset	Supporting quotes from original transcripts
Theme One: 'Being on a wild goose chase- challenges with getting the diagnosis"	P1	Confusion regarding diagnosis	"…one of the letters that I had read, that my neurologist had given me said acute disseminated myelitis……another one of my letters said I had viral encephalitis and transverse myelitis…so still at that point I wasn't able to make the connections…"
	P2	Diagnostic testing	"I was very seriously ill quick quickly and that the medical team maybe had the experience of encephalitis and I was …

			every type of test was done on me possible"
	P3	Complexities with diagnosis	"but I never suffered with depression sow when I was in the hospital and the brought down this psychiatrist and told them to put me in a ward for psychiatric disorder"
	P4	Lack of clarity- brain tumour/autoimmune argument.	"So they have a MDT, all the neurologists and the radiologist… and then they decided that maybe I actually had a brain tumour because the swelling was so large they couldn't identify what it was…that was a completely different diagnosis... but they were not all completely agreeing in on this"
	P5	Complexities with diagnosis	"And it was difficult to diagnose, and I

			spent three weeks in the hospital getting worse and worse and started to have other neurological and cognitive symptoms. After about two weeks they said there is nothing more we can do for you….."
	P6	Lack of understanding	"not crazy"; "I'd be locked in the room and they will stand over me when I took a bath or shower and that wasn't very nice... I was pregnant, and they thought I was crazy"
Theme Two: 'The emotional rollercoaster experience- facilitators and hindrances to adjustment'	P1	Support group-life line	"…it just makes you feel like you are not alone…so you feel more as ease because you are not the only one, you know if you have an illness and no one else around you knows what it is , knows how it works and how you are going to recover, you do just feel isolated…and having people out there

that know exactly what you are talking about exactly how you feels, it just make you feel more at ease…"

	P2	Shock and reality of consequences of illness	"….And I haven't driven since because I can't …I don't understand how to drive….So that was kind of like …that was a shock because I thought actually this is quite serious…"
	P3	Inadequate information provided	"popped in my car and drove down to xxx, I drove up to xxxxx…..I didn't have a clue where I was"

P4	Impact knowledge and privilege.	"Even things like I had to ask my GP to prescribe Calchew for my bone density because nobody was going to give it to me.. I had to ask and with my husband being a xxxx it was like you need to do a wee bit of exercise"
P5	Active engagement in survival	"I have access to information and have access to the pharma industry…so it is easier for me to find out stuff but you have to fight a lot for yourself. You are the only advocate you have…"
P6	Insensitive experience of diagnostic delivery	"…I don't' know where the doctor was from if he was from the hospital or

somewhere else and a couple of members

of staff in case I kicked off or something

ummm took me in a room and said you've

actually got an infection in your brain

ummm which is making you like this, but

we can't let you out incase you hurt

yourself or something like that, an that's

all I ever got "

Figure 1 showing the development of a super-ordinate theme for participant 4 (step four of analysis)

Complexities of the condition- need of expert experts.	Inadequate knowledge and understanding.	The psychological explanation is scary	"Nut job"- psychological means I'm crazy

Emergent themes relating to P4's assertions of the complexities of the illness and the impact of not being listened to.

"Being on a wild goose chase- challenges with getting the diagnosis"

This theme was developed by considering the challenges posed in diagnosing the illness. It represents highlights the fact that the illness was poorly understood by themselves, health professionals, and the public in general. It also highlights the potential benefit of taking on board patient's contribution to facilitate diagnosis.

Emergent themes relating to P4's assertions around the diagnostic uncertainties and the use of diagnostic testing to facilitate the process and the distress associated with testing.

False negative and not being believed.	More time in hospital- challenges of diagnosis.	Being in limbo. the unknown	Not understanding what is going on, lack of information

Figure 2 : Showing diagrammatic representation of themes

Figure 3 showing Leventhal's Common sense model.

Illness perception

1. **Identity**
2. **Cause**
3. **Consequence**
4. **Control**
5. **Timeline**

Illness stimuli - Symptoms of either infectious or non-infectious

Coping procedures/Strategies - (facilitators and hindrances to

Outcome appraisal of coping strategies - Adjustment.

Emotional Representation

Appendix 2A.

Author guidelines for *the Journal of Neuropsychology*

Author Guidelines

The Journal of Neuropsychology publishes theory-driven patient studies and Registered Reports. The central brief is to learn more from patients with brain dysfunctions to gain a better understanding of brain-behaviour relationships and to help future patients. Important developments in neuropsychology will follow from a multidisciplinary approach embracing neighbouring fields such as developmental psychology, neurology, psychiatry, physiology, endocrinology, pharmacology and imaging science. The journal publishes group and case studies addressing fundamental issues concerning the cognitive architecture of the brain. In addition, the journal includes theory-driven studies regarding the epidemiology of specific deficits, new assessment tools, and the evaluation of treatment regimes.

The journal is committed to a fast and efficient turn-around of papers, aiming to complete reviewing in under 90 days. Submissions are processed via a web-based system and reviewers are required to complete their referee report within 28 days.

Papers will be evaluated by the Editorial Board and referees in terms of scientific merit, readability, and interest to a general readership.

All papers published in The Journal of Neuropsychology are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

1. Quality Control

The content, format, quality and ambition of the JNP as a major outlet for theory-driven neuropsychological studies is under constant review by the Consulting Editors:

• Kenneth M. Heilman (University of Florida College of Medicine, Gainesville, USA)

• Donald T. Stuss (Rotman Research Institute, Baycrest, University of Toronto, Canada)

• Giuseppe Vallar (University of Milan-Bicocca, Italy)

• Elizabeth Warrington (National Hospital for Neurology and Neurosurgery, London, UK)

2. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

3. Paper formats and length

Research papers are full-length reports of original scientific investigations. Papers should normally be no more than 6000 words excluding abstract (maximum 250 words) and

references. Multiple citations for a single point are usually duplicative and authors are urged to cite the best reference. The Editor retains discretion to publish longer papers.

Theoretical or review articles are full-length reviews of, or opinion statements regarding, the literature in a specific scientific area. They need not be exhaustive but should give an interpretation of the state of research in a given field. They should normally be no more than 4000 words excluding abstract (maximum is 250 words) and references. The number of references should not exceed 40-45. Multiple citations for a single point are usually duplicative and authors are urged to cite the best reference. The Editor retains discretion to publish longer papers.

Brief communications are short reports of original research or case reports. They contain no more than 1500 words excluding abstract (maximum is 80 words), references, a total of up to three tables or figures, and no more than 10 references.

Fast-track papers are timely and relevant reports that, to the discretion of the Editor, are included in the issue following acceptance. Authors may ask that their submitted manuscripts are considered for fast-track.

Commentaries and rejoinders are short reactions to publications in JNP followed by an invited rejoinder from the original authors.

Special issues may be proposed to the Editor. The proposal should include a short description of the topic and a number of (possible) contributors. The same quality criteria apply as for other submissions.

4. Submission and reviewing

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Appendix 2B

Interview schedule.

 The interview schedule is for guidance only and will cover the following core areas:

- Life Pre-Encephalitis.
- Immediate experience following the Encephalitis
- Experience of receiving diagnosis.
- Life changes post-Encephalitis
- Debrief / opportunity to ask questions

The ensuing questions form an interview guide but the researcher will retain flexibility in following up previously unanticipated conversation threads relevant to the research question.

➢ Can you tell me what life was like before you started struggling with the symptoms of encephalitis?

➢ Can you tell me about when you started struggling with the symptoms?

➢ How long did you struggle with the symptoms for before going to the hospital?

➢ Can you describe your experience of your first encounter with a health professional? (What discussions did you have at the time and what advice were you given?

➢ What was that experience like?

➢ What was your path to diagnosis like ie how long did the process take and what processes were involved?

➢ What was your experience of the process?

➢ During the diagnostic process, can you describe your experience of the communication between you and the doctors?

➢ Who delivered the diagnosis and what was the experience like?

➢ Would you say you were well supported when the diagnosis was delivered? If yes, how?

➢ What was your knowledge of encephalitis before and what was it like hearing that you had encephalitis.

➢ Did your experiences of receiving the diagnosis help with adjusting to living life with the condition? If yes, how would you say it helped?

Appendix 2C

Reflective journal extract

Participant
from ~~Manville~~   4th May 2018.

Wow! Another Helpful Interview — I can't
believe that I didn't manage to keep to the time again.
I feel really tired and drained. Its obvious that she
had a lot to say and needed a medium to express
her thoughts about her experience. I think I have
done a lot better this time in managing the
session despite how I feel.

Her reflection and acknowledgement of the privilege
of her position as a health professional was interesting.
She wondered what the faith of other people who
didn't have ~~the~~ the type of access she had would
be's. Her privilege helped her diagnostic journey
–especially with diagnostic testing and having the
knowledge to challenge and ask questions. If the
last participant I interviewed had this maybe
her experience would have been different.
     I wonder what it must be like not having
access to these sort of privileges. I guess the
consequence would be that people will have
to wait a bit longer to be seen and not
have the knowledge to ask the right question
to facilitate their journey towards recieving
the diagnosis or even getting an explanation
about their symptoms.

     She also displayed a lack of respect for
her GP and appeared not to trust him/her because
of their a inadequate level of knowledge about
her difficulties. Instead she also aligned
herself with people/professionals who she
felt had some knowledge and understanding about
encephalitis.

The lack of understanding shown by her GP left her feeling all over place with her emotions. I guess this highlights the importance of the way in which a diagnosis is delivered, especially when it is not understood by the patient.

When I spoke to her about how she coped with the distressing experience of receiving the diagnosis — she stated that she was grateful that her mother was there. I guess this highlights the importance of social support in coping or managing the journey towards receiving a diagnosis of encephalitis.

Another interesting reflection of this participant is her realisation that only a few people were confident in their knowledge of the condition. She even had to educate people treating her about the condition ('even a consultant neurologist). I guess that says a lot about the nature of this illness.

I wonder what that must feel like to be sat in a room with different highly qualified professionals not being able to reach an agreement about what your symptoms are.

Section Three: Critical Appraisal

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Overview

This paper aims to provide my personal reflections on the journey towards completing this research. Firstly, I will provide a summary of the findings of the systematic literature review (SLR) as well as an overview of the research paper. Secondly, I will discuss the limitations and the strengths of the research process, followed by considerations for further research. Thirdly, I will draw attention to comparisons between the findings in the SLR and the main research paper. I will then briefly discuss the different research paradigms used in clinical psychology and how my epistemological stance influenced my choice of analysis. Finally, I will discuss my reflections on the entire research process.

Summary of findings

The SLR aimed to explore the experience of adjusting to a traumatic brain injury (TBI). The findings of the study suggest that aspects of the immediate impact of the injury led to the experience of loss in various aspects of the participants' lives, perhaps most difficult being the loss of their 'old self'. Participants reflected on difficulties with not knowing, with the review highlighting the usefulness of social support and other helpful coping strategies in attaining post-traumatic growth (PTG). Through the meta-synthesis of 25 studies, four themes were generated; 'early impact of the injury', 'extrinsic factors that influenced the recovery process', 'intrinsic factors that influenced the recovery process', and 'post-injury growth'.

Participants discussed the experience of the early impact of the injury, which began with a sense of loss due to the life-changing impairments. They reflected on physical aspects of the loss, the loss of their dreams, and loss of future ambitions. In addition to the sense of loss, participants reflected on missing gaps in the knowledge of what happened during and after the accident, and not having a good understanding of what was happening now, and therefore they needed to fill in the gaps to come to a place of understanding. However, filling

the gaps made apparent the disparity between their 'new selves' and their 'old selves', which

was a challenging experience for them. Furthermore, their ability to navigate this change was

key to their adjustment to the injury.

Participants described utilising support from both other people and within themselves.

Support from other people included the use of health professionals and significant others

which was essential in facilitating adjustment to the injury. In addition to this, participants

utilised coping strategies from within, including getting to a place of acceptance of the new

self and subsequently actively engaging in their rehabilitation and utilising emotion-focused

strategies. Acceptance helped them strike a balance regarding actively engaging in activities

as opposed to exempting themselves from them but also knowing where their new limits were

because of the injury. The utilisation of internal and external support resulted in some

participants experiencing PTG. Generally, most of the participants reflected on feeling like

better people because of the injury; however, some of them were more mindful of the need to

continue to engage and utilise the support, as it was key to them remaining well.

There are similarities between this metasynthesis and Levack, Kayes and Fadyl's

(2010) study. Levack, Kayes and Fadyl (2010), also described participants experiencing a

sense of loss but from a perspective of a disconnect between one's mind and body resulting

from the injury. Participants within their study also reflected on the disrupted sense of self

and the road to the reconstruction of the self as being a challenging one associated with

several factors, which are similar to the extrinsic and intrinsic factors that facilitated

adjustments in this study. Differences within Levack, Kayes & Fadyl's (2010) study and this

study include aspects of the emotion focused coping strategies utilised by participants in this

study and peoples' experiences of PTG after the injury.

The research paper aimed to explore participants' experience of adjusting to a

diagnosis of encephalitis but with a particular emphasis on the diagnostic journey and the

effects of this on their adjustment. The findings of the study suggest that participants

experience encephalitis as an illness that is not well understood, filled with much uncertainty,

and the journey towards the diagnosis was difficult. Participants also described facilitators

and hindrances towards adjusting to the diagnosis, highlighting the overwhelming impact of a

lack of information, which appeared to be a significant factor in facilitating the sense-making

of the illness.

Three superordinate themes were identified through interpretative phenomenological

analysis (IPA); 'being on a wild goose chase', 'emotional rollercoaster experience' and 'the

significance of information and others'. Participants in the study described encephalitis as a

complicated illness that is poorly understood by themselves, the clinicians they worked with

and the general public. Their accounts reflect the challenges posed in diagnosing the

condition due to the limitations of the diagnostic pathways and the disease presentation.

Participants also reflected that while it was evident that the doctors were often struggling with

the challenges diagnosing the condition posed, attempts to contribute towards helping the

diagnostic process were not listened to. Participants reported experiencing having to go

through complicated and emotional diagnostic testing procedures because of the uncertainties

surrounding the illness, which left some of them feeling traumatised.

Participants also described the difficult emotions experienced during the diagnostic

process and highlighted the impact a lack of information had in restricting their adjustment.

This lack of information was particularly overwhelming for some, especially regarding the

unexpected secondary consequences of the illness. Participants' journeys to adjustment

stemmed from a craving driven by a lack of information and lack of understanding. In

addition to this and more significantly, participants highlighted the importance of support

from others, which came in the form of a particular charity. Five out of the six participants

that opted into the study mentioned this charity. It appears that it helped to facilitate the journey to understanding and adjusting to the illness.

There are similarities between this study and that done by Atkin, Stapley and Easton (2010). Atkin, Stapley and Easton's (2010) study explored the individuals' experience of living with encephalitis from the perspective of a broader family and social relationship context. Similar to this study, Atkin, Stapley and Easton's (2010) study highlighted participants were experiencing the difficulties and the lack of understanding associated with receiving the diagnosis with some participants also stating that they were initially misdiagnosed with a psychiatric illness. However, compared to this study, where approximately 85% had this challenging experience, their study indicated that only approximately 34% of people had this experience. Several factors could be responsible for this, some of which include the focus of Atkin, Stapley and Easton's (2010) study on living with encephalitis as opposed to receiving the diagnosis.

In summary, the findings of this research paper highlight the importance of information given throughout the diagnostic process. In addition, the study highlighted the need for an acknowledgement of the complexities by clinicians, which may consequently help in the management of the patient-doctor relationship. This could help patients feel listened to and facilitate their journey towards adjustment.

Comparisons between the SLR and the research paper.

Exploring the comparison between the SLR and the research paper was an interesting prospect because even though both are forms of an acquired brain injury, the mechanisms through which the injuries are acquired are different (Headway, 2015). However, it is important to note that even though the mechanisms are different, some studies, in their definition of the terms, struggle to differentiate between ABIs and TBIs. This fact made the

process of the SLR more difficult as some studies had to be read to confirm if the type of

injury being discussed was a TBI or a non-TBI.

An interesting commonality between both studies is the lack of information reported

by participants and the distressing implication it had on their well-being and ability to adjust

to the injury. In addition to this, both studies highlighted the ripple effect this lack of

information had on their families and caregivers, which affected the quality of care that they

could provide. The lack of information reported in both studies included information

regarding the nature of the illness or injury but more especially, the secondary consequences

of the injury. Several studies have highlighted the widespread challenges of a lack of

information and its impacts on adjustment similar to that described in both studies (Hassan,

Khaw, Rosna & Husna, 2011; Lefebvre, Pelchat, Swaine, Gelinas & Levert, 2005).

In addition to the lack of information, another similarity between the studies is

feelings of loss. Interestingly, this experience of loss was more prominent in the participants

with TBI as opposed to those with encephalitis. Worthy of note is the fact that the majority of

literature regarding loss and grief is centred around TBIs as opposed to non-TBIs (Carrol &

Coetzer, 2011; Kontos, Miller, Colantonio & Cott, 2014; Petersen & Sanders, 2015). This

might be because TBIs have been studied in greater depth (Teasell et al. 2007) when

compared with non-TBI's or because of the different aetiologies of non-TBI's (Cullen, Park,

& Bayley, 2008).

Another commonality between both studies is the fact that brain injuries are generally

complex and challenging for health professionals. In both studies, the relationship between

clinicians and the participants was a key factor as many felt that because of the nature of the

injury, many questions were left unanswered. This affected the quality of relationships

between patient and clinician in both studies. Finally, the positive impact of family and

caregivers, as well as the impact of engaging in active coping strategies in facilitating

adjustment to the injury, was shared by both studies.

Research strengths and limitations

The choice to focus on all forms of encephalitis might be perceived as a limitation of

the study. This is because, as a result of recent advances, it could be argued that there are

separate and distinguishing diagnostic criteria for both infectious and non-infectious causes

of the illness with several countries publishing different algorithms for the initial

management of adults with suspected encephalitis (Graus et al., 2016; Lee & Lee, 2016;

Olsen et al., 2015; Venkatesan & Geocadin, 2014). An example is that Solomon et al. (2012)

suggest that symptoms such as fever, abnormal mental status, nausea and vomiting are typical

signs of infectious encephalitis. In addition, Graus et al. (2016) highlight specific criteria to

be considered for autoimmune encephalitis, which are categorically different from symptoms

suggested by Solomon et al. (2012) for the infectious types. However, despite these attempts

to clearly distinguish between the diagnostic criteria for both types, all the studies have

highlighted the difficulties in reaching a diagnosis of encephalitis with many of them

suggesting that up to 50% of the cases are not diagnosed. Nonetheless, the subject of interest

in this study is the experience of the diagnostic process, which is an experience that people

with both types of the illness will experience. A study focused on exploring the experience of

people who have received similar types of diagnosis might be helpful; however, this could be

a focus for future research.

Another limitation that is also a strength of this study is the recruitment of only

women in the study. Gender, personality, age and cultural characteristics are significant in

illness perception as they form part of the personal and cultural context in which the subject

is embedded (Benyamini, 2011). This assertion means that contextual factors play a role in

the way people organise their health-related knowledge and experience in the structures that

can facilitate adjusting and coping with the illness (Benyamini, 2011). Several studies have

highlighted the importance of gender differences in the way certain illnesses are perceived

(Boonsatean, Carlsson, Dychawy Rosner, & Östman, 2018; Pesut et al., 2014; Trovato et al.

2012). Therefore, the outcomes of this study may not be a general reflection of people with

encephalitis' view of the diagnostic process. However, notwithstanding, an argument could

be made that this study made a significant contribution from the female perspective as Al-

Smadi, Ashour, Hweidi, Gharaibeh and Fitzsimons (2016) suggest that services who have

knowledge of gender differences in illness perception are able to facilitate tailor-made

interventions that can improve health outcomes.

Research design and epistemological position- Reflections on the use of IPA

The question of what it means to know in the world and to be known is a debate that

has been ongoing for centuries (Guba and Lincoln, 2005). These arguments or debates were

centred on paradigms encompassing a range of methodological, epistemological and

ontological positions (Guba and Lincoln, 2005). The salience of this in research is supported

by Guba and Lincoln's (1994) suggestion that "Paradigm issues are crucial; no inquirer, we

maintain, ought to go about the business of inquiry without being clear about just what

paradigm informs and guides his or her approach" (p.116). This assertion highlights the fact

that when doing research, it is crucial for the researcher to align himself or herself to a

methodology that fits with their stance as well as addresses the aims of the research.

In relation to the methodological stances, the centre of the debate lies between

quantitative and qualitative research, with the former until recently generally seen as the

predominant way of conducting high quality research (Yanchar, 2006; Westerman, 2006;

Guba & Lincoln, 2005). However, Guba and Lincoln (1994) argue against this view and the

dominance of quantitative research stating that they lack context and offer limited real-world

applicability. Hiles (2001) asserts that the quantitative methodology is useful for a paradigm

of psychological inquiry, however he emphasises that "there is a desperate need for an

approach to psychological inquiry that sets out to study meaningful phenomena in context,

using qualitative data that is exploratory, participatory, and clearly open to all aspects of

human experience and action…"(p.15)

Therefore, after careful consideration of these arguments while at the stage of

generating my research question, my perception of what counts as the truth and how it can be

sought within the context of my subject of interest – receiving the diagnoses of encephalitis -

was meticulously weighed and thought out. This consideration, which constitutes the

paradigm or the set of beliefs that form the framework of the research process, is the most

vital aspect of the research process as it sets down the purpose and prospects of the research

(Polkinghorne, 1993).

Consequently, a qualitative research approach was appropriate because it stems from

an interpretivist paradigm that follows a relativist position that assumes that there are

multiple realities of a phenomenon, which are constructed in the minds of the individuals

(Guba & Lincoln, 1994; Lincoln & Guba, 1985; Schwandt, 1994). I believe that peoples'

realities are influenced by their knowledge and perceptions of their social environment and

that there is not one objective truth. Finlay (2006) suggests that people conducting research

must adopt an epistemological position, which they can relate to. Advocates of this paradigm

suggest that the essence is to attempt to understand lived experience of a phenomenon from

the perspective of those who have lived through or are living with the experience, which in

this case is the study of the phenomenon of the experience of adjusting to the diagnosis of

encephalitis (Schwandt, 1994, 2000).

Qualitative approaches to research are concerned with obtaining rich and contextual

information as to the meaning people give to their experiences (Creswell, 2013). More

specifically, IPA reviews in-depth personal accounts of the phenomenon that is being studied (Smith, 2004). IPA is a methodology that has been suggested to inquire into how people make sense of occurrences in their life (Smith, Flower & Larkin, 2009) hence my preference for this methodology. One to one semi-structured interviews were conducted which enabled participants to offer an in-depth reflection and description of their experience of receiving the diagnosis.

While several studies have highlighted the usefulness and credibility of IPA; it has also been criticised for being full of uncertainty, lacking standardisation and being just an anecdotal methodology, which lacks sufficient interpretation (Giorgi, 2010; Tuffour, 2017). However, Smith (2011) highlights the fact that the scientific thoroughness in qualitative research is dependent on the researcher's skills in carrying out the suggested procedures rather than a prescriptive method. Therefore, the onus is on the researcher and not the methodology (Smith, 2011). Within this study efforts were made to ensure Smith's (2011) suggested criteria for what constitutes a good IPA were followed. These include sufficient transparency, clearly following and reporting the theoretical principles of IPA, coherent and well-focused analysis and ensuring that the data interpretation is robust, giving voice to the participants' experiences followed by adequate interpretation of their narratives (Smith, 2011; Tuffour, 2017).

Reflections on the research process

Reflexivity. As discussed above, the interpretivist paradigm on which this study was founded posits the centrality of the interaction between the researcher and the participants (Ponterotto, 2005). An argument could be made that this interaction can affect the quality of the research and one way of ensuring quality and credibility is via the use of reflexivity (Morrow, 2005). Rennie (2004) defines reflexivity as "self-awareness and agency within that self-awareness" (p.183). Morrow (2005) highlights the importance of reflexivity as a

medium of managing and separating prejudices and traditions that come from the researcher's life experiences, giving them a platform to understand how these experiences can influence the research process.

As suggested by Morrow (2005) and Vicary, Young, and Hicks (2017), I found the use of a reflective journal, both written and audio, very useful. The use of the journal permitted me to record my thoughts immediately after and in between interviews, keeping a record of my experiences and unconscious processes that became conscious during or immediately after the investigation. An example of this was one of my reflections after my first interview, which comprised of an acknowledgement of the shock of my emotional involvement with the topic of choice. Being able to reflect on this made me conscious of the potential influence this could have on the research, which consequently made me engage in another form of reflexive strategy, which is the utilising of supervision (Hill et al., 2005; Morrow & Smith 2000). Supervision supported me in voicing my concerns but also helped me to think about it from a different perspective and encouraged me to focus on Heshusius' (1994) concept of the 'participatory consciousness' which is the "the awareness of a deeper level of kinship between the knower and the known" (p.16). Therefore, while being mindful of the potential impact of my experience before the research commenced, I managed to separate and compartmentalise it in subsequent interviews but also appreciated the close connection I felt towards participants.

I chose this topic because years before I started clinical psychology training I worked in a child and adolescence mental health tier four service. During my time in the service, a young girl was admitted, sectioned under the Mental Health Act, and treated for psychotic symptoms. Because of her section, she was subjected to treatment against her will (such as medication). I remember her repeatedly saying "I am not supposed to be here", "I am not mad" and nobody seemed to listen. While she was on the ward, she went through different

courses of investigations and diagnostic tests, and after about 6 to 8 weeks of being there, she

had a lumbar puncture and received a diagnosis of encephalitis. I never forgot her after I left

the service as I wondered what the process of receiving a diagnosis was like for her. What

was also interesting to me was the fact that no one in the ward knew what encephalitis was

and we had doctors coming from different services to assess her because of the rarity of the

illness. Therefore, when I had the chance to research something novel, I decided to look

more into the illness. I was shocked at the prevalence rate in the UK (Granerod et al., 2010),

the morbidity rates (Granerod, Cousens, Davies, Crowcroft & Thomas, 2013), the complexity

of the illness and the challenges regarding diagnosis (Granerod et al., 2013; Solomon et al.

2012). I therefore decided to explore the experience of adjusting to the diagnosis of

encephalitis using the diagnostic journey as a fulcrum for the investigation. Similarities

between one of the participants in this study and my experience at the CAMHS service was

particularly difficult and challenging but gave credence to my choice of research.

Final reflections on conducting the research. I found this experience a gratifying

one filled with ups and downs. I was overwhelmed by the reaction I received from social

media groups, especially Facebook. Individuals consistently expressed their gratitude, and so

many of them were willing to help, even though they did not meet the inclusion criteria.

Many of them felt like they had been forgotten and that the pain and difficulties associated

with the illness were not seen. The feelings of gratitude stemmed from the fact that they were

happy that someone was finally talking about encephalitis and that they now had a voice. A

few of them compared encephalitis to other illnesses such as cancer and stroke, stating the

need for the illness to receive similar attention.

There are also similarities between some of the things participants talked about in this

research and some of my placement experiences during training. My final placement was in

a service focused on administering neuropsychological tests in two or three sessions,

discussing the results with the consultant and subsequently discussing the outcomes with the

client. While the distress associated with the neuropsychological testing procedures and the

potential consequences is evident (Lai, Hawkins, Gross & Karlawish, 2008; Tiberti et al.

1998), the service is not commissioned to give space to support the clients or their families.

This myopic view resonates with the discussions from the SLR stating that neuropsychology

is more focused on the quality of the testing while ignoring the holistic picture and the human

that presents in front of them.

The research highlights the powerful impact a specific charity has had on the lives of

the participants in the study. Five out of the six participants reflected on the importance of

this charity. It is important to note that these participants were from different parts of the

country but reflected similar experiences. This further buttresses the importance of third

sector organisations and the importance of utilising them as an adjunct to the NHS as

highlighted by several policies (Department of Health, 2010; National Health Service

Scotland, 2010)

My final reflection has to do with the importance of maintaining boundaries in

research. While conducting the interviews, I had to negotiate the balance between letting

people tell their story as well as their need for therapy and the aims of the research. This

approach counts as engaging in the necessary and essential skills in undertaking research

(Davison, 2017), however it also highlighted the fact that the participants might benefit from

some therapeutic input of some sort. Some of the participants were already engaging with

some form of talking therapy, which they found helpful.

Conclusion

In conclusion, this research highlights the complexities around encephalitis as well as

the uncertainties that result because of the complicated nature of the illness. It highlights the

inadequacies in clinicians' understanding of the illness and its complexity prompting a wide

variety of diagnostic tests, which can be traumatic for the patients. The nature of the illness

and the uncertainty surrounding it affects the clinician-patient relationship. Central to this

disruption in the clinician-patient relationship is the lack of adequate information provided to

the client, which in turn affects the illness perception and consequently their adjustment to the

illness. However, participants were able to utilise some coping skills, which facilitated the

commencement of adjustments. A key importance in the study is the emphasis on clinicians

tolerating uncertainty and bearing in mind a biopsychosocial model to adjustment and not

solely a biomedical one. A focus on the biopsychosocial model may allow them to be more

sensitive to the impact their communication can have when dealing with complex diagnoses,

the patient's adjustment and their subsequent quality of life after the illness.

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Section Four: Ethics Section

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ETHICS SECTION

Research Protocol

████████████████████████████████████

Title: an exploration into the experience of adjusting to the diagnosis of encephalitis in adults of a working age: a qualitative investigation.

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████████████

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ETHICS SECTION

Introduction

Encephalitis is the "the inflammation of the brain parenchyma associated with neurologic dysfunction" (Venkatesan et al, 2013, p. 1115). In other words, it occurs as a result of the swelling of the main parts of the brain involved in performing all the fundamental functions of the brain (Sutter, Chalela, Leigh, Kaplan, Yenokyan, Sharshar & Stevens, 2015) which could consequently lead to cognitive and psychological difficulties for the sufferer (Easton, 2016; Tyerman, 2016). Despite the advances in the understanding of this condition over the last decade, it is evident that diagnosing the condition still poses a difficulty for clinicians. Solomon, Hart and Beeching (2007) report that primarily diagnosis in practice is done if people present with appropriate clinical symptoms. However, they assert that proper diagnosis can only be done if there is tissue confirmation which is done by either an autopsy or brain biopsy. In addition to the difficulties relating to the diagnosis, encephalitis is associated with higher rates of illnesses and loss of life (Granerod, Cousens, Davies, Crowcroft & Thomas, 2013). However, in recent years progress has been made with a recent study indicating an incidence of 6000 people being diagnosed with the condition in the UK each year (Granerod et al, 2010). The diagnosis of encephalitis is normally referred to as a diagnosis of exclusion and clients with the condition have to go through various intrusive procedures that are not necessarily conclusive (Easton, 2016; Solomon et al, 2012). There is added pressure to diagnose as the timing of the treatment after diagnosis is key to achieving positive outcomes and plays a role in the high mortality rate experienced with the condition (Granerod et al., 2010; Elbers et al., 2007.)

Encephalitis has been described by a variety of studies as a condition with a wide array of possible causes with Granerod et al. (2010) asserting that for most patients the cause of the condition is unknown. However, in general, Granerod, Cousens, Davies, Crowcroft & Thomas (2013) assert that encephalitis can generally be attributable to infectious and non-

infectious causes. Infectious encephalitis is caused by microorganisms which include viruses, bacteria, fungi and parasites (Kupila et al. 2006; Granerod et al. 2010). Kupila et al. (2006) suggest that there are over one hundred possible microorganisms that could possibly cause infectious encephalitis. The non-infectious causes, on the other hand, have more recently been discovered, an example of which is autoimmune encephalitis (Armangue,Petit- Pedrol & Dalmau, 2012; Granerod et al., 2010, Graus et al., 2016).

There are a lot of factors that contribute to the difficulties with the diagnosis of encephalitis. For instance, there are several causes of the disease which must be identified before a diagnosis can be made and treatment can commence. An example of a type of encephalitis, to buttress the point of the difficulties with diagnosis, is autoimmune encephalitis which occurs as a result of the specific antibodies within the body targeting certain proteins within the cells affecting neuronal activity (Armangue, Petit-Pedrol & Dalmau, 2012; Granerod et al., 2010, Graus et al., 2016). However, according to Lee and Lee (2016), the several types of autoimmune encephalitis antibodies can be categorised into three main groups with each group associated with a different type of autoimmune encephalitis. In addition, there are different cell surfaces, receptors, intracellular antigens or synaptic proteins targeted by these antibodies which are associated with different types of autoimmune encephalitis (Graus et al., 2016; Lee and Lee, 2016; Bost, Pascual & Honnorat, 2016). As a result, there are several types of autoimmune encephalitis which contributes to the difficulties with diagnosis (Graus et al., 2016; Lee and Lee (2016); Bost, Pascual & Honnorat, 2016).

Secondly, the diagnosis of encephalitis could be difficult because of the similarities between the symptoms associated with some other common conditions and other neurological conditions (Granerod et al., 2010; Matata et al., 2015). In addition to this, the diagnosis of encephalitis could be further hampered by issues or difficulties with testing.

(Lancaster, 2016; Armangue, Petit-Pedrol & Dalmau, 2012; Granerod et al., 2010). Various studies have reported the challenges with false positive or false negative results ensuing in the commencement of an incorrect treatment or delaying the commencement to treatment (Lancaster, 2016; Armangue, Petit-Pedrol & Dalmau, 2012; Granerod et al., 2010; Lee & Lee, 2016; Gresa-Arribas, et al., 2014).

Finally, difficulties in diagnosis occur as a result in the similarities between the symptoms of Herpes Simplex Virus (HSV) encephalitis, which is one of the most prevalent forms of encephalitis, and some autoimmune forms of encephalitis with some studies reporting that the symptoms are indistinguishable (Lancaster, 2016; Armangue, Petit-Pedrol & Dalmau, 2012; Granerod et al., 2010; Armangue, Leypoldt, & Dalmau, 2014). These difficulties result in a delay in diagnosis and subsequently the treatment of the condition.

Treatment of the condition varies depending on the cause identified by the clinician, however survivors of the condition suffer from long-term consequences, which as a result impact on the brain (Easton, 2016). These include memory impairments, changes in personality, behavioural abnormalities and a range of physical difficulties (Easton, 2016; McGrath, Anderson, Croxson & Powell, 1997). However, even though some of the consequences of encephalitis are similar to those experienced in other neurological conditions, Easton (2016) asserts that there are a number of reasons why survivors of the condition may make up a unique sub-population worthy of their own further investigation. Easton (2016), suggests that some possible reasons for this could stem from the fact that survivors of encephalitis do not suffer as much physically when compared to other conditions and they are not in hospital for as long. There is also poor understanding and awareness of the condition and the cognitive impairments associated with it are not easily noticed during discharge. These differences result in difficulties making sense of the diagnosis and the consequences of the condition for survivors of encephalitis (Easton, 2016).

In addition to this, the process of receiving the diagnosis of encephalitis is made more difficult for the survivors of the condition who have symptoms, such as paranoia and delusions, which might make the delivery of their diagnosis difficult (Easton, 2016; Matata et al, 2015). Subsequently, doctors are left with no choice but to deliver the diagnosis to family, meaning that the survivors may hear it from family members (Easton, 2016; Solomon et al, 2012).

Bearing all this in mind, one may have assumed that much research would have gone into understanding this condition and how people cope with it, however this is not the case (Easton, 2016; Granerod et al. 2010). This study aims to contribute to the research around this condition by attempting to understand the lived experience of receiving the diagnosis and adjustment of survivors of encephalitis who were at a working age at the time of diagnosis.

Several studies have highlighted the impact of the way the diagnosis is delivered to positive clinical outcomes and adjustment to the diagnosis generally (Palmer & Thain 2010; Mulligan, MacCulloch, Good & Nicholas, 2012; Jutel, 2016). These studies suggest that how patients evaluate and respond to information given to them about their health has an impact on the progression of the illness, but also the way the information is communicated to them plays a significant role in their coping trajectory. (Randall & Waern, 2005; de Haes and Bensing, 2009; Edo, Torrents-Rodas, Rovira & Fernandez-Castro, 2012). Other studies have also highlighted the impact of the doctor's interpersonal skills, which include their behaviour and emotional supportiveness during the diagnostic process on long term psychological adjustment to the condition (Mager & Andrykowski, 2002; Edo, Torrents-Rodas, Rovira & Fernandez-Castro, 2012). Jutel (2016) states that the "moment at which a diagnosis is delivered to a patient, particularly when it is serious, is an important social

moment…not only dictates the clinical pathway…also rewrites the patient narrative, shifts their identity, predicts potential outcomes, and foregrounds mortality" (p.92).

Therefore, bearing in mind the difficulties associated with diagnosing encephalitis highlighted above, it is pertinent that in order to promote physical and psychological adjustment to the condition a better understanding of patients' experiences of the process might be helpful. Therefore, this study will attempt to use interpretative phenomenological analysis (IPA) to explore survivor's lived experience of receiving the diagnosis from a psychological perspective with an attempt to review the meaning they have given the experience and aid our understanding of impacts that may not have otherwise been evident (Giorgi & Giorgi, 2003).

It is important to note that some studies have explored some aspects of patient's illness experience and diagnosis in relation to encephalitis. For example, Atkin, Stapley and Easton (2010), in their study, used the context of the family and wider social relations as a fulcrum to explore how individuals make sense of living with the consequences of encephalitis. Likewise, a study by Cooper, Kierans, Defres, Easton, Kneen and Solomon (2016) using narrative analysis, explored individuals in the general population who had suffered specifically from Herpes Simplex Virus (HSV) encephalitis experiences of diagnosis and treatment.

This study aims to make a unique contribution to this field of study by focusing on individuals who were of a working age at the time of diagnosis using IPA. IPA recommends analysing a homogeneous sample of individuals in order to elicit an in-depth exploration of experiences therefore it is felt that restricting the age at the time of diagnosis is important as the experience would be different for children or older adults (Smith, Flowers & Larkin, 2009).

Method

Participants

The proposed study will attempt to interview between six to 12 participants who have had a diagnosis of encephalitis confirmed by a neurologist. The participants will be individually interviewed following the guidelines of interpretive phenomenological analysis (IPA; Smith, Flowers & Larkin, 2009).

Inclusion criteria:

Participants must have been between 18 and 65 years at the time the diagnosis was received. The study is exploring the experience of receiving a diagnosis at working age, hence the lower and upper age limits which represents the adult working age in the United Kingdom.

Participants must have received a diagnosis of encephalitis.

At the time of recruitment, participants must have had their diagnosis for at least two years and not more than five years. The lower limit of the time frame is to allow some time for people to have adjusted to the diagnosis while the upper limit is to ensure that the experience of receiving the diagnosis remains as fresh as possible in the minds of the participants.

Participants must have the capacity to consent to the interview.

Due to the financial limitations regarding travel, participants will be recruited from areas within the United Kingdom that are within 5 hours of travel time from Lancaster University. This will be inclusive of whatever means of transportation used. In addition, bearing in mind our methodology and the requirement of homogenous samples, the interviews will be conducted in English and therefore will recruit only participants who can speak English and who live in the United Kingdom.

Participants with severe cognitive difficulties who have the capacity to consent have

the option to have a close family member or friend supporting them during the

interview.

Exclusion criteria:

Those with severe cognitive difficulties that might make engaging in such an

interview almost impossible.

Those that are deemed not to have the capacity to consent.

Participants will be recruited by utilising social media as a platform. This will be

done by enlisting the help of brain injury charities, such as the ███████████████

and other relevant charities. In addition to this, help with recruitment will be sought from the

facilitators or moderators of online encephalitis and head injury Facebook groups, █████

███████████████████████████████). The charities and online

groups contacted will assist with posting a banner or the advert of this study on their website

and group on Facebook respectively. Subsequently, prospective participants who are

interested in the study can opt in by contacting the lead researcher.

The option will be given to participants who might struggle with their

communication to have a close member of their support system to attend the interview to

support them in the interview, provided they give their consent to this happening.

Recruitment Procedure.

Following ethics approval from the Faculty of Health and Medicine Research and

Ethics Committee of Lancaster University, the main researcher will open a Facebook

account solely for the purpose of the research. The main researcher will then contact the site

administrators of the various closed encephalitis Facebook groups and discuss the study and

subsequently request permission to be added to the group so that the posters of the study could be advertised in the group. Examples of these Facebook groups include █ ███ ████████. These online groups serve as a medium of support for individuals, who have been affected by encephalitis. They also support friends, families and carers by providing information about recent developments in terms of living with the effects of the condition and generally giving a platform for people to share their experience and support each another. In addition to the Facebook groups, the main researcher has approached other head injury charities and related health (encephalitis and brain injury) forums to discuss the study. The correspondence sent was centred on the aims of the study and geared towards requesting that the poster for the study be uploaded on to their website and advertised to prospective participants. Finally, a snowballing sampling technique will be employed whereby participants will be asked if they know anyone who is eligible to take part in the study. If they do, they will be asked if they would kindly give them an information sheet or sign post them to the information on the online group.

The posters created for the study will discuss in simple terms the general aims of the study and subsequently request for interested participants to contact the main researcher for further details. The poster will include the main researcher's email address as well as his research mobile phone number.

Subsequently, after initial interest has been shown, the researcher would telephone potential participants to ensure that they meet the inclusion criteria. If all the criteria are met by the participants, the main researcher will proceed to post out a participant's information pack. In addition, during the initial conversation with prospective participants, the main researcher will request for consent to contact them 14 days after the information pack has been sent. Hopefully, the time frame given will give prospective participants enough time to

read and understand the information sent and therefore, contacting them will provide an

opportunity for them to verbally consent to the interview. This will then enable us to arrange

for the interview. Contacting them would also give them the opportunity to decline taking

part in the study.

Recruitment of participants into the study will be done after the completed

expression of interest and consent forms have been received from 12 participants. If more

than 12 forms are received, participants will be selected to give the most homogenous

sample as in line with our methodology of choice, which is interpretative phenomenological

analysis (IPA; Smith & Osborn, 2003). If such a situation arises, that is where people meet

the inclusion criteria and are not included in the study, a message will be sent via their mode

of communication of choice based on information in their expression of interest forms.

Materials

The potential participants will be provided with an information pack which will

consist of an expression of interest form, a participant information sheet, and a stamped

envelope for the participant to either opt in or opt out of the research (see appendix B and

D). Also included in the pack is a consent form (see appendix E) which participants will be

asked to fill in and return in the stamped envelope. In addition to the consent from, there will

also be an eligibility checklist (see appendix C). This checklist will be included to ensure

that all the parameters around the inclusion criteria are met before potential participants opt

in. This checklist will also ensure that potential participants are aware that they must have

received the diagnosis of encephalitis from a neurologist before they can participate in this

study. A study invitation poster for the research will also be created to advertise the study on

the online groups and on webpages of some head injury charities. (see appendix A). As a

semi-structured interview will be conducted, there will a semi-structured interview schedule based on broad topic areas around the diagnostic experience to guide the questioning (see appendix F). Also, bearing in mind the potential distress reliving experiences like this could trigger, a resource for further support (see appendix G) will be given to the participant at the end of the interview if it is required. Finally, the interviews will be recorded using a digital recording device.

Consent.

The primary medium in which participants will be made aware of the study is through the closed encephalitis Facebook groups, through the posters advertised on the head injury charities' websites and related health (encephalitis and brain injury) forums. Participants interested in the study are then requested to contact the main researcher using details which will include a university supplied mobile number, university email, or postal address to the university site. After this contact has been made by potential participants, they will be sent a participant information pack; which will include the eligibility checklist, expression of interest form, consent form, participant information sheet, and a prepaid return envelope. Prospective participants who do not return the required documentation will not be contacted again. However, participants who return the prepaid envelope with the signed consent form and other required documentation will be contacted again and an interview will be arranged.

The after-effects of encephalitis can leave individuals with cognitive deficits which could impair their capacity. Therefore, the researcher will be mindful to address issues around capacity in line with The Mental Capacity Act (2005). In order to facilitate the process of ensuring that the participants have the capacity to engage, the consent forms will be reviewed again with the participants at the start of the interview. This is to ensure that

they have a good understanding of what they have consented to and to reiterate the fact that they do not have to participate. Participants will also be reminded at the start of the interview of their right to withdraw their consent from study up to two weeks after the interview. Participants will also be reminded of the confidentiality agreement which is written in the participant information sheet (See appendix B).

If it appears that at the point of interview, a potential participant does not have capacity to consent, the interview will be discontinued. At the end of the interview process, debrief forms (See appendix G) will be administered to the participants and a verbal debrief will also be given.

Interview.

As soon as the participants have expressed interest and consented to taking part in the study, they will be contacted and a suitable date and time for the interview will be agreed. However, bearing in mind that the recruitment for the study is going to be all areas within a 5 hours travel distance from Lancaster University, deciding on a location for the interview to take place is a big challenge. The main researcher had to weigh out different options as to what would work best for the study but most especially for the participants. After the considerations, it was decided that the interview will take place in the participant's homes if they consent to this. If potential participants struggle with this idea, another option will be to try to book a room in a National Health Service trust close to where the participants live. If the participants can travel, travel expenses that will be covered by the University, not expected to exceed £20, will be paid to the participants where necessary. In addition, the option for doing the interviews over another social media platform Skype will be given to the participants. This social media option might be useful if travel to potential participants is not possible because of the boundaries put in place regarding travel for this study. In coming

to this conclusion a few assertions were considered, one of which is Elwood and Martin's (2000) assertion that there is no perfect place to conduct an interview for a qualitative research but careful consideration should the given to the choice of location as it could have an impact on the result. In addition, fundamental ethical principles were taken into consideration, especially with regards to non-maleficence, beneficence and respect for autonomy (American Psychological Society, 2017). This involved on one hand giving participants the opportunity to decide where they want to be interviewed whilst considering the maintenance of their anonymity, as well as other logistics that would be involved in facilitating that process. Hence, the choice to have the interviews in the client's homes or via Skype. Therefore, throughout the process of each interview the researcher will remain mindful of personal safety and follow the lone working policy (Lancaster University fieldwork guidance available at

http://www.lancaster.ac.uk/smh/study/doctoral_study/dclinpsy/onlinehandbook/appendices/l cft_lone_working_policy.pdf.). This will involve the researcher informing a colleague before each interview of the details of the interview. The information given will include the destination, time of arrival, and estimated time of return. The main researcher will also be required to get in touch with the colleague before and after each interview. This procedure will also involve giving the chosen colleague details of the interview (like the address) in a sealed envelope which will be destroyed if not needed after the interview. If there is no contact from the researcher at the agreed time, emergency policies will be implemented. This will involve the opening of the envelope containing the address and other details about the interview and the alerting of the appropriate authorities by my colleague.

In order to gain a rich and detailed understanding of the experiences of the participants, the study will utilise semi-structured interviews. The researcher will utilise the interview schedule (see appendix F) to guide the interview. The interview will last for

between one hour to an hour and thirty minutes. The interviews will be recorded using a

digital audio recorder and, immediately or as soon as possible, the data will be transferred to

an encrypted USB drive. The data transferred will be saved under a filename that does not

contain any identifiable information. The original recordings will be deleted after the

transfer. Thereafter, the interviews will be transferred to the university server. Subsequently,

interviews will be transcribed by the main researcher and then analysed.

Pseudonyms will be utilised when transcribing and writing the report. Electronic

recordings will be stored in the university server until the project is submitted and then will

be deleted. However, the electronic version of the transcript of the interviews will be stored

on the secure university network for 10 years after submission or publication, whichever is

longer, and then destroyed by a member of the administrative staff to the Doctorate in

Clinical Psychology Programme (DclinPsy). The consent forms will also be scanned into the

university's secure network and then destroyed. The scanned copies are then kept for a

period of 10 years after submission or publication, whichever is longer, after which they will

be destroyed by member of the administrative staff of the DclinPsy programme.

Proposed analysis.

Interpretative Phenomenological Analysis (IPA) will be used to analyse the data

generated in the study. IPA is the methodological approach that attempts to examine how

people make sense of certain life experiences (Smith, Flowers & Larkin, 2009). According

to Smith (2008), it entails a rigorous examination of the participants' lived experience and

allows the researcher to make sense of the participant's world. Therefore, IPA has been

selected as an appropriate analysis of this research as it aims to better understand people's

experiences of receiving a diagnosis of encephalitis. Therefore, IPA will give us a better

insight into these experiences and enable us to generate some themes that encapsulates participants' collective response.

Transcripts from each interview will be analysed separately before similarities and differences between the experiences of the participants are considered. In order to ensure that tenets of IPA are adhered to, the researcher will ensure that after each analysis of the participant's transcripts notes are taken of the researcher's impressions and assumptions before proceeding to analyse subsequent interviews. This is to ensure that the researcher's own views and assumptions of the previous analysis do not influence the interpretation of the data (Elliot, Fischer & Rennie, 1999).

Service user/public involvement

The administrators of an ███████████████ were contacted in order to facilitate consultation of the recruitment documents (information sheet, informed consent, interview schedule and others). Due to the time constraints regarding the study, a four-week deadline was given to them to respond. Unfortunately, the expert by experience requested from the group was not able to facilitate consultation of the research documentation by the time of the resubmission to the ethics committee.

Practical Concerns

There are a number of practical matters concerned with this study. Potential participants will need to contact the main researcher directly should they be interested in taking part in the research. However, the University will provide the researcher with a mobile phone to be used primarily for the study to receive calls and text messages from potential participants. All the photocopying costs, cost for postage and printing costs will be covered by the University. Finally, because the study is targeting participants all over the

country, there is a potential that the main researcher might have to travel long distances, the cost of which will be covered by the University.

Ethical concerns.

A few ethical concerns have been identified in relation to the study, one of which is the potential for participants to be in touch with difficult feelings when reflecting about that period of their lives. This might leave them in a state of distress. This concern will be addressed by clarifying with the clients that they are aware of what they are about to be involved in using the participant information sheet (see appendix B). Also, some time will be given to the participants prior to the start of the interview to ask questions and these questions will be responded to. Participants will also be reminded that they do not have to answer any question they do not feel comfortable with and they will be also reminded about their right to withdraw their consent up to two weeks after the interview. Also, the main researcher being a trainee clinical psychologist, will have been trained to be mindful of signs of distress during the interview and will attempt to create an atmosphere in which the distress can be contained. Also, the main researcher will be mindful of the participants not being able to continue with the interview and terminate the interview if requested. Likewise, participants will be provided with information about relevant sources of support should they need it (see appendix G).

Participants will also be reminded about the confidentiality agreement and circumstances in which the agreement would be broken, that is if there is any risk of participants harming themselves or others will be discussed. At the end of every interview, the researcher would take time to debrief the participants and others involved. Time will be spent discussing potential distressing issues that have come up as a result of the interview.

Another probable ethical issue is the fact that the researcher would be conducting the interview alone, potentially in participant's homes. Therefore, to reduce any risk to the researcher, the Lancaster University lone working policy would be observed.

Timescale

The main researcher will apply for ethical approval from the Lancaster University Research Ethics Committee in December 2017, if granted, it is hoped that data collection will be over by the end of February 2018. The study will end in June 2018 and the project will be submitted. Participants who have requested a feedback will be given one following the submission of the final report. Required amendments will be made and the research will be submitted for publication by September 2018.

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Appendices

APPENDIX A   Study invitation poster / forum advertisement.

APPENDIX B   Participant Information Sheet.

APPENDIX C   Checklist for participant.

APPENDIX D   Expression of interest form.

APPENDIX E   Consent form.

APPENDIX F   Interview schedule.

APPENDIX G   Sources of further support sheet.

APPENDIX H   Link to the Lone working policy utilised by Lancaster University (Guidance on safety in fieldwork)

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APPENDIX A

Encephalitis research study – request for help

Study title: An exploration into the experience of adjusting to the diagnosis of encephalitis in adults of a working age: a qualitative investigation.

My name is ▮▮▮▮▮▮ and I am conducting this research as a student in the Doctorate of Clinical Psychology programme at Lancaster University, Lancaster, United Kingdom.

What is this study about?

The process of receiving a diagnosis is a very crucial process and research has shown that the way a diagnosis is delivered and the way the individual experiences the diagnostic process has an impact on the way people adjust to the diagnosis. This study aims to gain more insight into how people experience receiving the diagnosis of encephalitis, and to explore how that experience impacted on adjusting to life after encephalitis.

Who can participate in this study?

Anyone living in the United Kingdom who has been given a diagnosis of encephalitis within the last 5 years (aged between 18 and 65 at the time) and can engage in an interview on their own or with the support of friends and family.

What will I be asked to do if I take part?

If you decide that you would like to take part, please contact the main researcher either by post, email or phone using the details below. The main researcher will then send you some more information regarding the study and how to take part in an information pack. If you meet all the criteria for the study and you agree to take part, you will be asked to take part in an interview talking about your experience of receiving the diagnosis.

Interested in taking part in this research?

If you would like more information about taking part in this research, please contact the main researcher using the details below and an information pack will be sent to you.

Name: ▮▮▮▮▮▮

Address: Clinical Psychology Programme, Division of Health

Research, School of Health and Medicine,

Lancaster University, Lancaster, LA14YT

Telephone: 07852515788

Email ▮▮▮▮▮▮▮▮

Please note that receipt of an information pack does not commit you to take part; full details of taking part are contained within the information

ETHICS SECTION

Appendix B

Participant Information Sheet

Title of Research

"An exploration into the experience of adjusting to a diagnosis of encephalitis in adults of a working age: a qualitative investigation"

Hi, my name is ████████ and I am conducting this research study as part of my clinical training course.

Thanks for your interest in this study. I invite you to take part in it. However, before you make your decision, it is essential that you understand what the study is about and what you will be asked to do.

Please take your time to read the information below and discuss it with significant people around you if you need to. It is up to you to decide whether or not to take part. I am also available to answer any questions that you might have about the study.

What is the study about?

The purpose of this research study is to gain more insight into how people with a diagnosis of encephalitis experience receiving the diagnosis and to explore how that experience impacted on adjusting to life after encephalitis. As a result of the nature of the condition diagnosing encephalitis can pose a challenge for clinicians and consequently patients and their families as they may have to go through a difficult process before a diagnosis is reached.

The process of receiving a diagnosis is a very crucial process and research has shown that the way a diagnosis is delivered and the way individuals experience the diagnostic process has an impact on the way people then adjust to the diagnosis. The information gained from this study will hopefully contribute to the ever-growing literature on encephalitis and will be used to make recommendations for best practice to inform the diagnostic process for people who are being investigated for possible encephalitis.

Why would you like me to be involved?

We are interested in collecting information from individuals who received a diagnosis of encephalitis that has been diagnosed by a neurologist (a hospital doctor who specialises in conditions affecting the brain). Within the pack is the checklist of eligibility for this study. If you think you meet all the criteria and would like to take part in the study, I would be very grateful if you fill in the expression of interest form, consent form and the eligibility form and then send it to me using the stamped addressed envelope enclosed. Once I receive the required documentation, I will then contact you to make arrangements for us to meet so as to conduct the interview. Ideally, I will visit your home to conduct the interview, or utilise if possible a National Health Service trust site close to where you live.

However, we could have a conversation about your preference. The interview should last for between 60 to 90 minutes

Do I have to take part?

No, the choice is entirely up to you whether you decide to take part in the study or not. If you decide not to take part, you will not hear from me again. Also, if you decide to take part, you are still free to withdraw from the study up to two weeks after the interview has taken place.

What will be required of me if I take part?

If you decide to take part, you can contact me directly by post, email or by telephone. Alternatively, you can fill in the expression of interest forms, consent forms and eligibility forms and return them using the stamped addressed envelopes enclosed in this pack and I will contact you. The interviews will take place at your home or any National Health Trust service around your location provided you feel comfortable with that and there are rooms available. In a situation where you might need to travel, we will have had a conversation about it before the interview and travel expenses of up to £20 will be reimbursed to you by me upon receiving receipts.

During the interview, I will ask you some questions about your experience of receiving the diagnosis. The interview will be audio recorded and then subsequently transcribed, analysed and then written up.

Will my information be kept confidential?

All the information provided by you will be kept confidential. All information collected will be stored on a secure network at Lancaster University, my research supervisor (████████ ████████ and I will have access to the data below:

> The signed consent forms will be scanned and uploaded to the secure University network. They will be stored for a period of 10 years after submission or publication whichever is longer. The paper copy will then be destroyed immediately after scanning.
> Audio recordings transferred to the University secure network and the originals will be deleted after transfer. Once the project has been submitted for examination, the audio recording will be destroyed. While the typed version of your interview will be made anonymous by removing any identifying information including your name and will be kept in a locked cabinet until submission of the report, June 2018.

ETHICS SECTION

At the end of the study, electronic copies of anonymised interview transcripts will be kept securely in the University's secure network for a period of 10 years after submission or publication after which, it would be destroyed.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this. If possible, I will tell you if I have to do this.

What will you do with my information?

The results will be summarised and reported in an academic project and may be submitted for publication in an academic or professional journal. Should any participant in the study request a brief summary of the finding, this can be made available to them on request. All you need to do is to get in touch with me or my research supervisor by emailing:

What are the risks of taking part in this research?

People's experience of receiving a diagnosis varies. However, for some people, talking about these experiences could be distressing. If you experience any form of distress during or following the interview, it would be helpful if you inform the researcher or make contact with the support mediums provided at the end of this sheet.

Are there any benefits to taking part?

There are no direct benefits from taking part.

Who has reviewed the project?

This 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.

What should I do next?

If you wish to take part, or for more information on the research, please fill in the expression of interest, consent and eligibility forms and I will get in touch with you. You can also email or telephone me using the contact details at the end of this document. If you do not wish to take part, please ignore this information.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact:

The main researcher:

██████.
Doctorate in Clinical Psychology Course
Furness Building
Lancaster University
LA1 4YT
Phone: 01524 592970
Email: ████████████████
(University supplied number to be inserted)

Academic supervisor:

████████████

Division of Health Research
Doctorate of Clinical Psychology Course
Furness Building
Lancaster University
LA1 4YT
Email: ██████████████████████

Field Supervisor:

████████████

Principal Clinical Psychologist

████████████
██████████████
████████████
██████████
██████
████████████████████

Complaints
If you wish to make a complaint or raise concerns about any aspect of this study and do not
want to speak to the researcher, you can contact:

Name: ██████████████████
Tel: (████████████████
Email: ██████████████████
Clinical Psychology
Division of Health Research
Furness College
Lancaster University
Lancaster
LA1 4TY

If you wish to speak to someone outside of the Clinical Psychology Doctorate Programme, you may also contact:

████████████████

Associate Dean for Research
Email: ████████████████
████████████████

(Division of Biomedical and Life Sciences)
Lancaster University
Lancaster
LA1 4YG

Thank you for taking the time to read this information sheet

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance:

Contact your **GP** in the event of concerns you have about your wellbeing.

Minds Matter

Brief psychological intervention for people who may be struggling with common mental health difficulties for example low mood and anxiety. People are normally seen within GP surgeries or community setting. Sessions are offered face to face, over the phone or online. You can self-refer or referrals can be made through your GP.

Phone number: 01524 550552

ETHICS SECTION

APPENDIX C

Checklist for eligibility.

Study title: **An exploration into the experience of adjusting to the diagnosis of**

Encephalitis in adults of a working age: a qualitative investigation.

Researcher ████████████

Please fill in the following check list and send it back to the main researcher in the self-addressed envelope enclosed.

The person who has had the diagnosis of encephalitis must meet ALL of the following criteria to be eligible to take part:

☐ I received a diagnosis of encephilitis between 2 to 5 years ago.

☐ I was aged between 18 and 65 at the time of diagnosis.

☐ I understand what this study is about and understand what it means to take part.

☐ I am able to engage fully (or with help as below) in an interview process in English

and I live in the United Kingdom.

☐ I am willing to take part in this interview.

Please indicate if the following applies to you so that we may make necessary arrangements:

☐ I am struggling with communicating details about my experience of the diagnosis, I

am willing to consent to a close family or friend to support me during the interview process.

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APPENDIX D

EXPRESSION OF INTEREST FORM

Study title: **An exploration into the experience of adjusting to the diagnosis of**

Encephalitis in adults of a working age: a qualitative investigation.

Researcher ███████ **, Trainee Clinical Psychologist, Lancaster University**

If you would like to take part in the study, please fill in and return the completed form together with the enclosed checklist so that I can make telephone contact with you to arrange a suitable interview date and time.

If you would like to contact me by telephone or email instead, you may do so on [*insert research mobile number once known*] or ███████████

Your details:	(Please enter or circle responses where required below)
Name of person with a diagnosis of encephalitis:	
Contact number:	
Address:	
Contact number:	
Who would you prefer me to contact to arrange the interview time?	**Me / My partner / others**
Name of partner/others and their contact details if required	
Encephalitis survivor's gender:	**M / F**
Encephalitis survivor's current age:	**Years**
Encephalitis survivor's age at time of Encephalitis:	**Years**

Current employment status: **Employed full-time / Employed part-time / Not employed / Student**

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APPENDIX E

CONSENT FORM

Study title: **An exploration into the experience of adjusting to the diagnosis of Encephalitis in adults of a working age: a qualitative investigation. Researcher███████, Trainee Clinical Psychologist**

Please initial the boxes to confirm that you agree to the following statements:

Please initial box:

1.   I confirm that I have read and understood the information sheet for the above
study and have had the opportunity to ask questions.

2.   I understand that my participation is voluntary and that I am free to withdraw
from the study without giving a reason, up until 2 weeks after interview. In this instance
my data will be destroyed and not used.

3.   I agree to information being audio recorded, and understand that this recording
will be labelled anonymously and be stored password-protected on the researcher's
computer until the report is written up.

4.   I give my permission for anonymised quotes from my interview to be used in
the doctoral thesis report of the study and in academic journal articles.

5.   I understand that relevant sections of the data collected during the study may be
looked at by individuals from regulatory authorities (research supervisor- ███████),
where it is relevant to my taking part in this research. I give permission for this individual
to have to this data.

6.   I understand that the information I provide will be treated respectfully and confidentially,
    unless there are concerns that I may be at risk of harm to myself or others, in which case
    the main researcher may share this information with support or health services.

7. I understand that the information I provide will be electronically stored in a secure
database, and I consent to Lancaster University keeping my information (anonymised
transcribed interview and consent forms) for 10 years after the study has completed.

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

_____

_____ _____   _____   _____

Your name   Date   Signature

_____ _____   _____

Researcher   Date   Signature
     1 copy for the participant, 1 copy for the researcher

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APPENDIX F

Interview schedule

The interview schedule is for guidance only and will cover the following core areas:

- Life Pre-Encephalitis.
- Immediate experience following the Encephalitis
- Experience of receiving diagnosis.
- Life changes post-Encephalitis
- Debrief / opportunity to ask questions

The ensuing questions form an interview guide but the researcher will retain flexibility in following up previously unanticipated conversation threads relevant to the research question.

Can you tell me what life was like before you started struggling with the symptoms of encephalitis.

Can you tell me about when you started struggling with the symptoms?

How long did you struggle with the symptoms for before going to the hospital?

Can you describe your experience of your first encounter with a health professional? (What discussions did you have at the time and what advice were you given?

What was that experience like?

What was your path to diagnosis like ie how long did the process take and what processes were involved?

What was your experience of the process?

During the diagnostic process, can you describe your experience of the communication between you and the doctors?

Who delivered the diagnosis and what was the experience like?

Would you say you were well supported when the diagnosis was delivered? If yes, how?

What was your knowledge of encephalitis before and what was it like hearing that you had encephalitis.

Did your experiences of receiving the diagnosis help with adjusting to living life with the condition? If yes, how would you say it helped?

APPENDIX G

<u>Sources of further information and support</u>

The encephalitis society

Website: http://www.encephalitis.info/

Tel: 01653692583; 01653699599

Email: webcontact@differentEncephalitiss.co.uk

Headway: the brain injury association

Website: www.headway.org.uk

Free nurse-led telephone helpline 0808 800 2244 (**9am - 5pm, Monday to Friday)**

Email helpline: helpline@headway.org.uk

Local support group contact: Diane Bridge (North West Regional Coordinator): 07826 907989.

Minds Matter

Brief talking therapy for people who may be struggling with common mental health difficulties for example low mood and anxiety. People are normally seen within GP surgeries or community setting. Sessions are offered face to face, over the phone or online. You can self-refer or referrals can be made through your GP.

Phone number: 01524 550552

Should you experience significant distress; you are strongly advised to contact your own **GP** for further support and advice.

APPENDIX H

http://www.lancs.ac.uk/depts/safety/files/Fieldwork.pdf.

**Faculty of Health and Medicine Research Ethics Committee
(FHMREC) Lancaster University
Application for Ethical Approval for Research**

for additional advice on completing this form, hover cursor over guidance.

Guidance on completing this form is also available as a word document

Title of Project:
An exploration into the experience of adjusting to the diagnosis of encephalitis in adults of a working age: a qualitative investigation.

Name of applicant/researcher ███████████

ACP ID number (if applicable)*:   **Funding source (if**

applicable) Grant code (if applicable):

*If your project has *not* been costed on ACP, you will also need to complete the Governance Checklist [link].

Type of study

☐ Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. **Complete sections one, *two* and four of this form**

☒ Includes *direct* involvement by human subjects. **Complete sections one, *three* and four of this form**

SECTION ONE

1. Appointment/position held by applicant and Division within FHM   Trainee Clinical Psychologist

2. Contact information for applicant:
E-mail ███████████   **Telephone** ██████████ (please give a number on which you can be contacted at short notice)

Address

3. **Names and appointments of all members of the research team (including degree where applicable)**

███████████████████████
███████████████████
██████████████

September 2016

Kommentar [guidance1]: In completing your application:

Be specific and thorough in the information you provide in the application form. You may use short sections from your research protocol, cutting and pasting as relevant.
Make sure that the *application form* includes all the important points of information about the study so that committee members can evaluate your submission thoroughly from the application form itself. This may mean repeating (or cutting and pasting) elements of your protocol.
Be sure that information provided is consistent between your application, research protocol, and supporting materials. Repeating information is likely to be necessary.
Organise the information clearly. If you have different phases or components to your research, clearly present and address issues for each component (using headings, etc.) so that it is easy to understand what you plan to do.
For projects involving human participants, and being reviewed by the full committee: a lead reviewer is appointed from the FHMREC who will take the lead on reviewing your application. The lead reviewer may contact you prior to the meeting if any clarification of your application is needed.

Kommentar [guidance 2]:
Make your title short and descriptive so that people can easily identify the main topic of the research; you do not need extensive detail. The title of your project does not need to be the same as the title you propose to use for your publication (e.g. your thesis).

3. 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 masters projects should complete **FHMREC form UG-tPG**, following the procedures set out on the FHMREC website

PG Diploma ☐   Masters by research ☐   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

4. Project supervisor(s), if different from applicant: ███████████████████
██████████████████

5. Appointment held by supervisor(s) and institution(s) where based (if applicable):
██
██████████████████████████
████████████████████████████████

SECTION TWO
Complete this section if your project involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants

1. Anticipated project dates (month and year)
Start date: End date:

2. Please state the aims and objectives of the project (no more than 150 words, in lay-person's language):

Data Management
For additional guidance on data management, please go to Research Data Management *webpage, or email the RDM support email:* rdm@lancaster.ac.uk
3. Please describe briefly the data or records to be studied, or the evaluation to be undertaken.

4a. How will any data or records be obtained?

4b. Will you be gathering data from websites, discussion forums and on-line chat-rooms no
4c. If yes, where relevant has permission / agreement been secured from the website moderator? no
4d. If you are only using those sites that are open access and do not require registration, have you made your intentions clear to other site users? no

4e. If no, please give your reasons

5. What plans are in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with the Data Protection Act 1998.

6a. Is the secondary data you will be using in the public domain? no
6b. If NO, please indicate the original purpose for which the data was collected, and comment on whether consent was gathered for additional later use of the data.

Kommentar [guidance 3]:
These dates should indicate when recruitment will begin, (taking into account the timescale of the ethical approval process) and when funding ends or your thesis will be submitted.

Kommentar [guidance 4]:
This summary should concisely but clearly tell the reader (in simple terms and in a way which would be understandable to a general audience) what you are broadly planning to do in your study.

Kommentar [guidance5]: Data storage: non-audio and non-video data. State clearly where and what format your data will be stored.
Timescales: The standard guidance we provide to people about length of time for retaining data is 10 years. This is a requirement. Your study may have a rationale for retaining data longer and for various intended purposes, but if so, please explain. For example, some data may be specifically collected with intent to be added to a formal databank (quantitative or qualitative), or there may be plans for secondary data analysis that is anticipated from early in the design of the project. Where electronic data is to be stored for longer than the recommended period, we recommend storing data on University storage. If data is collected or stored by own devices they need to be encrypted. For data sharing with external partners we recommend using Box.
Data Stewardship: Please state who will have guardianship of the stored data (and if you are a student, who will be responsible for storing/deleting your data once you have completed your course).
For DMP purposes: how will the data be documented and described i.e. how will you make others understand your data. We recommend writing a description/abstract, adding a Readme file, using meaningful file names and version numbers.
Location: If your data is stored centrally or will be accessible to others, you should note in your application who will have access to the data.
Data security: Data stored on all portable devices (eg laptops) should be encrypted as well as pass word protected; data stored on the University server does not, however, need to be encrypted.
If you are based and work predominantly away from the University, give consideration to how you will store the data securely as you undertake your research, and how it will be securely transferred to the LU campus for long term storage.

Please answer the following question *only* if you have not completed a Data Management Plan for an external funder
7a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

7b. Are there any restrictions on sharing your data?

8. Confidentiality and Anonymity
a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications?
yes
b. How will the confidentiality and anonymity of participants who provided the original data be maintained?

9. What are the plans for dissemination of findings from the research?

10. What other ethical considerations (if any), not previously noted on this application, do you think there are in the proposed study? How will these issues be addressed?

SECTION THREE
Complete this section if your project includes *direct* involvement by human subjects

1. Summary of research protocol in lay terms (indicative maximum length 150 words):

Encephalitis is a condition that occurs as a result of an infection of some parts of the brain. In the United Kingdom around 6000 people are diagnosed with the condition each year.
One of the reasons why people die from the condition is because diagnosing it is very difficult. People with the condition have to go through a series of tests.

Various studies have identified the importance of how the diagnosis of a condition is delivered to adjusting to the condition. Therefore, an understanding of how people make sense of the diagnosis might help with diagnosis delivery and inform the support put in place to aid adjustment. This study aims to get some more insight into how people of a working age with a diagnosis of encephalitis have come to make sense of the diagnosis and how that has helped in adjusting to life after the diagnosis.

2. **Anticipated project dates (month and year**

only) Start date: 01/2018   End date:

05/2018

Data Collection and Management
For additional guidance on data management, please go to Research Data Management *webpage, or email the RDM support email:* rdm@lancaster.ac.uk

3. Please describe the sample of participants to be studied (including maximum & minimum number, age, gender):

Between 6 to 12 participants with a diagnosis of encephalitis.
We will recruit for people that were within the working age at the time of diagnosis.

Inclusion criteria:
• Participants must have been 18 years and not older than 65 (working age) at the time the diagnosis was received. The study is exploring the experience of receiving a diagnosis at working age, hence the lower and upper age limits which represents adult the working age in the United Kingdom.
• Participants must have received a diagnosis of encephalitis.

• At the time of recruitment, participants must have had their diagnosis for at least two years and not more than five years. The lower limit of the time frame is to allow some time for people to have adjusted to the diagnosis while the upper limit is to ensure that the experience of receiving the diagnosis remains as fresh as possible in the minds of the participants.

• Due to the financial limitations regarding travel, participants will be recruited from areas within the United Kingdom that are within 5 hours of travel time from Lancaster University. This will be inclusive of whatever means of transportation used. In addition, bearing in mind our methodology and the requirement of homogenous samples, the interviews will be conducted in English and therefore will be recruiting only participants who can speak English and who live in the United Kingdom.
• Participants must have the capacity to consent to the interview.

• Participants with severe cognitive difficulties who have the capacity to consent have the option to have a close family member or friend supporting them during the interview

Exclusion criteria:
• Those with severe cognitive difficulties that might make engaging in such an interview almost impossible.
• Those that are deemed not to have the capacity to consent.
4. How will participants be recruited and from where? Be as specific as possible. Ensure that you provide the *full versions* of all recruitment materials you intend to use with this application (eg adverts, flyers, posters).

Following ethics approval from the Faculty of Health and Medicine Research and Ethics Committee of Lancaster University, the main researcher will open a Facebook account for the purpose of the research. The main researcher will then contact the site administrators of the various closed encephalitis Facebook groups and discuss the study and subsequently request permission to be added to the group so that the posters of the study could be advertised in the group. Examples of these Facebook groups include the Encephalitis Recovery Group, Encephalitis Global, Survivors Plus and Inspire Encephalitis for carers. These online groups serve as a medium of support for individuals, who have been affected by encephalitis. They also support friends, families and carers by providing information about recent developments in terms of living with the effects of the condition and generally giving a platform for people to share their experience and support each another. In addition to the
Facebook groups, the main researcher has approached other head injury charities and related health (encephalitis and brain injury) forums to discuss the study. The correspondence sent was centred on the aims of the study and geared towards requesting that the poster for the study to be uploaded on to their website and advertised to prospective participants.

Finally, a snowballing sampling technique will be employed whereby participants will be asked if they know anyone who is eligible to take part in the study. If they do, they will be asked if they would kindly give them an information sheet or sign post them to the information on the online group.

 The posters created for the study, will discuss in simple terms the general aims of the study and subsequently request for interested participants to contact the main researcher for further details. The poster will include the main researcher's email address as well as his research mobile phone number.
Subsequently, after initial interest has been shown, the researcher would telephone potential participants to ensure that they meet the inclusion criteria. If all the criteria are met by the participants, the researcher would proceed to post out a participan'ts information pack.

In addition, during the initial conversation with prospective participants, the main researcher will request for consent to contact them 14 days after the information pack has been sent. Hopefully, the time frame given will enable the prospective participants have enough time to read and understand the information sent and therefore, contacting them will provide an opportunity for them to verbally consent to the interview which would then enable us to arrange for the interview. Contacting them would also give them the opportunity to decline taking part in the study.

Recruitment of participants into the study will be done after the completed expression of interest and consent forms have been received from 12 participants. If more than 12 forms are received, participants will be selected

to give the most homogenous sample as in line with the methodology of choice, which is interpretative phenomenological analysis (Smith & Osborn, 2003). If such a situation arises, that is where people meet the inclusion criteria and are not included in the study, a message will be sent via their mode of communication of choice based on information in their expression of interest forms. .

5. Briefly describe your data collection and analysis methods, and the rationale for their use.

A qualitative methodology was chosen in order to gain a depth of understanding into how the participant's experienced receiving the diagnosis of encephalitis. Denzin and Lincoln (2000) assert that qualitative research as a ŵethodologiÐal fraŵeĺork serĺes as a ŵeaŶs through ĺhiÐh peopĺs edžperieŶÐes ÐaŶ ďe studied iŶ ĺaLJ iŶ ĺhiÐh quantitative research cannot. Which in this case is the lived experience of individauls who have received a diagnosis of encephalitis.
Data will be collected by the use of semi-structured interviews. This is to enable the researcher to draw from areas included in previous research whilst ensuring that the interview process is still being guided by the participant.

Interpretative Phenomenological Analysis (IPA) will be used to analyse the data generated in the study. IPA is the methodological approach that attempts to examine how people make sense of certain life experiences (Smith, Flowers & Larkin, 2009). According to Smith (2008), it entails a rigorous examination of the participant's lived experience and allows the researcher to make sense of the participant's world. Therefore, IPA has been selected as an appropriate analysis of this research as it aims to better understand peoples' experiences of receiving a diagnosis of encephalitis

6. What plan is in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc.)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with the Data Protection Act 1998.

Each interview will be transcribed verbatim by the main researcher and the transcribed data will be anonymised and hence will only be identifiable by the researcher. The transcribed paper copies will be kept in a locked cabinet in the main researcher's home and will be destroyed by the main researcher after the sumission of the project.

Any documentation with personal information; such as the consent forms will be scanned and then transferred to the University's secure network.   Consent forms will be kept on the secure university server for 10 years or 10 years from publication if published.

7. Will audio or video recording take place?   ☐ no   ☒ audio   ☐ video
a. Please confirm that portable devices (laptop, USB drive etc) will be encrypted where they are used for identifiable data. If it is not possible to encrypt your portable devices, please comment on the steps you will take to protect the data. Yes the USB drive will be encrypted.

b What arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

 The recorded interviews will be transferred to an encrypted USB drive with a filename that does not contain any identifiable information. This will be done immediately or as soon as possible after the interview to ensure the safety of the data during travel. The encrypted USB drive will then be kept securely in a locked bag. Subsequently, interviews on the USB drive will be transferred to the University of Lancaster's secure network. The original copy of the interview will be deleted after the transfer has been completed. The recorded interview will be accessed directly from the secure network for transcription of the data by the main researcher. Electronic transcripts of interviews will be stored on the secure University network for 10 years after submission or publication, whichever is longer, and then destroyed by administrative staff of the Doctorate in Clinical Psychology (DclinPsy) Programme responsible for research matters.

Please answer the following questions *only* if you have not completed a Data Management Plan for an external funder

8a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?
 The main researcher will be allocated a space in Lancaster UŶilersitLĴs secure network. All data will be sent to a member of the Dclinpsy administrative team using an electronically secure method of data transfer and then uploaded to the university network. Data will be stored for 10 years and then it will be deleted by a member of the DÐliŶpsLĴs adŵiŶistratile teaŵ.

8b. Are there any restrictions on sharing your data ?
Data will only be accessible to the main researcher, however, parts of the digital recording might be reviewed by the research tutor from Lancaster University in order to consider any necessary adaptation to the interview schedule or style. The research supervisor is bound by the same terms of confidentiality the main researcher is bound by and prospective participants have been made aware of the possibility of this happening in the participant information sheet.

9. Consent
a. Will you take all necessary steps to obtain the voluntary and informed consent of the prospective participant(s) or, in the case of individual(s) not capable of giving informed consent, the permission of a legally authorised representative in accordance with applicable law? yes

b. Detail the procedure you will use for obtaining consent?
The primary medium in which participants will be made aware of the study is through the closed encephalitis Facebook groups, through the posters advertised on the head injury charities and health forums and through snowballing sampling technique.

Participants interested in the study are then requested to contact the researcher at which point they are sent a participant information pack which includes the eligibility checklist, expression of interest forms, consent forms and participant information sheets in a prepaid envelope. Prospective participants who do not return the required documentation will not be contacted again. However, participants who return the prepaid envelope with the signed consent form and other required documentation will be contacted again and an interview will be arranged.
The after-effects of encephalitis can leave individuals with cognitive deficits which could impair their capacity. Therefore, the researcher will be mindful to address issues around capacity in line with Mental Capacity Act (2005). In order to facilitate the process of ensuring that the participants have the capacity to engage, the consent forms will be reviewed again with the participants at the start of the interview. This is to ensure that they have a good understanding of what they have consented to and to reiterate the fact that they do not have to participate. Participants will also be reminded at the start of the interview of their right to withdraw their consent up to two weeks after the interview. Participants will also be reminded of the confidentiality agreement which is written in the participant information sheet.

10. 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.

There is a potential for participants to be distressed during the interview as a result of putting them in touch with experiences that are potentially distressing. However, by virtue of the main researcher's training, should such a situation arise, they can be managed during the interview. If the participant is too distressed to continue, the main researcher will end the interview. At the end of each interview, each participant will be debriefed and given some resources for further support should they need it. In addition, at the start of the interview, participants will also be reminded of their right to withdraw their consent from study up to two weeks after the interview.

11. 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).

Page 6

There is a poteŶtial risk to the ŵaiŶ researĐher as the iŶterǀieǁs ǁill ďe ĐoŶduĐted iŶ the ĐlieŶťs homes or where possible, a National Health Service trust in a location close to the prospective participants or via Skype. The researcher would be mindful of personal safety and adhering to the Lancaster University's lone working policy in order to minimise risk. This will involve the main researcher giving details of the interview to a colleague. These details will include the date, time of arrival, and the estimated time of return which will be enclosed in a sealed envelope. In addition, the main researcher will make sure he has his phone with him at all times and should be available to be contacted at a pre-arranged time before the interview and after the interview. Should the main researcher not return at the agreed time, it has been agreed that the sealed envelope will be opened and emergency procedures will be implemented. This will involve the opening of the envelope containing the address and other details about the interview and the alerting of the appropriate authorities by my colleague.

Additional support will be provided by the main researcher's academic supervisor and well as one of the field supervisors should this be needed after every interview.

12. 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.

Participants will not get any direct benefit from engaging in this research.

13. Details of any incentives/payments (including out-of-pocket expenses) made to participants:
There will be no incentives for particition paid made to participants. Participants may only be reimbursed to the tune of £20 if necessary for travel expenses. This amount will be paid by the University.

14. Confidentiality and Anonymity
a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? yes
b. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality.
Data from the participants will be anonymised during transcription by the main researcher. The research supervisor involved in the study will have access to aspects of the data. Participants will be informed of this arrangement and consent will be sought before proceeding. Confidentiality will be discussed in detail with the participants as well as details of secure storage of their data. Limits to confidentiality will also be discussed, which is, if what is said during the interview makes the researcher think that the participant, or someone else, is at significant risk of harm. Should this sort of situation occur, it represents a limit to the confidentiality agreement and it will be broken at such instances.

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

The administrators of an online Encephalitis group were contacted in order to facilitate consultation of the recruitment documents (information sheet, informed consent, interview schedule and others). Due to the time constraints regarding the study, a four week deadline was given to them to respond. Unfortunately, the expert by experience requested from the group was not able to facilitate consultation of the research documentation as at the time of the resubmission to ethics committee.

16. What are the plans for dissemination of findings from the research? If you are a student, include here your thesis.

The research will be submitted to Lancaster University as a doctoral thesis. The research will be written for publication in an academic peer reviewed journal.

17. 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?
There are no further ethical considerations identified.

SECTION FOUR: signature

Applicant electronic signature: ▮▮▮   Date 15/12/17

Student applicants: please tick to confirm that you have discussed this application with your supervisor, and that they are happy for the application to proceed to ethical review   ☒

Project Supervisor name (if applicable): ▮▮▮▮▮▮,   Date application discussed 15/12/17

Kommentar [guidance 28]:
If you are a student, make sure that you have discussed the project *and the application* with your supervisor. Build in enough time in your preparation schedule for your supervisor to properly review your application and give you comments before you give it to him/her for signing.

You must submit this application from your Lancaster University email address, and copy your supervisor in to the email in which you submit this application

Submission Guidance

1. Submit the following materials for your study if relevant:

    a.   Your full research proposal (background, literature review, methodology/methods, ethical considerations).

    b.   Advertising materials (posters, e-mails)

    c.   Letters/emails of invitation to participate

    d.   Participant information sheets

    e.   Consent forms

    f.   Questionnaires, surveys, demographic sheets

    g.   Interview schedules, interview question guides, focus group scripts

    h.   Debriefing sheets, resource lists

Kommentar [guidance 29]: We recommend that you use and amend the sample information sheet and consent form on the FHM Research Ethics Committee website as the basis for these documents. Ensure that you use the most recent relevant logo on your participant materials. Consider any special requirements that your intended research participants may have, and endeavour to accommodate these. For example if your participants include people with a learning disability, your information sheet and consent form should include pictorial representations of the information you are trying to communicate (Makaton). For more information go to http://www.makaton.org/

   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. Collate the FHMREC form and any relevant materials listed above into a single **word document**. Submit this document by email to Diane Hopkins d.hopkins@lancaster.ac.uk. **Before submitting, ensure all guidance ĐoŵŵeŶts are hiddeŶ ď'y goiŶg iŶto Ŗelieľ iŶ the ŵeŶu aďʼole theŶ ĐhoosiŶg** *show markup>balloons>show all revisions in line.*

3. Submission deadlines:

    a.   Projects including direct involvement of human subjects **[section 3 of the form was completed]**. The *electronic* version of your application should be submitted to Diane Hopkins **by the committee deadline date.** Committee meeting dates and application submission dates are listed on the FHMREC website. Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application. Please ensure you are available to attend the committee meeting (either in person or via telephone) on the day that your application is considered, if required to do so.

    b.   The following projects ǁill ŶorŵallLJ ďe dealt ǁith ǀia Đhair̊s aĐtioŶ, aŶd ǁaLJ ďe suďŵitted at aŶLJ
           time. **[Section 3 of the form has *not* been completed, and is not required].** Those involving:
        i.   existing documents/data only;
        ii.   the evaluation of an existing project with no direct contact with human participants;
        iii.   service evaluations.

Applicant: ███████ Supervisor: █████████
Department: Health Research FHMREC Reference:
FHMREC17029

18 January 2018

Dear ██

Re: An exploration into the experience of adjusting to the diagnosis of encephalitis in adults of a working age: a qualitative investigation?

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.

Approval is given with the caveat that you submit for an amendment including the materials which will be used on your social media (Facebook) page, once set up.

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:- 01542 592838
Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

████████████

Research Integrity and Governance Officer, Secretary to FHMREC.

RE: Ethics approval letter

██████████████

Reply all

Mon 22/01, 15:37

██████████

Inbox

Flag for follow up. Start by 21 September 2018. Due by 21 September 2018.

You forwarded this message on 21/02/2018 20:45

Thanks for confirming ██
Since that is the only document you will be uploading, and it has already been approved, you can commence your study with no further action needed in relation to ethical approval. If you do make any changes, please submit an amendment as noted in my original approval email.

Best wishes
████

From ████████████
Sent: 22 January 2018 15:34
To: ██████████████████████@lancaster.ac.uk>
Subject: Re: Ethics approval letter

Hi █████
Yes that is the only document to be uploaded to social media.
Many thanks

████

From █████████████<█████████@lancaster.ac.uk>
Sent: 22 January 2018 14:05:09
To: ██████████
Subject: RE: Ethics approval letter

Hello ███ it may be that the lead reviewer didn't realise that the advert you had included was the FB advert. Can I check if appendix A (see attached) is the only material which will be uploaded to the fb page?

Best wishes
████

From: █████████
Sent: 19 January 2018 11:43
To: █████████████████████████>
Subject: Re: Ethics approval letter

Hi █████
Many thanks for getting this back to me.
I just wanted to clarify the caveat as I had the advertisement that will be used on social media included in the appendices already submitted.
I would appreciate some advice regarding this as I am keen to get started with advertising/recruitment.
Thanks for your help

████

From ███████████████████████████>
Sent: 18 January 2018 10:48:31
To: █████████
Cc: █████████
Subject: Ethics approval letter

Dear ███, please find attached your ethics approval letter.

Approval is given with the caveat that you submit for an amendment including the materials which will be used on your social media (Facebook) page, once set up.

Please note that any changes to your project from this point on, including to your participant materials, must be submitted for review as part of an amendment application.

If you have any queries, please let me know.

Best wishes

███

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████████████

Research Integrity and Governance Officer
Research Services
Room B14, Furness College
Tel: +44 (0) 1524 592838
FHM Research Support web page: Sharepoint

Ethical approval of research:
FHMREC deadline: 12 noon on Wednesday 24 January for the meeting on Thursday 8 February 2018.
guidance and documentation: http://www.lancaster.ac.uk/fhm/research/research-ethics/

Please note that I work part-time. My working days are Mondays & Tuesdays, and Thursday morning.